


Guidance for the post-discharge rehabilitation of children, adolescents and young adults with Acquired Brain Injury



Toolbox 2022/2019/2018

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INTRODUCTION

Guidance for the post-discharge rehabilitation of children, adolescents and young adults with Acquired Brain Injury

A great deal of best practice is available for the post-discharge rehabilitation of children, adolescents and young adults with Acquired Brain Injury (ABI). However, not all professionals involved in the support of these individuals, particularly within the low- and middle-income countries, may be aware of the wide range of tools and programmes available.

This toolbox was initiated by the International Paediatric Brain Injury Society (IPBIS), and produced with the support of The Eden Dora Trust for Children with Encephalitis. It gathers tools and programmes used for the rehabilitation post-discharge from acute care, of children from birth to young adults aged 25 years, with mild to severe ABI.

The wide range of tools and programmes are indexed according to the deficit(s) addressed and the target user(s). The tools and programmes are divided into those that are free (Index A) and those that have to be paid for (Index B). Web addresses and/or contact details are provided so that further information can easily be obtained. It is assumed that the reader will select and use a particular tool or programme according to their own requirements. Tools and programmes are submitted biennially, reviewed and then added to the toolbox.

The majority of the tools and programmes included have been reviewed in peer-reviewed journals, and/or presented at national or international conferences. The IPBIS toolbox project team reviews the summaries of the tools and programmes submitted; those included in the toolbox are not endorsed or recommended by the organisation.

The IPBIS would like to thank The Eden Dora Trust for Children with Encephalitis for its continued help, support and collaboration with this project, and to all the healthcare professionals that have submitted tools and programmes.

IPBIS Board

QUESTIONS AND ANSWERS

WHO CAN USE THE TOOLBOX?

The toolbox is intended for use by all rehabilitation professionals who work with children from birth to young adults aged 25 years, with mild to severe ABI, as well as families and carers.

WHAT DOES THE TOOLBOX INCLUDE?

The toolbox includes tools and programmes for the rehabilitation of individuals with ABI post- discharge from acute care. ABI is defined as:

ABI is any injury to the brain which has occurred following birth. It includes Traumatic Brain Injuries (TBIs) such as those caused by trauma (e.g. a blow to the head from a road traffic accident, fall or assault), and non-TBIs related to illness or medical conditions (e.g. encephalitis, meningitis, stroke, substance abuse, brain tumour and hypoxia).

The tools and programmes address the physical, cognitive, academic and psychosocial problems associated with ABI.

HOW CAN I SUBMIT NEW TOOLS OR PROGRAMMES?

New tools and programmes can be submitted by completing the submission form accessed at www.ipbis.org/toolbox and emailed to lblakeborough@chapterfive.co.uk.

ARE THE TOOLS/PROGRAMMES SUBMITTED AUTOMATICALLY INCLUDED IN THE TOOLBOX?

Each tool/programme summary is reviewed by the IPBIS toolbox project team using agreed criteria. Depending on the outcome of the review, the tool/programme summary is then included.

HOW OFTEN IS THE TOOLBOX UPDATED?

New tools/programmes are reviewed biennially.

DO I HAVE TO BE A MEMBER OF THE IPBIS TO ACCESS THE TOOLBOX?

Membership is not a pre-requisite to accessing the toolbox. The toolbox is accessible on www.ipbis.org, www.internationalbrain.org and www.edendoratrust.org

TOOLBOX 2022

INDEX A: FREELY* AVAILABLE TOOLS/PROGRAMMES

The tools and programmes are indexed according to the deficit(s) addressed:

P/C/A/PS: Tool/programme addresses **P**hysical, **C**ognitive, **A**cademic and/or **P**sych**S**ocial deficits

and the target users:

H/P/F/E/CSW: Tool/programme will be used by the **H**ealthcare professional, **P**atient and/or **F**amily, **E**ducator, **C**ommunity **S**ervice **W**orker

The following tools and programmes are free*. Web addresses and/or contact details are provided so that further information can easily be obtained. It is assumed that the reader will select and use a particular tool or programme according to their own requirements.

*IPBIS is not responsible for any charges associated with the use of the tools/programmes

Tool No.	Tool/programme title	Deficit addressed				Target user				
		P	C	A	PS	H	P	F	E	CSW
1	N-ABLES ABI Return to Education	√	√	√	√	√	√	√	√	
2	Return to School website			√				√	√	
3	ABI School Aware Award			√	√				√	
4	Early Years Training Course	√	√	√	√			√	√	
5	Spooniekids	√	√	√	√	√	√	√	√	√
6	REACTIONS	√	√			√	√	√	√	√
7	Virtual Concussion Examination Training Manual			√		√				

N-ABLES ABI RETURN TO EDUCATION

1

TOOL/PROGRAMME SUMMARY

The Acquired Brain Injury (ABI) Return to Education (RTE) resources comprise:

- 1) ABI Return booklet: the information in this booklet helps professionals involved in helping children and young people (CYP) with an ABI to prepare for, and achieve, a successful RTE and to help progress their recovery
- 2) ABI Return poster: explains the guiding principles of a child returning to education
- 3) Special Educational Needs Coordinator (SENCo)/keyworker checklist: a practical resource to ensure that all vital steps have been carried out by educational professionals before the CYP returns to school, and helps the return be as successful as possible for the child
- 4) Supporting information: a practical resource for educational professionals to share information about a brain injury amongst members of their team in the school

BACKGROUND

The National ABI Learning and Education Syndicate (N-ABLES) was set up to identify ways to support education professionals in gaining a minimum level of awareness and understanding about ABI and the educational requirements of CYP with this condition.

It was established to support the recommendations made in the UK All-Party Parliamentary Group on ABI report entitled 'Acquired Brain Injury and Neurorehabilitation – Time for Change'. The report highlighted a widespread lack of education in this area for education professionals, problems in identifying the specific educational support needs of brain injured individuals and a lack of liaison between health and education professionals.

It is estimated that an average of one child in every classroom will experience an ABI, and it is therefore vital that their needs are understood and met by those working in education. Preparing an individualised plan and implementing adaptations will help to provide an appropriate teaching and classroom environment. This will enable the student to continue to make progress in their recovery, and to thrive personally, socially, and academically.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: H/P/F/E

KEY GOALS

- 1) To ensure children's' return to school following ABI is as successful and supportive as possible by offering practical resources for professionals
- 2) To promote an understanding of ABI and the educational needs of a young person with ABI amongst educational professionals
- 3) To encourage information sharing between education and healthcare professionals

HOW THE TOOL/PROGRAMME IS USED

The booklet and poster can be downloaded for free and contain information about ABI, and the difficulties a CYP may experience at school as a result of their injury. This can increase awareness and understanding of ABI for educational professionals. The booklet also offers guidance on how to use the checklist and supporting information documents. The checklist and supporting information document are also free to download and can be printed and used by necessary professionals. The checklist offers easy to follow steps to complete when a child is RTE following an ABI and allows for identification of the responsible professional(s) for each step. The supporting information is a summary of the CYP's injury and needs in school and is designed to be patient centred and unique to that child.

KEY OUTCOMES

- 1) Educational professionals gain a better understanding of ABI
- 2) Educational professionals have structured resources to help guide them when a child is returning to the classroom after ABI
- 3) The CYP with ABI has their educational needs met on their return to school, allowing them to reach their full potential

REFERENCES

- 1) Presented at IBIA World Congress, July 2021, virtual
- 2) Presented at UK Acquired Brain Injury Summit, London, November 2021

Contact for further information: Emily Morley (N-ABLES Assistant Psychologist): NABLES@UKABIF.org.uk

RETURN TO SCHOOL WEBSITE

2

TOOL/PROGRAMME SUMMARY

The Return to School website, designed for educators and parents who support students with brain injury, has a range of resources for use in the classroom. For example, the site hosts over 35 archived webinars on topics of relevance for educators (e.g., Inclusive Practices for Students with Traumatic Brain Injury (TBI), Promoting Successful Hospital to School Transitions for Students with Brain Injury). The site includes a range of tools and downloadable resources on topics (e.g., a matrix of symptom-based accommodations, basic information about brain injury, and guidelines for setting up a Concussion Management Team, assessment strategies, supporting students in the virtual learning environment).

The site also includes In the Classroom (ITC) after Concussion: Best Practices for School Success, a web-based training course in TBI. ITC includes content relevant for each of the school personnel involved in providing educational supports for students with concussion/brain injury in the school setting – (i.e., counsellors, teachers, school administrators, athletics staff, school nurses). The interactive learning modules offer specific strategies and resources for supporting students with concussion symptoms. Training content is grounded in educational practices shown to be effective with students with concussion and other disabilities (Glang *et al* 2008). The training was developed iteratively with input from educators, parents, and students. Results from a randomised controlled trial (Glang *et al* 2019) showed that ITC produced gains in educator skills, knowledge, and self-efficacy in working with students with TBI. A second study focused on knowledge translation validated these findings with a sample of educators in Washington (McCart *et al* 2020). Educators can receive continuing education for completion of the course, or can view individual modules on topics of interest.

All resources are provided free of charge.

BACKGROUND

The website was developed by the Center on Brain Injury Research and Training (CBIRT), Oregon, USA.

DEFICIT ADDRESSED: A
TARGET USER: F/E

KEY GOALS

- 1) To provide strategies on how to support students with a brain injury
- 2) To improve brain injury awareness and knowledge
- 3) To provide helpful information and resources for educators working with students with brain injury

HOW THE TOOL/PROGRAMME IS USED

Users can navigate through the website content by using the dropdown menu under each tab in the top navigation bar. In the Tools section users can click on the appropriate category to display and download resource documents.

KEY OUTCOMES

- 1) Increased concussion-related knowledge among educators
- 2) Supports the use of best-practice strategies for concussion in the school setting

REFERENCES

- 1) Glang A, McCart M, Slocumb J *et al.* Preliminary efficacy of online TBI professional development for educators: an exploratory randomized, clinical trial. *Journal of Head Trauma and Rehabilitation* 2019;34(2):65-76
- 2) Glang A, Ylvisaker M, Stein M *et al.* Validated instructional practices: application to students with traumatic brain injury. *J Head Trauma Rehabil.* 2008;23(4):243-251
- 3) McCart M, Glang A, Slocumb J *et al.* A quasi-experimental study examining the effects of online traumatic brain injury professional development on educator knowledge, application, and efficacy in a practitioner setting. *Disability and Rehabilitation* 2020; 42(17), 2430-2436
- 4) McCart M. Critical Issues in Youth. Best Practices in Return to School following Concussion. 32nd Annual Brain Injury Alliance of Utah Conference, Salt Lake City, USA, November 2021
- 5) McCart M and Glang A. Maximizing Functional Outcomes for Individuals with Traumatic Brain Injuries. American Speech-Language-Hearing Association, Online Conference, March 2020.
- 6) McCart M. Pediatric Acquired Brain Injury: Contemporary Advances Enhancing Clinical Care, Community Integration and Lifelong Living. National American Brain Injury Society, New Orleans, USA, February 2020.
- 7) McCart M. Solution Based Approaches to Training Professionals Working with Children and Supporting Successful Return to School After TBI (Invited Faculty/Co-Facilitator). International Brain Injury Association's 13th World Congress on Brain Injury, Toronto, Canada, March 2019
- 8) McCart M. Statewide Acquired Brain Injury School Reintegration, Consultation, and Training Programs -Decades of Experience: A Review of Three U.S. State Programs. International Brain Injury Association's 13th World Congress on Brain Injury. Toronto, Canada, March 2019
- 9) McCart M. State of Schools: Strengths and Weaknesses. International Pediatric Brain Injury Society Pre-Conference: Successful Education Following Childhood TBI. Queen's University, Belfast, Northern Ireland, UK, October 2018

Contact for further information: Melissa McCart: mccart@uoregon.edu | <https://returntoschool.org/>

ABI AWARE SCHOOL AWARD

3

TOOL/PROGRAMME SUMMARY

This best practice/quality framework, developed by the UK Child Brain Injury Trust (CBIT) in collaboration with the Eden Dora Trust for Children with Encephalitis, enables schools to work towards achieving whole school awareness, knowledge and understanding of childhood acquired brain injury (ABI); enabling children with an ABI to be fully supported within the education setting.

BACKGROUND

A greater awareness, knowledge and understanding of ABI within education is required to ensure children who have an ABI have access to appropriate support in order to achieve their education goals; currently there is little or no understanding about this hidden disability and the impact it has on a child's education achievements. All education professionals should have a minimum level of awareness and understanding about ABI and the educational requirements of children and young people with this condition. Additional training should be provided for the named lead professional who supports the individual with ABI, and for Special Educational Needs Coordinators (see All-Party Parliamentary Group on Acquired Brain Injury report 'Acquired Brain Injury and Neurorehabilitation Time for Change September 2018').

The ABI Aware Award provides the support, tools, and training to ensure schools can differentiate the needs of children following childhood ABI from other areas of special educational needs. All training is approved and certified with CPD hours by The CPD Service (UK-based). This award is available for settings educating children aged 5-18 years.

DEFICIT ADDRESSED: A/PS

TARGET USER: E

KEY GOALS

- 1) Whole school knowledge of childhood ABI and the need for specialist support in education, enabling high quality education and support for pupils/students affected by childhood ABI
- 2) Increased awareness within education of childhood ABI
- 3) Better outcomes for children and families affected by childhood ABI

HOW THE TOOL/PROGRAMME IS USED

The framework has 7 Elements. Each element is broken down into 39 criteria that schools have to evidence for assessment:

Element 1 – Leadership and Management

This element requires schools to have a whole school approach to supporting ABI, and policies are person centred. It requires schools to work closely with families to maintain optimum support levels.

Element 2 – Awareness, Understanding and Prevention

Awareness and understanding of ABI, how it manifests, the behavioural outcomes and how to support specific needs are imperative to supporting a child affected by ABI. Element 2 focusses on training to both prevent and support ABI.

Element 3 – Identification and Support

Element 3 helps to identify those children who may have an ABI who as yet have not been given a diagnosis, or have been misdiagnosed as having ADHD, Autistic spectrum disorders and other learning difficulties. It is about how well the school is able to support the specific needs of children affected by ABI.

Element 4 – Learner Environment

Children affected by ABI can be very easily over stimulated and require the right environment and resources to help them succeed; Element 4 aims to ensure this happens.

Element 5 – Family Support and Communication

Element 5 facilitates an open dialogue between the school and parents/guardians/carers so that the strategies to help support and learn can be consistent over school and home.

Element 6 – Transition/Return

Element 6 ensures that the ABI Aware School has all the right policies and support in place to aid a smooth transition.

Element 7 – Local Support Information Pack

For Element 7 the school must produce an information pack to signpost families to services, support groups and social opportunities that a family may need for their child affected by ABI.

Each school is provided with an Assessment tool to help them collate evidence on how they meet each of the criterion, and to evidence all the training elements that have been undertaken by both staff and pupils. When the school is ready, they submit their evidence, which is assessed by CBIT. If the school meets 95% or more of the criterion, they are given an 'ABI Aware School' status. The school will be listed on a data map of schools classed as being ABI Aware. Schools who achieve the Award reapply after three years and undertake interim training if any of the Lead SEN team changes.

ABI AWARE SCHOOL AWARD (continued)

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KEY OUTCOMES

- 1) Improved educational outcomes for children and young people following childhood ABI
- 2) Greater parental choice of school in being able to search for schools that are recognised as being 'ABI Aware'
- 3) Specialist CPD certified training for education professionals, where currently there is little or none

REFERENCES

- 1) Child Brain Injury Trust Virtual Conference 2021
- 2) NR Times, September 2021
- 3) Connect (NASEN magazine) – November 2021

Contact for further information:

Email: office@cbituk.org

| <https://childbraininjurytrust.org.uk/abi-aware-schools-award/>

EARLY YEARS TRAINING COURSE

4

TOOL/PROGRAMME SUMMARY

The Early Years Training Course developed by the Child Brain Injury Trust (CBIT) is an open-ended, modular self-study, Continuing Professional Development (CPD) certified, on-line training programme for professionals working with children in an Early Years under-fives setting. The course provides participants with a general understanding of childhood acquired brain injury (ABI). Professionals can apply to attend the course at any time; there is a rolling registration via the CBIT website:

2022 Early Years Course – this is an open-ended course; you can register at any time – Child Brain Injury Trust

The course comprises four online e-learning Modules of directed self-study, and participants submit 500/1000-word assignments to assess their level of learning. Participants receive their next module once the previous module is completed, and the assignment approved. The participants and course progression are overseen by the CBIT Head of Information and Learning who also reviews the assignments. After completing the four Modules and approval of the final 1000-word assignment, participants sit an online Assessment of Learning; if they receive a score of 85% or more they will receive an individual accreditation certified by The CPD Group.

If more than 50% of staff in the setting pass the course an ABI Aware U5s certificate is issued and valid for three years. Participants/settings are required to re-sit a knowledge assessment for re-certification. Each qualifying setting also receives free resources:

- 1) 'Oops I've bumped my head' stickers for children
- 2) 'Bump slips' for the nursery to complete about accidents, with advice about head injuries for parents
- 3) 'Head Injury Aware Setting' leaflets for the setting to give to parents as part of their induction process

Families can access the e-learning modules without submitting assignments or participating as an 'educator', to learn more about ABI. These requests are managed case-by-case.

BACKGROUND

Over 50% of all children 15 years and under attending Accident and Emergency Departments in England are under the age of five years and the majority report falls (Department of Health and Social Care). It is therefore imperative that those working in the Early Years under-fives setting have an understanding and awareness of childhood ABI, and how children under five years of age can acquire a brain injury. With improved knowledge Early Years professionals may be better placed to identify missed developmental milestones and investigate the reasons.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: F/E

KEY GOALS

- 1) Improved awareness, knowledge, understanding and prevention of ABI in early years education settings
- 2) Better support and early intervention, and thus improved outcomes for children affected by childhood ABI
- 3) Improved awareness for parents/families and carers from when their child is young

HOW THE TOOL/PROGRAMME IS USED

After preparatory study before each of the four individual modules, participants can access CBIT's online E-learning sessions. They submit a 500-word written assessment of their learning from each module, prior to the release of the next self-study preparatory work and access to the next module.

At the end of the fourth module participants write a 750-word assignment explaining key learning outcomes that could be shared with colleagues to provide an overview of what has been learned about ABI.

Each assignment is reviewed by the CBIT Head of Information and Learning, and feedback provided to clarify and reinforce understanding of learning. This is done for each assignment and provides opportunities for reflection and further understanding of the module.

Delegates are required to sit an online multiple-choice assessment, requiring a 90% pass in order to be awarded a Certificate of Attendance.

Module 1 – Course Induction and ABI Overview – 40 minutes

Pre-module preparation: 45 minutes

Public Health England Report – Reducing unintentional injuries in and around the home among children under five years

Post-module assignment: 500 Words – Why is this course important for Early Years practitioners?

Module 2 – Basic Brain Function – 90 minutes

Pre-module preparation: 30 minutes

Research on neurons, two Video Clips

Post-module assignment: 500 Words – Why is the frontal lobe important? What is the possible impact if the frontal lobe is damaged?

Module 3 – Understanding Childhood Acquired Brain Injury – 90 minutes

Pre-module preparation: 30 minutes

Case Study

Post-module assignment: 500 Words – What are the case study's missing milestones? What could you do as a early years professional do to support him and his family?

Module 4 – prevention, awareness, and strategies: 60 minutes

Pre-module preparation: 30 minutes

Case Study

Post-module assignment: 750 Words – Prepare an overview of the whole learning from this course, to share with colleagues

Online Assessment of Learning – 45 Minutes

On completion of the Early Years Course participants will further their understanding of:

Why there needs to be greater awareness of ABI in early years settings

Basic Brain functions and the impact of ABI on a young child

How children acquire brain injuries

Prevention of head injury and ABI

The impact on the family of having a child with an ABI

The impact of an ABI in relation to the Early Years Statutory Framework (England)

Strategies for support

KEY OUTCOMES

- 1) Better awareness, understanding and knowledge of ABI within Early Years under-fives setting
- 2) Improved educational and social outcomes for children under 5 years who are affected by ABI
- 3) Greater general awareness of ABI within the general population (parents/carers and guardians)

REFERENCES

- 1) Presented at Neuro Convention 2019, Birmingham, UK
- 2) Early Years Educator (online resource website www.earlyyearseducator.co.uk) accepted for publication and scheduled for Spring 2022
- 3) Under 5 magazine (produced by Early Years Alliance www.eyalliance.org.uk) accepted for publication and scheduled for Spring 2022

Contact for further information: Email: office@cbituk.org

TOOL/PROGRAMME SUMMARY

The tool aims to support individuals living with fatigue by promoting an increased understanding of the nature and management of fatigue following a brain injury. The aim is to enable and enhance participation in meaningful activities for the children, young people and families who are experiencing fatigue, both within a specialised setting but also crucially within the context of the child's community, taking a targeted approach to further support the management of what can sometimes be long standing and life affecting condition following a brain injury.

It aims to outline the impact that fatigue has on children, young people and their families following a brain injury and to explore practical ways to (help) manage the impact that fatigue can have on participation, providing a systematic but flexible approach it aims to support the development of effective and individualised action plans.

BACKGROUND

Research highlights a significant association between high levels of fatigue, limited participation, and diminished quality of life. (Wilkinson *et al.*, 2018 and van Markus-Doornbosch *et al.*, 2020).

In particular, cognitive fatigue was reported in up to 50% of patients seven years after injury (Camara – Costa *et al* 2020). The general consensus from the research is that for children and young people fatigue is often a long-lasting and persistent symptom consequence of ABI. However, little is documented in the research to date on the management of these symptoms.

The tool was developed in consultation with children and young people with lived experience. Spoon Theory was written and created by Christine Miserando. This theory has been adapted, and a resource developed (Spoonie Kids) for use with children, young people and their families by Joanna Hunt, specialist occupational therapist at The Children's Trust, UK. Spoons is the term developed through lived experience, named, defined, and described by the patient community. We can use it to support the targeted use once in the community, knowing that it allows for this expansion should it be needed. Spoons offers a simple yet powerful analogy that enables children to be heard and understood.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: H/P/F/E/CSW

KEY GOALS

- 1) To develop a better understanding of the impact that fatigue can have on participation and how to help manage the challenges
- 2) To provide resources to help cope with fatigue and share strategies on how to avoid boom and bust cycles whilst promoting attendance and engagement in varied life situations
- 3) To promote autonomy in the children and young people living with fatigue whilst supporting caregivers in also feeling confident that they are supporting their child safely, they are able to advocate for their needs and feel confident to focus on what they CAN DO, instead of what they cannot by increasing the knowledge, skills and understanding of how best to support the management of symptoms

HOW THE TOOL/PROGRAMME IS USED

The tool can be used in specialised and / or targeted educational or community settings and consists of four stages supported by use of the worksheet resource. Although not linear, There are four key stages to this approach which are also expanded below:

Stage 1: Education – creating a shared understanding

A spoon is a metaphor or code word for an amount of energy or currency which can be saved or spent on different tasks. You would first sit down with the child and family to introduce the resource, asking the question "what is spoon theory?" explaining what the term means, then saying something like: So how many spoons do we have? explaining broadly that a healthy individual starts with an abundance of spoons, a supply that although not limitless can be topped up throughout the day. In comparison, a 'spoonie' needs to plan, pace, and prioritise how best to spend and save their spoons, realising that there is not the limitless amount that they once thought there was.

Stage 2: Analysis – identifying triggers, (what things take up spoons?)

The second stage serves as an evaluative tool. Asking questions like: What things take up spoons? What things make it cost more? Does anything help save spoons? What does that look like? Are there any activities that might cost more than others"? by asking these Q's we are helping to support the analysis and evaluation of how fatigue impacts them, in their world. Using the worksheet and visuals may be very helpful here.

Stage 3: Intervention – monitoring energy, ‘what should I do if I run out of spoons’

Once there is greater understanding, the CYP and caregivers cease describing an exact number of spoons for a particular task. Instead ‘spoons’ becomes a common language that acknowledges and adapts to the fluidity of the situation as opposed to a prescriptive ‘well you said it cost four spoons to get dressed’. Instead, it is simply a ‘low spoons day’. All that the CYP needs to say then is something like “I have run out of spoons mummy”. The language has been provided that enables the child to say in a very simple way what their body needs and to know that they will be heard and understood reducing the focus on what they cannot do and instead allowing more opportunity for celebrating what they can do. Given the strong influence of contextual factors, the structure and key components discussed are unlikely to be a set of hard and fast rules, but a set of principles for action that are ‘contextually coloured in’

Stage 4: Re-evaluation – what worked? How did you save a spoon?

When a child has ran out of spoons, they might reach a point where their brains just ‘shut off’, so considering what strategies are needed in advance is key. It is important that this time is taken when they have enough spoons to do this reflection and evaluation. Through the process itself, by using coaching techniques, guided discovery, and experiential safe learning the CYP is building their skills to create both an adaptable and individualised toolkit that works for them, not just in the safety of familiar settings but across all areas of life.

By using the resource within context, it allows for experiential shared learning, which become the foundation for collaborative and individualised management plans.

KEY OUTCOMES

- 1) To increase the knowledge, skills and understanding of how best to support the management of fatigue, providing an overview of the necessary framework and tools to effectively implement strategies and aims to increase health related quality of life for the children, young people and families living with this condition
- 2) Using the analogy of Spoons to better articulate, understand and manage fatigue, enabling young people to make choices and participate more fully in activities of their choice
- 3) To promote a values-based approach and support a positive sense of self so that young people feel safe to express their body’s needs in the context of their community
- 4) To shift the focus of life from what you CAN’T do to what you CAN do

REFERENCES

- 1) Presented at the Royal College of Occupational Therapists Specialist Section: Children Young People and Families, Annual National Conference (online) October 2021
- 2) Accepted as an oral presentation at the European Academy of Childhood Disability Conference, Barcelona, Spain, May 2022
- 3) Presentation scheduled for 2022 The Children’s Trust (UK) Virtual Seminar series
- 4) Since 2019 the resource has been presented across a range of settings/trusts including both acute and community NHS Trust services, as well as to schools and nurseries across the UK. Organisations currently using the resources include The Children’s Trust where the resource is being used as part of their Functional Neurological Disorder pilot programme, Great Ormond Street Hospital for Children NHS Foundation Trust, Enable Ireland: The Children’s Disability Network, St George’s University Hospitals NHS Foundation Trust, University College London Hospitals NHS Foundation Trust, Hounslow & Richmond Community Healthcare NHS Trust, Salford Royal NHS Foundation Trust, NHS Lothian, Nevada Virtual Academy online public school

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<https://www.thechildrenstrust.org.uk/brain-injury-information/latest/spoonie-kids-launches-help-manage-fatigue>

REPORT OF EARLY CHILDHOOD TRAUMATIC INJURY OBSERVATIONS AND SYMPTOMS (REACTIONS)

TOOL/PROGRAMME SUMMARY

Caregivers or health professionals complete this observational questionnaire to document the presence of post-concussive symptoms (PCS) in the child. Parents are asked to report whether their child verbalises symptoms typically associated with concussion or to indicate whether the child manifests behaviours that could be associated with these symptoms. Three domains of PCS are considered: cognitive (attention/concentration, memory, thinking or moving slowly), physical (headache, nausea, balance, fatigue, sleep, vision, sensitivity to light/noise/touch) and behavioural (irritability, mood and motivation, anxiety, regression, comfort seeking).

BACKGROUND

Children 0 to 5 years of age have the highest rate of presentation to emergency departments (EDs) for traumatic brain injury/concussion among paediatric groups. In older school-aged children, even mild injuries (mTBI or concussion) can result in PCS including physical (e.g., headache, sleep disturbances), cognitive (e.g., forgetfulness, poor attention), and behavioral (e.g., irritability, anxiety) changes. Tracking PCS is therefore a cornerstone of diagnosis, management, and treatment; yet very little is known about the presence and evolution of PCS after early mTBI. Some studies suggest that caregivers of young children may underreport PCS1–3; however, this could be due to the absence of any validated measure to capture PCS in infants, toddlers, and preschoolers. Given the lack of any validated PCS measure for children five years of age and younger, and the need for a developmentally appropriate approach to documenting PCS in preverbal and emerging talkers, the Report of Early Childhood Traumatic Injury Observations and Symptoms (REACTIONS) inventory was created.

DEFICIT ADDRESSED: P/C

TARGET USER: H/P/F/E/CSW

KEY GOALS

- 1) Document PCS in infants, toddlers, and preschoolers
- 2) Provide validation information for the Report of Early Childhood Traumatic Injury Observations and Symptoms (REACTIONS) inventory

HOW THE TOOL/PROGRAMME IS USED

The questionnaire is completed either on paper or electronically using an online survey platform. Instructions for completing the measure are provided directly on the questionnaire.

KEY OUTCOME

- 1) Identify PCS in young children (0-8 years approx)

REFERENCES

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- 2) Laurendeau J, Beaudoin C, Désiré N *et al.* Preliminary validation of the REACTIONS questionnaire. Conference proceedings of the International Neuropsychological Conference, New York, USA, 2019
- 3) Ibrahim A, Laurendeau-Martin J, Beaudoin C *et al.* REACTIONS to traumatic brain injury: Validating a new post-concussive symptoms and observations checklist for early childhood. Poster presented at Congrès Provincial de la Recherche Mère-Enfant, Montréal, QC, May 2018

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VIRTUAL CONCUSSION EXAMINATION TRAINING MANUAL

TOOL/PROGRAMME SUMMARY

The Virtual Concussion Examination (VCE) Training Manual was developed to assist front-line primary care physicians conduct a virtual concussion examination (VCE). The VCE was developed for use by family doctors who are caring for patients that may have barriers to being seen in person or have already had an in-person assessment and require follow-up. The VCE harmonises recommendations from the Living Guideline for Pediatric Concussion Care and the Ontario Neurotrauma Foundation adult mTBI guidelines^{1,2}. The VCE manual tool is freely accessible via a pdf on the internet, includes embedded training videos, and was refined using iterative feedback from family physicians.

BACKGROUND

Patients with suspected concussion should be assessed by a physician or nurse practitioner as soon as possible to rule out more severe injury. Early diagnosis and management of concussion is associated with faster recovery^{3,4}. All patients presenting with suspected concussion require a medical assessment. Patients with diagnosed concussion are required to return for a medical re-assessment 1-2 weeks after acute injury. The comprehensive medical assessment is comprised of a detailed medical history and a physical examination (vital signs, level of consciousness, mental status, neurological examination, cervical spine examination, and an examination of the visual and vestibular systems). Management of concussion includes guidance on rest and the safe and gradual return to mental and physical activities including school, work, and sport. Early referral to interdisciplinary concussion care for those at risk of a prolonged recovery is associated with best outcomes^{3,4}.

Best practice guidelines for managing concussion are evolving quickly and there is variance in the baseline comfort of primary care practitioners with concussion examinations. The pivot to virtual primary care during the SARS-Cov-2 pandemic highlighted the following deficits: (1) evidence-based guidance to determine who would benefit from a virtual concussion medical examination; (2) adaptation of in-person medical assessments to virtual assessments for patients who would benefit; and (3) dissemination and implementation of a VCE to ensure front-line primary care physicians have the tools available to deliver high-quality care at the right time and in the right place.

With the easing of pandemic restrictions, the VCE training manual resource is an important tool to support clinicians returning to in-person or in-person-virtual care hybrid models. Dissemination and implementation of this resource in clinical practice will standardise high-quality care for youth and adults with concussion and ensure that the best care is delivered as efficiently as possible.

DEFICIT ADDRESSED: A
TARGET USER: H

KEY GOAL

1) To standardise evidence-based concussion care for youth and adults by disseminating a virtual concussion care training manual that is based on up-to-date clinical guidelines and standards of care pathways

HOW THE TOOL/PROGRAMME IS USED

This tool is designed as a standalone training document for primary care physicians. The interactive pdf format has been optimised for desktop computers, tablets, and cell phones. The resources include a link to the Living Guideline for Pediatric Concussion Care 'Considerations for telemedicine and virtual care algorithm' that was developed in collaboration with over 40 concussion experts and clinicians from North America to provide medical professionals treating patients with concussion, with a tool to determine which patients meet eligibility criteria for a telemedicine/virtual concussion assessment. The VCE is estimated to take approximately 15 minutes and 30 seconds to complete. It includes a physical assessment of the neck and sub-occipital region, face, jaw, cranial nerve, vestibular ocular motor screening, an assessment of a person's physical coordination, upper extremity gross and sensorimotor screening, positional sensitivity, and lower extremity gross motor and sensorimotor screening; all adapted from validated in-person examinations.

The VCE training resource can be accessed at the following web link: <https://pedsconcussion.com/virtualconcussionexammanual/>

VIRTUAL CONCUSSION EXAMINATION TRAINING MANUAL (continued)

KEY OUTCOMES

- 1) Provides primary care physicians with the tools needed to conduct a virtual concussion examination
- 2) The VCE improves access to timely care in a safe and evidence-based manner

REFERENCES

- 1) Reed N, Zemek R, Dawson J *et al.* The living guideline for pediatric concussion care [Internet]. PedsConcussion. 2021. Available from: <https://pedsconcussion.com>
- 2) Marshall S, Bayley M, McCullagh S *et al.* Guideline for Concussion/Mild Traumatic Brain Injury (mTBI) and Prolonged Symptoms (3rd edition, 2018) [Internet]. Ontario Neurotrauma Foundation. 2018. Available from: <http://braininjuryguidelines.org/concussion>
- 3) Kontos AP, Jorgensen-Wagers K, Trbovich AM *et al.* Association of Time Since Injury to the First Clinic Visit With Recovery Following Concussion. *JAMA Neurol* 2020;77(4):435–40
- 4) Eagle SR, Puligilla A, Fazio-Sumrok V *et al.* Association of time to initial clinic visit with prolonged recovery in pediatric patients with concussion. *J Neurosurg Pediatr* 2020;1–6

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TOOLBOX 2019

INDEX A: FREELY* AVAILABLE TOOLS/PROGRAMMES

The tools and programmes are indexed according to the deficit(s) addressed:

P/C/A/PS: Tool/programme addresses **P**hysical, **C**ognitive, **A**cademic and/or **PS**ychoso**S**ocial deficits

and the target users:

H/P/F/E/CSW: Tool/programme will be used by the **H**ealthcare professional, **P**atient and/or **F**amily, **E**ducator, **C**ommunity **S**ervice **W**orker

The following tools and programmes are free*. Web addresses and/or contact details are provided so that further information can easily be obtained. It is assumed that the reader will select and use a particular tool or programme according to their own requirements.

*IPBIS is not responsible for any charges associated with the use of the tools/programmes

Tool No.	Tool/programme title	Deficit addressed				Target user				
		P	C	A	PS	H	P	F	E	CSW
1	Brains Ahead!	√	√	√	√	√	√	√		
2	SCHOOLFirst	√	√	√		√	√	√	√	√
3	Social, Participation and Navigation (SPAN)				√	√				
4	Concussion Awareness Training Tool (CATT)	√	√	√		√	√	√	√	
5	Seeing Brain Injury Clearly (SPECS)	√	√	√	√	√			√	√
6	Active-8 Your Brain	√	√		√	√	√			
7	Parents In Mind	√	√	√	√	√	√			
8	The Children's Trust Brain Injury Community Service (BICS)		√	√	√	√	√	√	√	√
9	Cognitive and Linguistic Scale (CALS)		√			√				
10	Upper Extremity Measurement Scale (UEMS)	√				√				
11	Physical Abilities and Mobility Scale (PAMS)	√				√				
12	CanChild Concussion Management Return-to-Activities Guidelines	√	√	√	√	√	√	√	√	
13	CanChild Concussion Management Return-to-School Guidelines	√	√	√	√	√	√	√	√	
14	Mental Health Considerations Algorithm	√	√			√				
15	Management of Prolonged Mental Health Disorders Algorithm	√	√			√				
16	Sample Letter/Email from School to Parents	√	√	√	√				√	

TOOLBOX 2019

INDEX A: FREELY* AVAILABLE TOOLS/PROGRAMMES

Tool No.	Tool/programme title	Deficit addressed				Target user				
		P	C	A	PS	H	P	F	E	CSW
17	Letter Template from Concussion Team to Child/Adolescent's School	√	√	√	√				√	
18	Manage Acute and Prolonged Concussion Symptoms Algorithm	√	√			√				
19	Strategies to Promote Good Sleep and Alertness	√	√				√	√		
20	Prolonged Post-Concussion Sleep Disturbances Algorithm	√	√			√				
21	Concussion Implications and Interventions for the Classroom	√	√	√	√				√	
22	'Four Ps' – Prioritise, Plan, Pace and Position	√	√	√			√			
23	Checklist of Factors that may influence Sleep/Wake Cycle	√	√			√				
24	Post-Concussion Vision, Vestibular and Oculomotor Disturbances Algorithm	√	√			√				
25	Post-Concussion Information Sheet	√	√	√			√	√	√	
26	Post-Concussion Headache Algorithm	√	√			√				
27	Letter Template from Physician to Child/Adolescent's School	√	√	√	√				√	

Deficit addressed: **P**hysical, **C**ognitive, **A**cademic and/or **PS**ychosocial deficits

Target user: **H**ealthcare professional, **P**atient and/or **F**amily, **E**ducator, **CSW** Community Service Worker

BRAINS AHEAD!

1

TOOL/PROGRAMME SUMMARY

Brains Ahead! is a psychoeducational intervention for children and adolescents with mild Traumatic Brain Injury (mTBI) and for their caregivers. It combines an inventory of symptoms, psychoeducation and follow-up, involving the child's family in the process. The Brains Ahead! intervention is expected to prevent long-term post-concussive symptoms and problems in activities and participation. The advantage of the intervention is the standardised psychoeducational information, combined with an individual approach, starting at an early stage after the injury. The intervention is currently being evaluated in a multicentre randomised controlled trial.

BACKGROUND

mTBI is the most common cause of Acquired Brain Injury (ABI) among children and adolescents. In many countries the usual care for these individuals consists of short hospitalisation or immediate discharge. At discharge, they may receive an information leaflet to take home, with recommendations to return to the general practitioner or hospital if there is frequent vomiting, increasing drowsiness and/or an increase in other symptoms during the following days. For this group of patients there is no international consensus on structural follow-up by a (paediatric) neurologist or rehabilitation physician, despite the fact that approximately 20% of them have a variety of long-term physical, cognitive, emotional or behavioural symptoms. As a result these children may develop long-term limitations in activities and participation, for example, in school and social relations.

Several studies indicate that early education, re-assurance and even early cognitive behavioural approaches may be effective in preventing long-term problems after TBI in both children and adults and, more specifically, post-mTBI. Brains Ahead! was developed to prevent long-term symptoms and to establish a more successful return to activities and participation after mTBI in children and adolescents aged 6-18 years.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: H/P/F

KEY GOALS

- 1) To enable individuals with mTBI and caregivers recognise and anticipate the relevant symptoms at an early stage post-mTBI
- 2) To prevent long-term problems for individuals with mTBI in activities and participation

HOW THE TOOL/PROGRAMME IS USED

During the first 2-4 weeks post-injury, a health professional experienced in working with children with mTBI schedules a face-to-face appointment with the child and their parents. During this one-hour meeting, general information and a standardised questionnaire about brain injury related symptoms are used to screen for consequences. Depending on the results of the questionnaire individualised education is provided. The psychoeducation is administered using a presentation on a laptop and a standardised booklet containing information to take home. There is a booklet for parents, a booklet for children aged 6-12 years and a booklet for children aged 12-18 years. From 6-8 weeks post-injury a telephone follow up of 30 minutes is planned. The children and parents can contact the professional more often, and referral for rehabilitation treatment can be arranged if needed. The inventory of symptoms and the psychoeducational session takes place in the hospital where the child was seen in the emergency department at the time of the injury. The intervention is administered by a professional, experienced and educated in paediatric rehabilitation after mTBI in children and adolescents.

KEY OUTCOME

- 1) Patients and caregivers can recognise and anticipate the relevant symptoms at an early stage, and prevent longer-term problems in activities and participation

REFERENCES

- 1) Renaud MI, van de Port IG, Catsman-Berrevoets CE. Clinical Rehabilitation 2018; 32 (11):1440-1448 <https://journals.sagepub.com/doi/full/10.1177/0269215518785418>
- 2) Presented at the 3rd International Conference on Paediatric Acquired Brain Injury, Belfast 2018

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TOOL/PROGRAMME SUMMARY

SCHOOLFirst is a user-friendly, accessible, interactive and evidence-based resource that has been transformed into a website. The bilingual (English and French) website provides a compilation of information and resources that assists the education community in supporting students with re-integration and return-to-school (RTS) after a concussion. The new website also includes videos from different users such as educators on the importance of supporting students with RTS after a concussion and how the resources on the website can help. Content on the website can also be downloaded into a PDF format. The original SCHOOLFirst resource and the website were developed by an interdisciplinary team, in consultation with key stakeholders who have experience of supporting students to reintegrate and RTS after concussion. Visit the SCHOOLFirst website at: <https://schoolfirstconcussion.ca/> or <https://fr.schoolfirstconcussion.ca/>

BACKGROUND

The field of paediatric concussion is young, growing and not yet standardised. After a concussion, it is important that young people are supported in their RTS but it is a difficult task. Re-engagement in school-based roles and activities is paramount for young people following concussion, but there is inconsistent information available regarding the RTS process. While protocols and resources are available to inform 'what' steps to take to RTS after sustaining a concussion, resources provide insufficient support on 'how' to put these steps into action. To address this gap, 'SCHOOLFirst' was developed to assist school personnel (teachers, administrators and staff) with supporting students to successfully return-to-school post-concussion. With the emergence of concussion evidence and resources, the SCHOOLFirst pdf resource was transformed into a website.

DEFICIT ADDRESSED: P/C/A

TARGET USER: H/P/F/E/CSW

KEY GOALS

- 1) To develop 'Concussion Champions' in each school
- 2) To provide ideas on how to support students with a concussion
- 3) To improve concussion awareness and knowledge

HOW THE TOOL/PROGRAMME IS USED

The website is user-friendly, accessible, and interactive, providing the user with links to explore on the topics of 'building your knowledge', 'creating a supporting culture', and 'knowing your role' as it relates to supporting students RTS after a concussion. A <https://www.youtube.com/watch?v=qvvRPRjVOt8> introductory video has been created for users to learn more about SCHOOLFirst and how to use the website to support students RTS. The website includes descriptive content, videos and links to external resources to advance learning. The entire website can also be downloaded into a pdf format. The usability of the website has been measured and participants provided positive feedback.

KEY OUTCOMES

- 1) 'Concussion Champions' are available in the school
- 2) Students with concussion are supported
- 3) Concussion awareness and knowledge is increased

REFERENCES

- 1) 3rd International Conference on Paediatric Acquired Brain Injury, Belfast 2018
- 2) 13th World Congress on Brain Injury Toronto, Canada, 2019
- 3) Canadian Academy of Sport and Exercise Medicine Annual Symposium Vancouver, Canada, 2019

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Nick Reed: nreed@hollandbloorview.ca | Website: <https://schoolfirstconcussion.ca/>

or <https://fr.schoolfirstconcussion.ca/>

TOOL/PROGRAMME SUMMARY

Social, participation and navigation (SPAN) is an app-based coaching intervention for adolescents and emerging young adults with Acquired Brain Injury (ABI).

BACKGROUND

Adolescents and emerging young adults with ABI are often restricted in their participation in school, home, and community life. Evidence-based interventions to promote social participation are lacking, despite evidence that social participation is critical for successful outcomes across the lifespan. To address this need SPAN, an app-based coaching intervention for adolescents and emerging young adults with ABI was developed, tested and refined by a team of researchers led by Dr Shari Wade (Cincinnati Children's Hospital and Medical Center) and Dr Gary Bedell (Tufts University).

Teenagers with ABI who participated in SPAN were able to develop and achieve social participation goals, and the majority reported that they liked the virtual coaching sessions with college student coaches. However, a key limitation was that the mobile app initially created for SPAN could only be used on iPhones and iPads. Additional technical challenges were identified with the mobile app usability, and participants using SPAN tips and information topics. To address these limitations, a new SPAN website and web app was created (July 2017 to February 2018) to enable users to use the app on multiple devices, and to improve overall app usability and knowledge uptake of the tips and topics for multiple stakeholders. Initial usability testing of the new SPAN website and web app was completed in May 2018. Additional usability studies are underway in preparation for larger implementation trials.

DEFICIT ADDRESSED: PS

TARGET USER: P

KEY GOALS

- 1) To support goal setting and the implementation of planned steps and strategies to accomplish social participation goals
- 2) To identify supports and barriers to goals achievement

HOW THE TOOL/PROGRAMME IS USED

Teenagers and young adults in the SPAN programme are given access to the web-based app to help them set and keep track of their goals. They also partner with a trained college student peer coach who helps them develop goals and actively work on a plan to achieve each goal. In SPAN, each person's strengths are emphasised, challenges acknowledged, and support provided to help each person find ways to achieve their goals.

The SPAN website and app includes key topics and brief tips with information and strategies to support social participation, goal planning, problem solving, self-monitoring, self-control, staying positive, joining conversation and groups. Additional tips and topics are currently being developed. Individuals meet weekly coaches via Skype, and coaches are supervised on a weekly basis. Currently the website is freely available, but the web-based app is by permission only. Refinements to the coach training and guidelines are underway, as are collaborations with colleagues who are translating the app into other languages, modifying for other populations (that need assistance related to social and executive functioning), and/or considering integration into clinical or community-based practice or use with different types of coaches (eg: existing peers or members in circle of support).

KEY OUTCOMES

- 1) Increased social participation
- 2) Increased goal planning and strategy generation
- 3) Identification of supports and barriers to goal achievement

REFERENCES

- 1) Bedell G, Wade SL, Turkstra LS *et al.* Informing design of an app-based coaching intervention to promote social participation of teenagers with traumatic brain injury: Stakeholder perspectives. *Developmental Neurorehabilitation* 2017; 20:408-417. <https://doi.org/10.1080/17518423.2016.1237584>
- 2) Narad ME, Bedell G, King JA *et al.* Social Participation and Navigation (SPAN): Description and usability of app-based coaching intervention for adolescents with TBI. *Developmental Neurorehabilitation* 2018;21(7):439-448. <https://doi.org/10.1080/17518423.2017.1354092>
- 3) Wade SL, Bedell G, King JA *et al.* Social Participation and Navigation (SPAN) program for adolescents with acquired Brain Injury: Pilot findings. *Rehabilitation Psychology* 2018; 63(3):327-337 <http://dx.doi.org/10.1037/rep0000187>
- 4) Presented at the 3rd International Conference on Paediatric Acquired Brain Injury, Belfast 2018

CONCUSSION AWARENESS TRAINING TOOL (CATT)

4

TOOL/PROGRAMME SUMMARY

The Concussion Awareness Training Tool (CATT), produced by Canada's British Columbia Injury Research and Prevention Unit, is a series of online educational modules and resources for standardising concussion recognition, diagnosis, treatment and management.

CATT is a comprehensive, evidence-based resource and includes 5 e-learning modules and all are free-of-charge:

- CATT for medical professionals
- CATT for coaches
- CATT for parents
- CATT for school professionals
- CATT for school administrators

Research and the evidence-base on concussions is evolving and the knowledge base is continually changing. As a result, the website is updated on a regular basis to provide current information, tools, and resources to support concussion recognition, diagnosis, treatment and management.

The programme is available in English and French.

BACKGROUND

Sport plays an important role in maintaining mental and physical wellbeing, however, concussion is an under-recognised, under-diagnosed and under-treated medical condition requiring both physical and mental rest. Good concussion management is pivotal to minimising the risk of brain damage and may reduce long-term health consequences. CATT was developed to address the gap by increasing knowledge and awareness among appropriate specific audiences.

CATT for medical professionals was originally launched in 2013, focusing on the recognition and diagnosis of concussion. The new CATT for medical professionals launched in 2018, addresses current gaps and variations in practice for the initial assessment and management of acute concussion patients in the office setting. CATT for parents and coaches, launched in 2014, covers concussion identification and management, with resources including the Smartphone accessible Concussion Response Tool and Questions to Ask Your Doctor. CATT for school professionals, launched 2016, includes Return-to-Learn protocol and resources to support teachers, administrators, counsellors and others in the school setting. CATT for workers and workplaces, launched in 2018, focuses on concussion management in the adult population.

DEFICIT ADDRESSED: P/C/A

TARGET USER: H/P/F/E

KEY GOALS

- 1) To increase knowledge and awareness amongst key audiences
- 2) To support the standardised treatment and management of concussion

HOW THE TOOL/PROGRAMME IS USED

The easy-to-use website steers the audience through the information, resources and videos that are most appropriate.

KEY OUTCOMES

- 1) Increased concussion-related knowledge amongst all users
- 2) Supports the implementation of a standardised protocol for the recognition, treatment, and management of sport-related concussion

REFERENCE

- 1) Presented at the 3rd International Conference on Paediatric Acquired Brain Injury, Belfast 2018

Contact for further information: concussion@bcchr.ca | <https://cattonline.com/>

SEEING BRAIN INJURY CLEARLY (SPECS)

5

TOOL/PROGRAMME SUMMARY

Seeing Brain Injury Clearly (SPECS) is a psychosocial training for professionals working with children and young people with Acquired Brain Injury (ABI). It is an acronym for core psychosocial factors that are important to address in successful neurorehabilitation: Social, Physical, Emotional, Cognitive and Spiritual.

SPECS comprises an introductory and advanced day training programme each concentrating on different aspects of psychosocial care, including:

Introductory day:

- Introduction to SPECS
- In the parents' shoes
- Grief and loss
- Managing expectations and transition
- Difficult questions and communication
- Behaviour that challenges others

Advanced day:

- Cultural and family belief systems
- Adjustment, grief and loss, the concept of reasonable hope
- Managing expectations and community transition
- Behaviour that challenges others and complex presentations

BACKGROUND

Psychosocial factors are major predictors of long-term outcome in this population. Very few training packages exist for professionals that specifically address the unique psychosocial needs of children and young people with severe ABI, as well as their families and the staff looking after them.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: H/E/CSW

KEY GOALS

- 1) Improve confidence in providing high quality psychosocial care
- 2) Improve competence in providing high quality psychosocial care
- 3) To promote a truly holistic approach in paediatric neurorehabilitation

HOW THE TOOL/PROGRAMME IS USED

The training is currently provided to interdisciplinary groups at The Children's Trust (UK) in order to support shared learning and explore multiple perspectives. The delivery includes multi-model learning methods (didactic approach, films, reflective exercises, TED talks, parent and children/young people pieces, self-directed learning, group learning), with a balance of practical information and non-technical use of language. It is accessible to staff across both clinical and non-clinical backgrounds.

KEY OUTCOMES

- 1) Key benefits to professionals have been reported as enhanced awareness, knowledge, confidence and skills to work effectively with children/young people and families affected by ABI
- 2) Families have reflected on the abilities of staff to support them in increasing their knowledge of ABI, enhancing coping, adjustment and adaptation and reducing a sense of isolation.
- 3) Increased confidence and competence of staff

REFERENCES

- 1) Davies S.C. (2012) Chief Medical Officer annual report 2012: children and young people's health. Our children deserve better. Department of Health and Social Care
- 2) Ross K.A, Dorris L and McMillan T. A systematic review of psychological interventions to alleviate cognitive and psychosocial problems in children with acquired brain injury. *Developmental Medicine and Child Neurology* 2011;53(8):692-701

Contacts for further information:

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TOOL/PROGRAMME SUMMARY

Active-8 is an 8-week intervention with young people aged 14-18 years which aims to increase post- Acquired Brain Injury (ABI) physical activity (PA) levels.

BACKGROUND

It is recognised that after an ABI many previously active young people have vastly reduced PA levels. As a result they experience decreased fitness, and fewer opportunities for engaging with the social and emotional benefits of physical activity. Given the known advantages of regular exercise on mood, cognition, fatigue and sleep, the Active-8 programme was designed to provide rehabilitative support, focused around increasing PA, using activity trackers, goal-setting and psychoeducation. The Active-8 programme was designed to support young people with an ABI who are frequently less physically active since their injury/illness. The programme uses goal-setting and psychoeducation to encourage participants to increase PA levels over an 8-week period. They are supported by a 'coach' and track their progress with a Fitbit.

DEFICIT ADDRESSED: P/C/PS
TARGET USER: H/P

KEY GOALS

- 1) To increase levels of PA
- 2) To improve participant understanding of the benefits of PA after ABI
- 3) To have a positive impact on mood, fatigue, sleep and participation

HOW THE TOOL/PROGRAMME IS USED

Participants who choose to take part are provided with an activity-tracker (Fitbit) and asked to track their physical activity over a 2-week baseline period. They are then seen by a clinical psychologist for an intervention (psychoeducation) session focused around the benefits of PA after ABI, and supported in setting goals targeting their PA levels. Participants then complete an 8-week intervention with weekly phone calls from the psychologist/coach to set goals, and to discuss progress and challenges. The young people and their parents/carers complete questionnaires before commencing the programme, and at the end of the 8-week period.

KEY OUTCOMES

- 1) Participants engaged well and selected a range of activities to set goals around. Most increased their levels of PA, and experienced improvements in ratings of self-esteem
- 2) Parents/carers also reported finding the programme valuable
- 3) All participants and their parents said they would recommend the programme to others
- 4) Identification of key challenges, and helpful contributors to increased PA assisted future goal setting and planning around participation

REFERENCES

- 1) Presented at the 3rd International Conference on Paediatric Acquired Brain Injury, Belfast 2018
- 2) Mabbott D, Riggs L, Piscione J *et al.* NC-10: Training the brain to repair itself: An exercise trial in paediatric brain tumour survivors. *Neuro Oncol* 2014;16(Suppl 5):v136. doi:10.1093/neuonc/nou263.10
- 3) Hamilton M, Khan M, Clark R *et al.* Predictors of physical activity levels of individuals following traumatic brain injury remain unclear: a systematic review. *Brain Injury* 2016;30(7):819-828

Contact for further information: Emily Bennett: emily.bennett@nuh.nhs.uk | <https://www.nuh.nhs.uk/a-z-of-all-services>

PARENTS IN MIND

TOOL/PROGRAMME SUMMARY

Parents in Mind is a 6-session support and information group for parents of children and adolescents with Acquired Brain Injury (ABI). It was developed to provide parents/carers with opportunities to develop their understanding of key neuropsychological issues and to access additional peer support. The group is delivered by two clinical/neuro psychologists in an evening session, weekly or fortnightly. Information covered during the group sessions includes presentations and discussions on psychological and neuropsychological issues associated with childhood ABI. Key content includes: cognition – memory, processing speed, attention, executive function; behaviour; emotions – anxiety, low mood, and anger/frustration; fatigue; working with schools and colleges.

BACKGROUND

Parents in Mind was developed by the Paediatric Neuropsychology team at Nottingham Children's Hospital (UK). It was created in response to parents' reports suggesting they often feel isolated and under-informed about their child's ABI, and wish to feel more confident in managing difficulties and advocating for their child.

DEFICIT ADDRESSED: P/C/A/PS
TARGET USER: H/P

KEY GOALS

- 1) To improve parent/carer understanding of key neuropsychological issues after childhood ABI
- 2) To increase parent/carer access to peer support
- 3) To increase parent/carer confidence in making changes/managing areas of difficulty/advocating for their child

HOW THE TOOL/PROGRAMME IS USED

Parents in Mind is a group programme delivered by clinical psychologists/neuropsychologists working with children with ABI. The group is delivered biannually and rotates through three core groupings of parents/carers – children with a brain tumour, children with an ABI (non-traumatic) and children with an ABI (traumatic). All parents of children who have experienced an ABI within a certain period of time (and are deemed appropriate) are invited. Parents/carers complete weekly and group-end satisfaction questionnaires. They are also asked to share their hopes and expectations for the group, and to consider whether these have been met at the end of the programme.

KEY OUTCOMES

- 1) Session-by-session and overall satisfaction ratings indicated parents/carers found the group supportive, helpful and relevant
- 2) Parents/carers valued opportunities to discuss concerns with professionals and other parents/carers
- 3) All said they would recommend it to others
- 4) Some parents had already made changes in light of the information provided by the end of the programme

REFERENCES

- 1) Presented at the 3rd International Conference on Paediatric Acquired Brain Injury, Belfast 2018
- 2) Bennett E, English MW, Rennoldson M *et al.* Predicting parenting stress in caregivers of children with brain tumours. *Psycho-Oncology* 2013;22(3):629-636. DOI: 10.1002/pon.3047
- 3) Coulson, N. S., & Greenwood, N. (2012). Families affected by childhood cancer: An analysis of the provision of social support within online support groups. *Child: Care, Health and Development* 2012;38(6):870-877. DOI: 10.1111/j.1365-2214.2011.01316

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<https://www.nuh.nhs.uk/a-z-of-all-services>

THE CHILDREN'S TRUST BRAIN INJURY COMMUNITY SERVICE (BICS)

TOOL/PROGRAMME SUMMARY

BICS is goal-orientated neurorehabilitation, delivered in the child's environment, by specialists from a range of clinical backgrounds. As a national service supporting children living anywhere in the UK, The Children's Trust works with the child, family, and their network, including school, focusing on the needs resulting from an Acquired Brain Injury (ABI). These may be social, emotional, cognitive, communicative and behavioural needs. The ultimate goal is to maximise the child/young person's participation in their everyday life.

The BICS pathway offers:

- Clinical screening, advice and onward referral – free of charge
- Community-based interdisciplinary neurorehabilitation (assessment and skills packages) – funded by Clinical Commissioning Group/local authority/private
- Long-term register – free of charge

The skills packages are delivered by an interdisciplinary team, consisting of occupational therapy, speech and language therapy and educational psychology. Integral to each skills package are baseline assessments, goal setting with the child and family and outcome measures. Each package has a number of sessions/visits allocated and are delivered in the child/young person's home and school. Visits are supplemented by phone and email support as needed. The team works with the child/young person and their network anywhere in the UK, including, family, peers and educators as required. Funding is required from government organisations, and parents are able to self-fund if statutory funding is unavailable.

BACKGROUND

BICS was developed from experience gained at The Children's Trust intensive neurorehabilitation service, and through partnership working with the UK National Health Service major trauma centres, which identified that a significant number of children and young people with ABI, including concussion, require community-based rehabilitation but are unable to access appropriate services and have unmet need.

DEFICIT ADDRESSED: C/A/PS

TARGET USER: H/P/F/E/CSW

KEY GOALS

- 1) To identify unmet needs following ABI and enable children and families to access appropriate support
- 2) To provide brain injury education and raise awareness of needs, including hidden disability
- 3) To maximise the child/young person's participation in their everyday life
- 4) To monitor the long term needs of children and young people during their childhood

HOW THE TOOL/PROGRAMME IS USED

Following referral, children and families access a clinical screening phone call and subsequent home/school visits, to identify their needs, provide brain injury education and advice. Onward referral to statutory and other sector agencies is made where required. Children who require further specialist interdisciplinary rehabilitation can access skills packages to target specific areas of need. The skills packages include: Understanding ABI, Developing learning skills, Developing study skills, Attention and concentration management, Memory management, Fatigue management, Developing access to community/leisure, Developing identity awareness, Developing independence in ABI, Developing social and interaction skills, School-to-school transition support, Teenage ABI safety training, Emotional well-being support, Behavioural support, Parent ABI coaching, Education, Health and Care Plan support and a comprehensive interdisciplinary assessment and consultation package.

Skills package sessions will take place in the home, school or relevant community environment and will involve the child, family, peers and educators, as appropriate. Comprehensive interdisciplinary assessment and consultation is also available. The long-term register provides follow up at three key stages of education transition.

KEY OUTCOMES

- 1) Children and young people's needs are identified and access is provided to the relevant services and support, including long term follow up
- 2) Children and young people with ABI, and those around them, have increased understanding of the injury and its impact
- 3) Children, families and educators are better equipped to manage the impact of the ABI

REFERENCE

BICS development was guided by recommendations outlined in:

- 1) McKinlay A, Linden M, DePompei R *et al.* Service provision for children and young people with acquired brain injury: Practice recommendations, *Brain Injury* 2016;30:1656-1664

COGNITIVE AND LINGUISTIC SCALE (CALs)

9

TOOL/PROGRAMME SUMMARY

The Cognitive and Linguistic Scale (CALs) is an assessment instrument developed by the Kennedy Krieger Institute (USA) that can quantify cognitive and linguistic functioning following an Acquired Brain Injury (ABI) during inpatient rehabilitation for children as young as 2 years of age through to adulthood.

BACKGROUND

The CALs was developed for serial administration to track recovery and assess outcome during inpatient rehabilitation. The CALs has adequate reliability and validity and is sensitive to change in children who are admitted to inpatient rehabilitation with limited responsiveness.

DEFICIT ADDRESSED: C

TARGET USER: H

KEY GOALS

- 1) Assess neurobehavioral functioning at admission to assist with treatment planning/goal setting
- 2) Track recovery over inpatient rehabilitation
- 3) Assess neurobehavioral functioning at discharge

HOW THE TOOL/PROGRAMME IS USED

The CALs includes 20 items measuring a range of neurobehavioral functions including lower level skills such as arousal and responsivity, to higher level skills such as complex language and problem solving. To maximise novelty and minimise practice effects, alternate versions are available for some items such as simple and complex planning. CALs administration time is between 20 and 30 minutes. Items scores range from 1 to 5; the total score ranged from 20 (floor) to 100 (ceiling); they are rated based on behavioral observation, performance on specific tasks or responses during a semi-structured interview.

KEY OUTCOMES

- 1) Improves understanding of the cognitive and linguistic profile of children with brain injury, at all levels of functioning, throughout inpatient rehabilitation to assist in initial goal setting
- 2) Allows for systematic, detailed tracking of cognitive and linguistic recovery during inpatient rehabilitation by comparing each child to that child's own functioning earlier in admission, to inform ongoing treatment planning and evaluate interventions on the basis of early trajectory of recovery
- 3) Early scores predict later outcomes to allow for better prognostication and to inform discharge planning
- 4) Use by multiple inpatient treatment team members promotes clarity and consistency in description of cognitive and linguistic deficits which facilitate communication among team members, patients, and families and facilitate interdisciplinary team process
- 5) Enhances programme evaluation; used in conjunction with other benchmarks to ensure a facility's brain injury population is making adequate progress during admission

REFERENCES

- 1) Blackwell LS, Shishido Y, Howarth R. Cognitive recovery of children and adolescents with moderate to severe TBI during inpatient rehabilitation. *Disabil Rehabil.* 2020 Jul 10;1-7. doi: 10.1080/09638288.2020.1788176. Epub ahead of print. PMID: 32649219
- 2) Svingos AM, Suskauer SJ, Slomine BS, Chen HW, Ellis-Stockley ME, Forsyth RJ. Rasch Properties of the Cognitive and Linguistic Scale and Optimization for Outcome Trajectory Modeling in Pediatric Acquired Brain Injury. *Arch Phys Med Rehabil.* 2021; Oct 30:S0003-9993(21)01519-7. doi: 10.1016/j.apmr.2021.10.009. Epub ahead of print. PMID: 34728191
- 3) Slomine BS, Eikenberg J, Salorio CF *et al.* Preliminary evaluation of the cognitive linguistic scale: A measure to assess recovery in inpatient rehabilitation following pediatric brain injury. *J Head Trauma Rehab* 2008;23(5):286-293. doi:10.1097/01.HTR.0000336841.53338.2f
- 4) Kramer ME, Suskauer SJ, Christensen JR *et al.* Examining acute rehabilitation outcomes for children with total functional dependence after traumatic brain injury: A pilot study. *J Head Trauma Rehab* 2013;28(5):361-370. doi:10.1097/HTR.0b013e31824da031
- 5) Pham K, Kramer ME, Slomine BS *et al.* Emergence to the conscious state during inpatient rehabilitation after traumatic brain injury in children and young adults: a case series. *J Head Trauma Rehab* 2014;29:E44-8. doi: 10.1097/HTR.0000000000000022
- 6) Slomine BS, Grasmick PH, Suskauer SJ *et al.* Psychometric properties of the Cognitive and Linguistic Scale: A follow-up study. *Rehab Psychol.* 2016; 61(3), 328-35. doi: 10.1037/rep0000096

Contact for further information: Beth Slomine: slomine@kennedykrieger.org

UPPER EXTREMITY MEASUREMENT SCALE (UEMS)

10

TOOL/PROGRAMME SUMMARY

The Upper Extremity Measurement Scale (UEMS) is an assessment instrument that was developed by the Kennedy Krieger Institute (USA) to quantify upper extremity function and fine-motor/visual motor skills, as they relate to activities of daily living and school-related tasks following acquired or traumatic brain injury during inpatient rehabilitation. It is used with children as young as 2 years of age through young adulthood, post-brain injury.

BACKGROUND

The UEMS was developed for serial administration to track recovery and assess outcome during inpatient rehabilitation. It has adequate reliability and discriminant validity; construct validity was moderately to highly correlated with Wee-FIM total, self-care, mobility, and cognition scores.

DEFICIT ADDRESSED: P

TARGET USER: H

KEY GOALS

- 1) Assess upper extremity motor function at admission to assist with treatment planning/goal setting
- 2) Track recovery over inpatient rehabilitation
- 3) Assess upper extremity motor function at discharge

HOW THE TOOL/PROGRAMME IS USED

The UEMS includes 7 items that address fine motor skills in bilateral upper extremities, and an additional 6 items that address a range of fine-motor/visual motor skills including ability to reach, grasp, release and other fine-motor skills as well as school-related tasks such as efficiency of touch screen technology access and scissoring skills. Quality of movement is also assessed. UEMS administration time is between 20 and 30 minutes. Items scores range from 1 to 5; the total score ranges from 20 (floor) to 100 (ceiling). UEMS items are rated based on clinical observation and performance on specific tasks, or self/family report can be used if direct observation cannot be completed.

KEY OUTCOMES

- 1) Improves understanding of the upper extremity and fine motor profile of children with brain injury, at all levels of functioning, throughout inpatient rehabilitation to assist in initial goal setting
- 2) Allows for systematic, detailed tracking of upper extremity and fine motor recovery during inpatient rehabilitation by comparing each child to that child's own functioning earlier in admission. This informs ongoing treatment planning and evaluates interventions on the basis of early trajectory of recovery
- 3) Early scores predict later outcomes to allow for better prognostication and to inform discharge planning
- 4) Use by inpatient treatment team members promotes clarity and consistency in description of fine motor deficits which facilitate communication among team members, patients, and families and facilitate interdisciplinary team process
- 5) Enhances programme evaluation; used in conjunction with other benchmarks to ensure a facility's brain injury population is making adequate progress during admission

REFERENCE

- 1) Dunkleberger K, Slomine BS, Salorio C *et al.* The Upper Extremity Measurement Scale. Poster Presentation at the 2nd Federal Traumatic Brain Injury Interagency Conference, Bethesda, MD, March, 2006

Contact for further information: Elizabeth MS Cater: cater@kennedykrieger.org

PHYSICAL ABILITIES AND MOBILITY SCALE (PAMS)

11

TOOL/PROGRAMME SUMMARY

The Physical Abilities and Mobility Scale (PAMS) is an assessment instrument that was developed by the Kennedy Krieger Institute (USA) to quantify gross motor functioning following Acquired or Traumatic Brain Injury (ABI/TBI) during inpatient rehabilitation in children as young as 2 years of age through young adulthood. PAMS has adequate reliability and validity and is sensitive to change in children who are admitted to inpatient rehabilitation with following ABI.

BACKGROUND

PAMS was developed for serial administration to track recovery and assess outcome during inpatient rehabilitation.

DEFICIT ADDRESSED: P
TARGET USER: H

KEY GOALS

- 1) Assess gross motor functioning at admission to assist with treatment planning/goal setting
- 2) Track recovery over inpatient rehabilitation
- 3) Assess gross motor functioning at discharge

HOW THE TOOL/PROGRAMME IS USED

PAMS includes 20 items measuring a range of gross motor functions, positioning and orthotic tolerance. PAMS administration time is between 20 and 30 minutes. Items scores range from 1 to 5; the total score ranged from 20 (floor) to 100 (ceiling). PAMS items are rated based on behavioral observation and performance on specific tasks.

KEY OUTCOMES

- 1) Improves understanding of the gross motor profile of children with brain injury, at all levels of functioning, throughout inpatient rehabilitation to assist in initial goal setting
- 2) Allows for systematic, detailed tracking of gross motor recovery during inpatient rehabilitation by comparing each child to that child's own functioning earlier in admission to inform ongoing treatment planning and evaluate interventions on the basis of early trajectory of recovery
- 3) Early scores predict later outcomes to allow for better prognostication and to inform discharge planning
- 4) Promotes clarity and consistency in description of gross motor deficits which facilitate communication among team members, patients, and families and facilitate interdisciplinary team process
- 5) Enhances programme evaluation; used in conjunction with other benchmarks to ensure a facility's brain injury population is making adequate progress during admission

REFERENCES

- 1) Trovato MK, Bradley E, Slomine BS *et al.* Physical Abilities and Mobility Scale: reliability and validity in children receiving inpatient rehabilitation for acquired brain injury. *Arch Phys Med Rehabil.* 2013; 94(7):1335-41
- 2) McLean HB, Slomine BS, Suskauer S *et al.* Early Head Control Ratings on the Physical Abilities and Mobility Scale (PAMS) Indicative of Potential for Alertness Progression in Children with Disorders of Consciousness (DOC). Oral abstract presentation at The First International Conference on Paediatric Acquired Brain Injury. September 2015, Liverpool UK
- 3) McLean HB, Slomine BS, Nicholson R *et al.* Re-Emergence of Head Control on the Physical Abilities and Mobility Scale is Associated with Resolution of Disorder of Consciousness during Inpatient Rehabilitation in a Larger Sample of Children with Brain Injury. Poster presentation at The Second International Conference on Paediatric Acquired Brain Injury. September 2017. Rome, Italy
- 4) McLean HB, Slomine BS, Suskauer S *et al.* Re-Emergence of Head Control is Associated with Resolution of Disorder of Consciousness during Inpatient Rehabilitation in Children with TBI. Poster presentation at the 11th World Congress on Brain Injury, The Hague, Netherlands, March 2016

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CANCHILD CONCUSSION MANAGEMENT RETURN-TO-ACTIVITY GUIDELINES

TOOL/PROGRAMME SUMMARY

CanChild specific Return-to-Activity (RTA) guidelines, which are more conservative than adult guidelines, were developed to guide management and the return to contact sport when young people sustain a concussion. These protocols are a step-by-step guide to support families and children in RTA. Implementation of these new pediatric specific recommendations is an important addition in the prevention of subsequent concussions during vulnerable recovery periods. These guidelines aim to facilitate recovery by preventing prolonged symptomatology, repeat injury and secondary sequelae such as depression and anxiety.

BACKGROUND

The science of concussion management is constantly evolving. The recently released 2017 Berlin Consensus Statement on Concussion in Sports identified areas particularly related to the amount and type of rest post-concussion that should be followed. The CanChild RTA and Return-to-School (RTS) guidelines reflect these updates.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: H/P/F/E

KEY GOALS

- 1) To educate families and children on concussion management
- 2) To prevent prolonged symptomatology, repeat injury and secondary sequelae

HOW IS THE TOOL/PROGRAMME USED

The RTA and RTS guidelines are to be used together when a child/young person sustains a concussion and assists them in getting back into their regular routines. The most important aspect of recovery and brain healing is ensuring that the brain is rested. An individual with concussion must not ignore their symptoms and should avoid physically and mentally demanding tasks, especially in the early stages of recovery, as this often makes symptoms worse. It is also recommended that a gradual return to regular activity, including school, occurs. These protocols provide suggested goals and appropriate activities for each stage.

KEY OUTCOMES

- 1) Raise awareness of the issues post-concussion for families and the individual
- 2) Provides guidance on how to return to active participation whilst ensuring that the brain can recover

REFERENCE

- 1) McCrory P, Meeuwisse W, Dvorak J *et al.* Consensus statement on concussion in sport – the 5th International conference on concussion in sport held in Berlin, October 2016. *BJSM* 2018;51:838-847

Contact for further information: Carol DeMatteo, McMaster University: concuss@mcmaster.ca |

<https://canchild.ca/en/diagnoses/brain-injury-concussion/brain-injury-resources>

CANCHILD CONCUSSION MANAGEMENT RETURN-TO-SCHOOL GUIDELINES

TOOL/PROGRAMME SUMMARY

CanChild specific Return-to-School (RTS) guidelines, which are more conservative than adult guidelines, were developed to guide management when youth sustain a concussion. These protocols are a step-by-step guide to support families and children in returning to school. Implementation of these new pediatric specific recommendations is an important addition to prevention of subsequent concussions during vulnerable recovery periods. These guidelines aim to facilitate recovery by preventing prolonged symptomatology, repeat injury and secondary sequelae such as depression and anxiety.

BACKGROUND

The science of concussion management is constantly evolving. The recently released 2017 Berlin Consensus Statement on Concussion in Sports identified areas particularly related to amount and type of rest post-concussion that should be followed, the CanChild Return-to-Activity (RTA) and RTS guidelines reflect these updates.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: H/P/F/E

KEY GOALS

- 1) To educate families and children on concussion management
- 2) To prevent prolonged symptomatology, repeat injury and secondary sequelae

HOW THE TOOL/PROGRAMME IS USED

The RTS and RTA guidelines are to be used together when a child/youth sustains a concussion to assist them getting back into their regular routines. The most important aspect of recovery and brain healing is ensuring that the brain is rested. An individual with concussion must not ignore their symptoms and should avoid physically and mentally demanding tasks, especially in the early stages of recovery, as this often makes symptoms worse. It is also recommended that a gradual return to regular school, occurs. These protocols provide suggested goals and appropriate activities for each stage.

KEY OUTCOMES

- 1) Raise awareness of the issues post-concussion for families and the individual
- 2) Provide guidance on how to return to active participation whilst ensuring that the brain can recover

REFERENCE

- 1) McCrory P, Meeuwisse W, Dvorak J *et al.* Consensus statement on concussion in sport – the 5th International conference on concussion in sport held in Berlin, October 2016. *BJSM* 2018;51:838-847

Contact for further information: Carol DeMatteo: concuss@mcmaster.ca

<https://canchild.ca/en/diagnoses/brain-injury-concussion/brain-injury-resources>

MENTAL HEALTH CONSIDERATIONS ALGORITHM

14

TOOL/PROGRAMME SUMMARY

The post-concussion mental health considerations algorithm provides a protocol for assessing the individual with mild Traumatic Brain Injury (mTBI) with timelines and recommendations for medical follow-up and referral.

There is also an algorithm available for the management of prolonged mental health disorders (see Tool 15).

BACKGROUND

Mental health disorders are common following mTBI; approximately 1 in 5 individuals may experience mental health symptoms up to 6 months after mTBI. Mental health disorders appear to be major determinants of post-mTBI wellness and functional recovery, including disorders of mood which consist of symptoms related to depression and anxiety. The etiology of mTBI/concussive mood disorders may be related to reactive or environmental factors such as the experience of the trauma resulting in the injury (eg: manifesting in post-traumatic stress symptoms, phobias and related anxieties), or to the negative outcomes following the injury (i.e. depression related to not participating in important roles such as work or school, sports etc). They may also manifest in response to the chronic symptoms that can follow concussion/mTBI or any physical injuries such as poor sleep, persistent headaches, chronic pain or medications etc. Indeed, all of these types of outcomes can contribute, causally, to distress and to disorders of mood. It is often difficult to obtain timely assessments and treatment interventions from mental health experts; delays can, and often do, contribute to worse outcomes, and so it is important that primary care providers intervene as soon as possible.

Screening for mental health symptoms and determining their etiology, as well as prescribing treatment, is crucial to facilitating a positive recovery. This algorithm will prompt health professionals to consider key decision points to aid timely assessment and referral.

DEFICIT ADDRESSED: P/C

TARGET USER: H

KEY GOALS

- 1) To facilitate health professionals in the mental health assessment of the individual with mTBI
- 2) To facilitate timely intervention for those individuals with mTBI who have mental health disorders

HOW THE TOOL/PROGRAMME IS USED

The list of considerations provided in the algorithm should be reviewed 1-4 weeks post-injury with medical follow-up and referral made to healthcare professionals/interdisciplinary concussion team. Early referral (<4 weeks) should be considered if the child/adolescent has modifiers that may delay recovery or a high risk of prolonged post-concussion symptoms. If the individual has symptoms lasting more than four weeks post-concussion then referral to a specialist or interdisciplinary concussion team is recommended, and from there referral is steered towards a range of therapists according to the symptoms.

KEY OUTCOMES

- 1) The individual with mTBI and mental health problems will be identified as early as possible
- 2) Early intervention will produce a positive recovery

REFERENCES

- 1) The Ontario Neurotrauma Foundation has given permission for the inclusion of this tool in the IPBIS toolbox
- 2) Living guideline for pediatric concussion care

Contact for further information: www.pedsconcussion.com

MANAGEMENT OF PROLONGED MENTAL HEALTH DISORDERS ALGORITHM

TOOL/PROGRAMME SUMMARY

The management of prolonged mental health disorders algorithm provides a protocol for managing the individual with mild Traumatic Brain Injury (mTBI) according to mild/moderate and severe with non-pharmacological and pharmacological treatments recommended.

There is also an algorithm available for the assessment of mental health disorders (see 14).

BACKGROUND

Mental health disorders are common following mTBI; approximately 1 in 5 individuals may experience mental health symptoms up to 6 months after mTBI. Mental health disorders appear to be major determinants of post-mTBI wellness and functional recovery, including disorders of mood which consist of symptoms related to depression and anxiety. The etiology of mTBI/concussive mood disorders may be related to reactive or environmental factors such as the experience of the trauma resulting in the injury (eg: manifesting in post-traumatic stress symptoms, phobias and related anxieties), or to the negative outcomes following the injury (i.e. depression related to not participating in important roles such as work or school, sports etc). They may also manifest in response to the chronic symptoms that can follow concussion/mTBI or any physical injuries such as poor sleep, persistent headaches, chronic pain, medications etc. Indeed, all of these types of outcomes can contribute, causally, to distress and to disorders of mood. There is no current evidence to indicate that the mental health problems of individuals who have suffered a mTBI should be treated any differently than mental health problems of other etiologies. As such, pharmacological and non-pharmacological interventions including therapeutic interventions that have been found to be helpful in the general population should be considered for individuals who have developed mental health problems post mTBI. However, the management of mental health disorders is complex and this algorithm was developed to steer health professionals in the management of individuals with mTBI.

DEFICIT ADDRESSED: P/C

TARGET USER: H

KEY GOALS

- 1) To facilitate health professionals in the management of mental health disorders in individuals with mTBI
- 2) To facilitate the referral for those individuals with mTBI who have prolonged mental health disorders

HOW THE TOOL/PROGRAMME IS USED

The algorithm steers the user, depending on whether the symptoms are mild/moderate or severe. If the symptoms are mild/moderate, management can be considered by the local health professional with non-pharmacological treatments suggested initially over a minimum of 8-10 sessions, and if symptoms do not worsen then they should be monitored and therapy continued. However if this is not successful, pharmacological treatments are proposed. If symptoms are severe, then a combination of pharmacological and non-pharmacological treatment is proposed from the outset, with referral to a psychiatrist, psychologist or neuropsychologist, followed by further non-pharmacological or pharmacological treatment depending on the individual's progress.

KEY OUTCOMES

- 1) To guide the treatment of the child/young person who has mTBI and mental health disorders
- 2) To optimise the recovery for the child/young person with mTBI and mental health disorders

REFERENCES

- 1) Adapted from Guideline for Concussion/Mild Traumatic Brain Injury and Persistent Symptoms. Third Edition. <https://braininjuryguidelines.org/concussion/fileadmin/media/adult-concussion-guidelines-3rd-edition.pdf>
- 2) The Ontario Neurotrauma Foundation has given permission for the inclusion of this tool in the IPBIS toolbox
- 3) Living guideline for pediatric concussion care

Contact for further information: www.pedsconcussion.com

TOOL/PROGRAMME SUMMARY

The sample letter/email provides questions addressed to the parents of a child who is returning to school (RTS) following a concussion. It contains tick boxes for the parent to complete. The information it contains will help to manage the child's RTS successfully. The template letter could also be used for the RTS of any individual with an Acquired Brain Injury (ABI).

BACKGROUND

There are many children and young people with ABI returning to education, with varying needs and unknown long-term trajectories. They have a wide range of difficulties that can change over time and impact on their learning ability. Many require bespoke management, regular monitoring and review for the duration of their education. On discharge from hospital schools and parents/carers need to be in communication so that the RTS can be planned. It is important that the teaching professionals are aware of the problems that the individual is experiencing, so they can implement the appropriate assessment tools, learning and evidence-based strategies and can then tailor the specific support required in the classroom. A simple letter for parents will guide teaching professionals on the needs of the child, both practical as well as academic.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: E

KEY GOALS

- 1) To manage the child's RTS following an ABI
- 2) To guide the necessary practical and academic adaptations required for a successful RTS

HOW THE TOOL/PROGRAMME IS USED

The sample letter asks questions about the child's fatigue, behaviour, memory, cognition, stamina, social aspects, and their awareness of the condition. Tick boxes (yes/no) are provided in order to facilitate responses from the parents. The letter should be completed by the parent and returned to the relevant contact person at the child's school.

KEY OUTCOMES

- 1) The school and teaching professionals are prepared for the child's return
- 2) The child with ABI feels supported in their RTS

REFERENCES

- 1) Developed by Vermont's Concussion Task Force, and used by the Ontario Neurotrauma Foundation (ONF) with permission from the Brain Injury Association of Vermont
- 2) The ONF has given permission for the inclusion of this tool in the IPBIS toolbox
- 3) Living guideline for pediatric concussion care

Contact for further information: www.pedsconcussion.com

LETTER TEMPLATE FROM CONCUSSION TEAM TO CHILD/ADOLESCENT'S SCHOOL

TOOL/PROGRAMME SUMMARY

The template letter is sent from the concussion team to update the school on the child/adolescent's recovery from a concussion, and advises them on what to expect during the individual's recovery period.

BACKGROUND

Following a concussion, it is common for children and adolescents to experience difficulties in the school setting. Cognitive difficulties, such as learning new tasks or remembering previously learned material, may pose challenges in the classroom. The school environment may also increase symptoms because of the exposure to bright lights and screens, or noisy cafeterias and hallways. Unfortunately, because most children and adolescents look physically normal after a concussion, teaching professionals often fail to recognise the need for academic or environmental adjustments. Appropriate guidance and recommendations from the concussion team may ease the transition back to the school environment and facilitate the recovery of the child or adolescent.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: E

KEY GOALS

- 1) To prepare the teaching professionals for the return of the child/adolescent following concussion
- 2) To facilitate the best possible environment for the child/adolescent's return to school (RTS)

HOW THE TOOL/PROGRAMME IS USED

The letter outlines the importance of recovery and return to function, and that a RTS is beneficial even if the child/adolescent may be symptomatic. It specifies the signs and symptoms that the student may continue to display and outlines what difficulties and sensitivities may arise. The letter makes recommendations for the school to follow. It is a simple but valuable tool.

KEY OUTCOMES

- 1) Teaching professionals can adapt programmes and activities to aid child/adolescent recovery
- 2) The child/adolescent is not expected to function 'normally' but can ease themselves back into the academic environment

REFERENCES

- 1) Adapted by Ontario Neurotrauma Foundation (ONF) from the authors: Sinclair Elder AJ, Kadel R, O'Keefe EK. Headin' for healin' Teacher's Letter, Colorado Springs, University of Colorado
- 2) The ONF has given permission for the inclusion of this tool in the IPBIS toolbox
- 3) Living guideline for pediatric concussion care

Contact for further information: www.pedsconcussion.com

MANAGE ACUTE AND PROLONGED CONCUSSION SYMPTOMS ALGORITHM

TOOL/PROGRAMME SUMMARY

The algorithm provides a process for health professionals to follow from the initial medical assessment of possible concussion through to specialised therapy, with indicators provided for the diagnosis and overall management.

BACKGROUND

Due to the varied nature of concussion, not all patients with concussion require all types of interventions from all providers; there is not one single course of treatment or recovery. It is necessary that all assessments and treatments are individualised. The majority of concussions will resolve within weeks, spontaneously, with some relative rest, guidance, follow-up from a primary care provider, and a stepwise return-to-activity. For individuals who experience persistent symptoms and those at risk of a delayed recovery, it is necessary that they have access to appropriate and timely, coordinated, interdisciplinary and evidence-based care. This algorithm was adapted from the Ontario Neurotrauma Foundation's 'Standards for Post-Concussion Care and developed with the involvement and expertise of over 65 experts, including individuals who had experienced persistent symptoms following concussion. The standards offer 15 criteria and several tools and resources to guide healthcare providers and interdisciplinary clinics in processes used to provide care.

DEFICIT ADDRESSED: P/C
TARGET USER: H

KEY GOALS

- 1) To optimise concussion management in children/adolescents
- 2) To ensure that children/adolescents receive appropriate and consistent acute and post-concussion care

HOW THE TOOL/PROGRAMME IS USED

The initial medical assessment and diagnosis of concussion should be done by a physician or nurse practitioner. A suspected structural brain injury or spinal injury demands immediate referral to neurosurgery or the emergency department. If concussion is diagnosed then 1-4 weeks following the acute injury there should be medical follow-up and referral to healthcare professionals/interdisciplinary concussion team. After more than 4 weeks of prolonged symptoms the specialised therapy/interdisciplinary concussion team should be involved. If concussion is diagnosed, the individual should receive medical clearance to return to full contact sport and high risk activities. The algorithm provides guidance throughout and indicators for follow-up monitoring.

KEY OUTCOMES

- 1) Have agreed standards for concussion care
- 2) Facilitate consistent management amongst health professionals
- 3) Children/adolescents with concussion have optimal care and recovery

REFERENCES

- 1) Adapted with permission from the Ontario Neurotrauma Foundation (ONF) Standards for Post-Concussion Care – Post Concussion Care Pathway
- 2) The ONF has given permission for the inclusion of this tool in the IPBIS toolbox
- 3) Living guideline for pediatric concussion care

Contact for further information: www.pedsconcussion.com

STRATEGIES TO PROMOTE GOOD SLEEP AND ALERTNESS

TOOL/PROGRAMME SUMMARY

This tool is for children/young adults who are recovering from concussion. It provides strategies for maintaining healthy habits to promote good sleep, guidance on nutrition, exercise and lifestyle, and how to provide a positive sleeping environment.

BACKGROUND

Following concussion a child/young adult may feel more tired than usual. The first several days after the injury the concussed individual will typically sleep more than they would usually do. However, after the first week or so, they may then have difficulty falling or staying asleep. Improving the sleeping pattern will aid recovery and the strategies outlined in this tool provide key tips on how to promote good sleep and alertness.

DEFICIT ADDRESSED: P/C

TARGET USER: P/F

KEY GOALS

- 1) To promote good sleep and alertness following concussion
- 2) To aid recovery from concussion

HOW THE TOOL/PROGRAMME IS USED

The strategies are outlined as bullet points in an easy-to-read style for parents/carers and/or the child/young adult to follow on a daily basis. They are very practical but simple recommendations and easy to follow. For example healthy habits to promote good sleep includes maintaining the same bed and wake times during the week and on weekends, having a fixed bed routine, turning off the computer and electronic devices at least 30 minutes before bedtime. With regard to nutrition, exercise and lifestyle, the tool recommends avoiding caffeine within four to six hours before bedtime, no energy drinks and having a balanced diet. There are several tips for improving the sleeping environment such as removing all sources of light in the bedroom whilst sleeping, keeping the room clean, tidy and quiet and turning digital clocks with numbers that light up away from the bed during sleep.

KEY OUTCOMES

- 1) Improved sleep and alertness
- 2) Assists concussion recovery

REFERENCES

- 1) Adapted by Ontario Neurotrauma Foundation (ONF) from the authors: C.Wiseman-Hakes, M-C Ouellet and S Beaulieu-Bonneau
- 2) The ONF has given permission for the inclusion of this tool in the IPBIS toolbox
- 3) Living guideline for pediatric concussion care

Contact for further information: www.pedsconcussion.com

PROLONGED POST-CONCUSSION SLEEP DISTURBANCES ALGORITHM

TOOL/PROGRAMME SUMMARY

The prolonged post-concussion sleep disturbances algorithm provides a protocol for assessing the child/young adult with mild Traumatic Brain Injury (mTBI) with timelines and recommendations for medical follow-up and referral.

BACKGROUND

Considerable research indicates that sleep disturbances and insomnia are more common and severe among individuals following a mTBI. Disturbed sleep is one of the most common complaints following mTBI and worsens morbidity and long-term sequelae. Sleep and TBI share neurophysiologic underpinnings with direct relevance to recovery from TBI. As such, disturbed sleep and clinical sleep disorders represent modifiable treatment targets to improve outcomes in TBI. This algorithm guides the monitoring of sleep disturbances and provides management recommendations.

DEFICIT ADDRESSED: P/C

TARGET USER: H

KEY GOALS

- 1) To manage sleep disturbances following concussion
- 2) To aid overall recovery from concussion

HOW THE TOOL/PROGRAMME IS USED

The algorithm provides guidance in 3 stages:

- 1) Sleep disturbances from 1-4 weeks
- 2) If sleep disturbances persist more than 4 weeks post-concussion
- 3) If sleep disturbances persist more than 6 weeks post-concussion and interventions at 4 weeks have been unsuccessful

At each stage the health professional is guided through medical follow-up, possible cognitive behavioural therapy or referral with healthcare professionals or interdisciplinary concussion team, and if sleep disturbance is prolonged, referral to a sleep professional and/or pharmacological treatment. The latter is only recommended on a short-term basis if sleep has not improved for more than 6 weeks post-injury; medications must not result in dependency and adverse effects must be closely monitored.

KEY OUTCOMES

- 1) Improved sleep disturbances
- 2) Assists concussion recovery

REFERENCES

- 1) The ONF has given permission for the inclusion of this tool in the IPBIS toolbox
- 2) Living guideline for pediatric concussion care

Contact for further information: www.pedsconcussion.com

CONCUSSION IMPLICATIONS AND INTERVENTIONS FOR THE CLASSROOM

TOOL/PROGRAMME SUMMARY

This tool provides proactive solutions for children/young adults with post-mTBI when their classroom behaviour is indicative of them having difficulties functioning on a physical, cognitive, social or emotional level.

BACKGROUND

Although children and young people may appear to make a good physical recovery a mTBI, the long-term effects may arise many months or even years later, when the injured part of the brain reaches a key stage of development, and they are unable to demonstrate some of the skills they otherwise would have had. The implications for education professionals are that the individual may begin to struggle in class and the reason for these difficulties is not understood. Behaviour issues may bring the individual with a mTBI to a teacher's attention and in school, these issues may be labelled as not learning, oppositional behaviour, impulsive, poor self-control, disorganisation or low motivation. When resources are stretched, poor motivation or withdrawal may lead the individual to being overlooked in a busy classroom. This tool has been developed as a checklist/reminder for teachers and provides proactive solutions.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: E

KEY GOALS

- 1) To identify the difficulties that the child/young adult is having in the classroom
- 2) To enable teaching professionals to provide proactive solutions for managing the difficulties in the classroom

HOW THE TOOL/PROGRAMME IS USED

The tool has physical, cognitive, social, emotional and behavioural areas of concern, and describes how these would manifest themselves in terms of behaviour in the classroom, and for each aspect the tool provides a proactive solution for the student. For example if the child/young adult has a headache then rest breaks should be allowed with hydration and a quieter location provided. If they are unable to concentrate the tool recommends providing information in smaller chunks. If they are feeling depressed then the teacher should point out the strengths and successes during each day. This is a useful and easy checklist to help and support the child/young adult post-concussion in the classroom.

KEY OUTCOMES

- 1) Assists teaching professionals to support the child/young adult with post-concussion in the classroom
- 2) Provides the child/young adult with support and facilitates the adaptation of classroom routines to accommodate post-concussion problems

REFERENCES

- 1) Adapted by the Ontario Neurotrauma Foundation (ONF) from DePompei R and Blosser J. Pediatric traumatic brain injury: proactive interventions. 2019. Plural Press:San Diego
- 2) The ONF has given permission for the inclusion of this tool in the IPBIS toolbox
- 3) Living guideline for pediatric concussion care

Contact for further information: www.pedsconcussion.com

TOOL/PROGRAMME SUMMARY

This tool provides key tips for the child/young adult with concussion/mild Traumatic Brain Injury (mTBI) on their return-to-school (RTS) and activity.

BACKGROUND

The RTS following a mTBI is particularly challenging. The medical and school systems must be prepared to support the return of the child/young adult, and medical providers must be trained in assessment and management skills with a focused understanding of the school demands. Schools must develop policies and procedures to prepare staff to support a gradual return process with the necessary academic accommodations. Ongoing communication between the family, student, school, and medical provider is essential to supporting recovery. Managing RTS and activity post-mTBI is a multifaceted process without a specific body of research evidence to guide the process as of yet. Nevertheless, medical providers need practical management strategies to assist the student's RTS and activity. Equally important, school systems must be prepared to provide appropriate academic supports to recovering students. The RTS and activity for the child/young adult requires specific coping strategies and this simple tool was developed as a checklist to help the student manage their school day.

DEFICIT ADDRESSED: P/C/A

TARGET USER: P

KEY GOAL

1) To provide simple coping strategies for the child/young adult to manage their daily activities, including in the classroom

HOW THE TOOL/PROGRAMME IS USED

The 4 'Ps' are 1) Prioritise, 2) Plan, 3) Pace and 4) Position. Each of the four sections poses a question and then provides tips on what to do next depending on the answers:

- 1) Prioritise – What is important? For example what are you able to do based on how you currently feel?
- 2) Plan – what are you going to do? For example organise what you need to do and do tasks that use more energy at times in the day when you feel best
- 3) Pace – How are you going to do it? For example take break if you don't feel well
- 4) Position – Where are you going to do it? For example noisy, busy distracting environments make it hard to concentrate

The child/young adult can use the tool as a simple prompt to guide them through returning to daily activities, including school.

KEY OUTCOMES

- 1) Enables the child/young adult with post-concussion symptoms to plan and modify activities according to how they feel
- 2) Provides the child/young adult with support

REFERENCES

- 1) Holland Bloorview Kids Rehabilitation Hospital: Concussion and You: A Handbook for Parents and Kids p9
- 2) The ONF has given permission for the inclusion of this tool in the IPBIS toolbox
- 3) Living guideline for pediatric concussion care

Contact for further information: www.pedsconcussion.com

CHECKLIST OF FACTORS THAT MAY INFLUENCE SLEEP/WAKE CYCLE

TOOL/PROGRAMME SUMMARY

This tool is a checklist of factors that can influence the child/young adult's sleep/wake cycle following mild Traumatic Brain Injury (mTBI).

BACKGROUND

Sleep-wake disturbances following mTBI are increasingly recognised as a serious consequence following injury and as a barrier to recovery. Injury-induced sleep-wake disturbances can persist for years, often impairing quality of life. Even in its mildest form individuals with TBI can suffer from persistent sequelae that prevent the return to normal physical, cognitive, and emotional functioning – all of which are important components of overall recovery. Sleep-wake disturbances are among the most prevalent and persistent symptoms following TBI and have been reported in up to 70% of individuals with mild, moderate, or severe TBI up to 3 years post-injury. Disrupted sleep contributes to several other complications, including memory and cognitive complaints, chronic pain, and psychological distress. It is therefore important to assess all the factors that may contribute to disrupted sleep/wake cycles post-concussion.

DEFICIT ADDRESSED: P/C
TARGET USER: H

KEY GOALS

- 1) To identify the causes of disruptive sleep/wake cycles
- 2) To support the child/young adult with mTBI in their recovery

HOW THE TOOL/PROGRAMME IS USED

The tool comprises 4 sections:

- Medical conditions
- Current medication use
- Comorbid psychopathology
- Unhealthy habits

Each section lists examples of factors and considerations so the health professional can make an informed decision.

KEY OUTCOME

- 1) Provides factors that can influence the sleep/wake cycle and facilitates management decisions

REFERENCES

- 1) The ONF has given permission for the inclusion of this tool in the IPBIS toolbox
- 2) Living guideline for pediatric concussion care

Contact for further information: www.pedsconcussion.com

POST-CONCUSSION VISION, VESTIBULAR AND OCULOMOTOR DISTURBANCES ALGORITHM

TOOL/PROGRAMME SUMMARY

The algorithm provides a process for health professionals to follow for vision, vestibular and oculomotor disturbances that occur from 1-4 weeks following the acute Traumatic Brain Injury (TBI), to symptoms lasting more than 4 weeks with management recommendations.

BACKGROUND

Normal function of the vestibulo-ocular reflex (VOR) coordinates eye movement with head movement, in order to provide clear vision during motion and maintain balance. Normal VOR function is necessary for carrying out activities of daily living (eg: walking) and is of particular importance in higher demand activities (eg: sports-related activities). Disruption or damage in the VOR can result in symptoms such as movement-related dizziness, blurry vision, difficulty maintaining balance with head movements, and even nausea. Dizziness is one of the most common symptoms following TBI and is considered a risk factor for a prolonged recovery. Assessment of the vestibular system is of particular importance following TBI, in conjunction with oculomotor control, due to the intrinsic neural circuitry that exists between the ocular and vestibular systems. The algorithm was developed to provide health professionals with a protocol for managing these symptoms following a concussion.

DEFICIT ADDRESSED: P/C

TARGET USER: H

KEY GOALS

- 1) To optimise the management of vision, vestibular and oculomotor disturbances post- concussion
- 2) To ensure that the child/young adult receives appropriate and consistent acute and post-concussion care

HOW THE TOOL/PROGRAMME IS USED

The tool provides recommendations for 1-4 weeks following acute injury including focused vision and vestibular history, physical examination and determining the need for imaging. Referral is recommended to health professionals/ interdisciplinary concussion team if the symptoms last longer than 4 weeks (or sooner as needed/using clinical judgement). Adjunctive testing may then be required and interdisciplinary management of the symptoms involving specific expertise involving physiotherapist, ophthalmologist, chiropractor and/or neuro-otologist.

KEY OUTCOMES

- 1) Provides a consistent management approach to addressing VOR symptoms post-concussion
- 2) Facilitates overall recovery for the child/young adult following concussion

REFERENCES

- 1) The ONF has given permission for the inclusion of this tool in the IPBIS toolbox
- 2) Living guideline for pediatric concussion care

Contact for further information: www.pedsconcussion.com

POST-CONCUSSION INFORMATION SHEET

TOOL/PROGRAMME SUMMARY

The information sheet can be given to the young adult and/or their families following a concussion and it provides useful guidance about the symptoms of the brain injury, recovery, Return-to-Activity (RTA) and Return-to-School (RTS) steps.

BACKGROUND

Concussions can occur in any sport or recreation activity. Parents, coaches, athletic trainers, school nurses, teachers, advisors, physicians, and athletes all need to know the signs and symptoms of concussion and what to do if a concussion is suspected.

Concussion is a Traumatic Brain Injury (TBI) and its indicators can be subtle. Symptoms may not appear until days or weeks following the injury or may even be missed, as the individual may look fine. This information sheet was developed to raise awareness of concussion and also to provide guidance on what to do if the child/young adult has concussion and the RTA and RTS.

DEFICIT ADDRESSED: P/C/A

TARGET USER: P/F/E

KEY GOALS

- 1) To raise awareness of concussion, its symptoms and management
- 2) To facilitate the best possible recovery
- 3) To provide guidance on the child/young adult's RTA and RTS and provide guidance on the most appropriate environment

HOW THE TOOL/PROGRAMME IS USED

The information sheet is easy-to-read. It addresses a series of questions:

- What is a concussion?
- What causes a concussion?
- When should a concussion be suspected?
- What are the visible signs of a concussion?
- What should a child/adolescent do if they think they or a friend has concussion?
- When should a child/adolescent with concussion go back to see a doctor or nurse?
- What can a child/adolescent do to help recover from a concussion?
- When can a child/adolescent return-to-school activities, and sports after concussion?
- What are the red flag symptoms?
- How long does it take to recover after a concussion?
- What can happen if a child/adolescent goes back to full-contact sports or game-play too early after a concussion?
- How can children/adolescents help prevent concussions and their consequences?

KEY OUTCOMES

- 1) Raises awareness of the symptoms and management of concussion
- 2) Supports the child/adolescent post-concussion
- 3) Prepares the child/adolescent for a gradual RTA and RTS

REFERENCES

- 1) The ONF has given permission for the inclusion of this tool in the IPBIS toolbox
- 2) Living guideline for pediatric concussion care

Contact for further information: www.pedsconcussion.com

POST-CONCUSSION HEADACHE ALGORITHM

26

TOOL/PROGRAMME SUMMARY

The algorithm provides a process for health professionals to follow for post-concussion headache from 1-4 weeks following acute injury, to more than 4 weeks post-concussion with referral recommendations.

BACKGROUND

Headaches are one of the most common symptoms after concussion in both children and young adults. The symptoms of a single simple concussion may resolve in a week or less for most children, but a few will have headaches and other symptoms related to concussion for weeks or even months after their injury. For some individuals, they can become a significant complication that persists long after the initial injury has occurred, developing into potentially chronic post-concussion headaches. The algorithm was developed to provide consistent management and referral recommendations for headaches between 1-4 weeks following acute injury and more than 4 weeks post-concussion.

DEFICIT ADDRESSED: P/C

TARGET USER: H

KEY GOALS

- 1) To optimise concussion management in children/adolescents
- 2) To ensure that children/adolescents receive appropriate and consistent acute and post-concussion care

HOW THE TOOL/PROGRAMME IS USED

The algorithm guides medical follow-up and referral 1-4 weeks following acute injury with a focused headache history, physical examination and the need for imaging determined. A headache and medication diary is recommended and if the symptoms last longer than 4 weeks referral is recommended to a healthcare professional/interdisciplinary professional concussion clinic. Headaches of more than 4 weeks duration require medical assessment by a physician with expertise in concussion, testing and interdisciplinary management by either a neurologist, physiotherapist, neuro-optometrist and/or chiropractor depending on the headache sub-type.

KEY OUTCOMES

- 1) Have agreed standards for concussion care
- 2) Facilitate consistent management amongst health professionals
- 3) Children/adolescents with concussion have optimal care and recovery

REFERENCES

- 1) The ONF has given permission for the inclusion of this tool in the IPBIS toolbox
- 2) Living guideline for pediatric concussion care

Contact for further information: www.pedsconcussion.com

LETTER TEMPLATE FROM PHYSICIAN TO CHILD/ ADOLESCENT'S SCHOOL

TOOL/PROGRAMME SUMMARY

The template letter is sent from the physician to update the school on the child/adolescent's recovery from a concussion, and provides recommendations on the support that the individual may require during the Return-to-School (RTS) and their recovery period.

BACKGROUND

Following a concussion, it is common for children and adolescents to experience difficulties in the school setting. Cognitive difficulties, such as learning new tasks or remembering previously learned material, may pose challenges in the classroom. The school environment may also increase symptoms because of the exposure to bright lights and screens, or noisy cafeterias and hallways. Unfortunately, because most children and adolescents look physically normal after a concussion, teaching professionals often fail to recognise the need for academic or environmental adjustments. Appropriate guidance and recommendations from the physician may ease the transition back to the school environment and support the recovery of the child or adolescent.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: E

KEY GOALS

- 1) To prepare the teaching professionals for the return of the child/adolescent following concussion
- 2) To facilitate the best possible environment for the child/adolescent's RTS

HOW THE TOOL/PROGRAMME IS USED

The letter confirms that the individual is medically cleared to RTS, and that a RTS is beneficial even if the child/adolescent may be symptomatic. It recommends a key person is allocated to the individual within the school to help implement a RTS plan. The letter attaches recommendations that may be helpful while the individual is re-integrating back into the school environment. It is a simple but valuable tool.

KEY OUTCOMES

- 1) Teaching professionals can adapt programmes and activities to aid child/adolescent recovery
- 2) The child/adolescent is not expected to function 'normally' but can ease themselves back into the academic environment

REFERENCES

- 1) Adapted by Ontario Neurotrauma Foundation (ONF) from the authors: Sinclair Elder AJ, Kadel R, O'Keefe EK Headin' for healin' Teacher's Letter, Colorado Springs, University of Colorado
- 2) The ONF has given permission for the inclusion of this tool in the IPBIS toolbox
- 3) Living guideline for pediatric concussion care

Contact for further information: www.pedsconcussion.com

TOOLBOX 2019

INDEX B: PAID FOR TOOL

The tool/programme is indexed according to the deficit(s) addressed:

P/C/A/PS: Tool/programme addresses **P**hysical, **C**ognitive, **A**cademic and/or **P**sycho**S**ocial deficits

and the target users:

H/P/F/E/CSW: Tool/programme will be used by the **H**ealthcare professional, **P**atient and/or **F**amily, **E**ducator, **C**ommunity **S**ervice **W**orker

The following tool/programme has to be paid for. The contact and email address are provided so that further information can easily be obtained. It is assumed that the reader will select and use a particular tool according to their own requirements.

Tool No.	Tool/programme title	Deficit addressed				Target user				
		P	C	A	PS	H	P	F	E	CSW
1	In the Classroom			√					√	

IN THE CLASSROOM (MODULES ARE FEE-BASED)

1

TOOL/PROGRAMME SUMMARY

The 'In the Classroom' training programme for teaching professionals is a comprehensive web-based educational and training resource. It includes 9 interactive learning modules offering specific strategies for managing Traumatic Brain Injury (TBI)-related cognitive, behavioral, and social problems in the school setting. Modules include Return-to-School, Study Strategies, Managing Behaviour and others. It also includes 21 lessons and 23 supplementary materials, printable forms, resource links and practical tools for classroom use. There are 10 hours of materials.

The course costs \$40 with group discounts for more than 5 users. Users receive a professional development unit (PDU) at completion.

<https://learn.cbit.org/1/course/view.php?id=13/>

BACKGROUND

Increasingly, it is recognised that most children with TBI receive rehabilitation services in the school setting. Unfortunately, few teaching preparation programmes include training on TBI in their coursework. Multiple surveys indicate that school professionals lack the knowledge and skills needed to adequately support students with TBI. A range of evidence-based assessment and instructional approaches can help mitigate the academic and behavioural challenges associated with TBI and the long-term problems that can follow these children into adulthood. The 'In the Classroom' training programme was developed in partnership with a national advisory board of educators, and rigorously tested with 100 educators from across the USA.

DEFICIT ADDRESSED: A

TARGET USER: E

KEY GOALS

- 1) To increase the knowledge of teaching professionals about the effects of brain injury
- 2) To increase the knowledge of teaching professionals about effective educational strategies for supporting students with TBI
- 3) To increase self-efficacy in supporting students with TBI in the school setting

HOW THE TOOL/PROGRAMME IS USED

The interactive programme has an empirically validated design that provides individually tailored video-based training using evidence-based instructional design principles. The programme consists of 20 brief modules which incorporate validated instructional design components, including:

- 1) Application exercises with assessment and remediation loops to ensure comprehension
- 2) Interactive segments involving real-life scenarios that test user comprehension
- 3) Sufficient practice and review to ensure content mastery

KEY OUTCOMES

- 1) Teaching professionals who completed the programme (in the RCT see below) had an improved ability to support students with concussion or brain injury
- 2) Teaching professionals who participated in the training course had more confidence working with students with TBI
- 3) All the participants in the RCT would recommend the training to a friend
- 4) Cost-effective approach to knowledge transfer and exchange in TBI professional development amongst teaching professionals

REFERENCE

- 1) Glang AE, McCart M, Slocumb J *et al*. Preliminary efficacy of online TBI professional development for educators. *Journal of Head Trauma and Rehabilitation* 2019;34(2):77-86

Contact for further information: Ann Glang: aglang@uoregon.edu

TOOLBOX 2018

INDEX A: FREELY* AVAILABLE TOOLS/PROGRAMMES

The tools and programmes are indexed according to the deficit(s) addressed:

P/C/A/PS: Tool/programme addresses **P**hysical, **C**ognitive, **A**cademic and/or **PS**ychoS**S**ocial deficits

and the target users:

H/P/F/E/CSW: Tool/programme will be used by the **H**ealthcare professional, **P**atient and/or **F**amily, **E**ducator, **C**ommunity **S**ervice **W**orker

The following tools and programmes are free*. Web addresses and/or contact details are provided so that further information can easily be obtained. It is assumed that the reader will select and use a particular tool or programme according to their own requirements.

*IPBIS is not responsible for any charges associated with the use of the tools/programmes

Tool No.	Tool/programme title	Deficit addressed				Target user				
		P	C	A	PS	H	P	F	E	CSW
1	Get Schooled on Concussion (GSOC)			√					√	
2	Remove/Reduce Educate Adjust/Accommodate Pace (REAP)	√	√	√	√	√	√	√	√	
3	Concussion and Traumatic Brain Injury – Information for families	√	√	√	√	√	√	√		
4	Re-establishment of Spatial Functions and Programming and Control for Adolescents with Acquired Brain Injury		√	√			√	√	√	
5	Counsellor-Assisted Problem Solving (CAPS)				√	√	√	√		
6	My best friend Buddy		√	√	√		√	√	√	
7	Family-based intervention at home	√	√	√	√		√	√		
8	Brain 101: The concussion playbook		√	√			√	√	√	
9	Follow-up for children with Traumatic Brain Injury	√		√		√	√			
10	SpeelsBrein (Playful Brain)		√			√	√	√		
11	Acquired Brain Injury Challenge Assessment (ABI-CA)	√				√	√			
12	Family Needs Questionnaire – paediatric version				√	√	√	√		√
13	Brain Injury Family Intervention for Adolescents (BIFI-A)			√	√	√	√	√		√
14	Concussion and You Handbook	√	√	√	√		√	√		

TOOLBOX 2018

INDEX A: FREELY* AVAILABLE TOOLS/PROGRAMMES

Tool No.	Tool/programme title	Deficit addressed				Target user				
		P	C	A	PS	H	P	F	E	CSW
15	Evaluation and Individualised Family-Based Rehabilitation Programme	√	√	√	√	√	√	√		
16	Quality of Life after Brain Injury Questionnaire (QoLIBRI)	√	√	√	√	√	√			
17	LEARNet problem-solving system			√			√	√	√	
18	Brain Injury Hub	√	√	√	√	√	√	√	√	√
19	My Brain and Me	√	√				√			
20	Brain Injury Alert		√		√	√	√	√	√	
21	Return to School Pathway and Guidance Document	√	√	√	√	√	√	√	√	
22	Comprehensive Care Programme (Including Outreach)	√	√	√	√	√	√	√	√	√
23	Acquired Brain Injury guidebook for family intervention	√	√	√	√	√	√	√	√	√
24	Context-Family Based Approach	√	√	√	√	√	√	√	√	√
25	Paediatric Acquired Brain Injury Community Outreach Programme (PABICOP)	√	√	√	√	√	√	√	√	√
26	Teen Online Problem Solving (TOPS)		√		√		√	√		
27	Transition Programme from Paediatric to Adult Services	√	√			√	√			
28	Peer Events		√		√		√			
29	Learning Parental Network and Learning Youth Network on Facebook	√	√	√	√		√	√		
30	Metacognitive Dimension Programme for Pre-adolescents and Adolescents	√	√	√	√	√	√	√	√	√
31	Quality Criteria and a Referral Guide – Care for Children with Brain Tumours	√	√	√	√	√	√	√	√	√
32	Standard of Care for Paediatric Traumatic Brain Injury	√	√	√	√	√	√	√	√	√
33	Graduated Return to School Pathway/Return to Play Guidelines	√	√			√	√	√	√	

Deficit addressed: **P**hysical, **C**ognitive, **A**cademic and/or **PS**ychosocial deficits

Target user: **H**ealthcare professional, **P**atient and/or **F**amily, **E**ducator, **CSW** Community Service Worker

TOOLBOX 2018

INDEX A: FREELY* AVAILABLE TOOLS/PROGRAMMES

Tool No.	Tool/programme title	Deficit addressed				Target user				
		P	C	A	PS	H	P	F	E	CSW
34	Child and Adolescent Scale of Participation (CASP)	√	√	√	√	√	√	√	√	√
35	Child and Adolescent Scale of Environment (CASE)	√	√	√	√	√	√	√	√	√
36	Child and Adolescent Factors Inventory (CAFI)	√	√		√	√	√	√		
37	Child and Family Follow-up Survey (CFFS)	√	√	√		√	√	√		
38	HEADS UP	√	√	√	√	√		√	√	

Deficit addressed: **P**hysical, **C**ognitive, **A**cademic and/or **PS**ychosocial deficits

Target user: **H**ealthcare professional, **P**atient and/or **F**amily, **E**ducator, **CSW** Community Service Worker

GET SCHOOLED ON CONCUSSION (GSOC)

1

TOOL/PROGRAMME SUMMARY

Get Schooled on Concussion (GSOC) is a website written by educators for educators, to help them better understand how a concussion can impact a student in the classroom on a daily basis. GSOC contains one-pagers for teachers, related service providers and administrators, and presents concussion in the language for the educator.

BACKGROUND

GSOC was developed by two professionals who work in the field of concussion but came from the field of education. While many return to learn (RTL) recommendations were being made by medical providers and athletic trainers, there was little RTL guidance actually being written by educators. GSOC helps to empower teachers by translating the symptoms of concussion into the 'teacher-language' of mental fatigue, processing speed and short term memory problems.

DEFICIT ADDRESSED: A
TARGET USER: E

KEY GOALS

- 1) To provide practical guidance in the classroom for the teacher on how to support a student who has had concussion
- 2) To provide information and empowerment of the teacher so she/he can adjust academic support for the student who has had concussion over 1-4 weeks of recovery

HOW THE TOOL/PROGRAMME IS USED

GSOC is a free website; on-site training is available and all of the one-pagers are pulled together into a manual that can be purchased.

KEY OUTCOMES

- 1) To help schools, primarily teachers, know how to support students with concussion regarding RTL
- 2) GSOC helps to de-mystify the diagnosis of concussion and allows the teacher to consider its impact on learning

REFERENCE

- 1) The research and literature behind the RTL Consensus paper supports GSOC suggestions. GSOC recommendations are in accordance with the USA Department of Education guidelines

Contacts for further information: Karen McAvoy: karenmcavoy11@gmail.com

Brenda Eagan Brown: brenda.eagan.brown@gmail.com | www.GetSchooledOnConcussions.com

REMOVE/REDUCE EDUCATE ADJUST/ACCOMMODATE PACE (REAP)

2

TOOL/PROGRAMME SUMMARY

Get Schooled on Concussion (GSOC) is a website written by educators for educators, to help them better understand how a concussion can impact a student in the classroom on a daily basis. GSOC contains one-pagers for teachers, related service providers and administrators, and presents concussion in the language for the educator.

BACKGROUND

GSOC was developed by two professionals who work in the field of concussion but came from the field of education. While many return to learn (RTL) recommendations were being made by medical providers and athletic trainers, there was little RTL guidance actually being written by educators. GSOC helps to empower teachers by translating the symptoms of concussion into the 'teacher-language' of mental fatigue, processing speed and short term memory problems.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: H/P/F/E

KEY GOALS

- 1) To provide practical guidance in the classroom for the teacher on how to support a student who has had concussion
- 2) To provide information and empowerment of the teacher so she/he can adjust academic support for the student who has had concussion over 1-4 weeks of recovery

HOW THE TOOL/PROGRAMME IS USED

GSOC is a free website; on-site training is available and all of the one-pagers are pulled together into a manual that can be purchased.

KEY OUTCOMES

- 1) To help schools, primarily teachers, know how to support students with concussion regarding RTL
- 2) GSOC helps to de-mystify the diagnosis of concussion and allows the teacher to consider its impact on learning

REFERENCE

- 1) The research and literature behind the RTL Consensus paper supports GSOC suggestions. GSOC recommendations are in accordance with the USA Department of Education guidelines

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CONCUSSION AND TRAUMATIC BRAIN INJURY: INFORMATION FOR FAMILIES

TOOL/PROGRAMME SUMMARY

The DVD entitled 'Concussion and Traumatic Brain Injury: Information for Families' is a compilation of 4 brief, helpful video clips and several state and national websites. This resource can be viewed by families while at the hospital or anyone needing to better understand this injury. It can also be incorporated into staff development training. The 15-minute video is captioned and also available in Spanish on the following website:

<http://tndisability.org/article/concussion-and-traumatic-brain-injury-information-families>

English with Captions: <https://youtu.be/xspCFq3MWZo>

Spanish with Captions: <https://youtu.be/wxbpHtK0byw>

BACKGROUND

While treating patients at a children's hospital, a nurse requested concussion information for families and hence this DVD was produced.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: H/P/F

KEY GOALS

- 1) To raise awareness about concussion for families
- 2) To provide general community brain injury education

HOW THE TOOL/PROGRAMME IS USED

This DVD can be used to educate patients and families while the child is either an inpatient or in an emergency department. It is viewable in several ways: via DVD player or online on a portable device; phone, tablet and or computer.

KEY OUTCOMES

- 1) Improved knowledge
- 2) Information provision
- 3) Access to resources

Contact for further information: Paula Denslow: paula_d@tndisability.org/brain | www.tndisability.org/brain

RE-ESTABLISHMENT OF SPATIAL FUNCTIONS AND PROGRAMMING AND CONTROL FOR ADOLESCENTS WITH ACQUIRED BRAIN INJURY

TOOL/PROGRAMME SUMMARY

The programme includes tasks for both spatial orientation and control. The first stage starts from the level of external concrete actions: the location and accommodation of objects by guided orientation in real space. The second is the level of symbolic actions using table games with orientation (e.g. Sea Battle) and construction of complex figures e.g. constructing a model of the solar system. The third stage is tasks of perceptive level e.g. drawing complex models and maps. The fourth stage is guided work with mathematic concepts, problem solving and understanding, and production of written texts. All tasks represent joint actions with the therapist.

BACKGROUND

- 1) Historical and cultural approach based on shared collective development (LS Vigotsky)
- 2) Conception of gradual formation of intellectual actions by stages starting from external and perceptive level before the level of abstract internal operations (PY Galperin)
- 3) Constant help and external control by shared orientation (NF Talizina and Y Solovieva)

DEFICIT ADDRESSED: C/A

TARGET USER: E and partially P/F

KEY GOALS

- 1) To facilitate recuperation of orientation starting from the external level
- 2) To facilitate recuperation of self-control starting from the level of shared external control
- 3) To enable rehabilitation of intellectual actions and the possibility to return to school

HOW THE TOOL/PROGRAMME IS USED

The programme is recommended for adolescents or young adults with Acquired Brain Injury where the main problem relates to spatial orientation, together with difficulties with self-control and regulation. The programme is used during individual sessions provided by neuropsychologist. Each session is one hour, for six to eight months or more, according to the severity and cognitive difficulties. All tasks are fulfilled as a communicative and reflexive solution of cognitive problems. The tasks have to be interesting for the patient and related to intellectual activity. There is no repetition, automatic execution or memorisation.

KEY OUTCOMES

- 1) Improved understanding of texts, problem solving problems and producing written texts
- 2) Improved understanding of own difficulties and increased motivation

EXAMPLE OF USAGE

The programme was applied to a male aged 14 years, a pupil at a secondary Private School in Mexico. Brief neuropsychological assessment was conducted before and after the rehabilitation programme.

Neuropsychological assessment revealed difficulties with the regulation of control and spatial integration. An individualised programme was designed for neuropsychological rehabilitation. The goals comprised re-organisation of intellectual activity by training of mechanisms of control and spatial analysis. Original interactive tasks were created in order to elevate motivation of the patient. As a result the patient fulfilled the tasks independently, obtained high marks and improved motivation for intellectual activity.

REFERENCES

- 1) International Congress on Brain Injury, IBIA, 2017, New Orleans, USA
- 2) In print as an article
- 3) Part of presentation of International Congress dedicated to the memory of AR Luria, Ekaterinburg, Russia, October 2017

Contact for further information: Yulia Solovieva: yulia.solovieva@correo.buap.mx

www.neuropsicologia.org.mx | www.colegiokepler.edu.mx

COUNSELLOR-ASSISTED PROBLEM SOLVING (CAPS)

5

TOOL/PROGRAMME SUMMARY

Counsellor-Assisted Problem Solving (CAPS) is a web-based, family-centred telehealth intervention. It focusses on problem-solving with the objective of improving the behavioural outcomes of children with Traumatic Brain Injury (TBI). CAPS involves a structured approach to developing a realistic and optimistic framework for addressing problems, and is an important general coping process that increases adaptive situational coping and behavioural competence, which in turn reduces and prevents the negative effects of stress on psychological well-being. This online family problem-solving programme is supported by synchronous sessions with a psychologist.

BACKGROUND

Clinical observation and research evidence suggest that young individuals with TBI exhibit specific deficits in problem-solving skills, and that these deficits contribute to interpersonal, vocational, and behavioural problems. Problem-solving therapy has been shown to provide an evidence-based approach for improving the behavioural outcomes of paediatric survivors of TBI. Telehealth interventions such as CAPS reduce the barriers to treatment access such as time and distance, transportation and perceived stigma.

DEFICIT ADDRESSED: PS

TARGET USER: H/P/F

KEY GOAL

1) To improve behavior

HOW THE TOOL/PROGRAMME IS USED

An initial assessment is conducted using a questionnaire, involving the primary caregiver and the individual. A child behaviour checklist is also completed at the start of the intervention and used to measure the outcomes. A series of sessions are planned by the therapist at regular intervals, with ongoing attention given to the injury-related issues identified on the questionnaire. The sessions include a self-guided online section providing didactic content regarding problem-solving skills, video clips modelling this skill, and exercises and assignments that provide the family with opportunities to practice the new skill. New material is then released upon completion of each online session with the therapist, and the individual and the family practice the problem-solving process.

KEY OUTCOME

1) Reduced behaviour problems

REFERENCE

1) Wade SL, Stancin T, Kirkwood MW *et al.* Counsellor-assisted problem solving (CAPS) improves behavioural outcomes in older adolescents with complicated mild to severe TBI. *J Head Trauma Rehabil.* 2014;29(3):198-207

Contact for further information: Shari L. Wade: shari.wade@cchmc.org

MY BEST FRIEND BUDDY

6

TOOL/PROGRAMME SUMMARY

'My Best Friend Buddy' is a programme devised to address specific behavioural and cognitive/communication issues faced by some children and young people (CYP) with an Acquired Brain Injury (ABI). It includes a storybook for parents or teachers to read with 8-12 year olds with an ABI, together with accompanying information, explanations and guidance notes for use by the adults. It explains the reasons for the difficulties represented in the story and explains how the child may be able to use an external prompt to self-manage certain situations, initially with adult assistance. In this instance this prompt is a toy dog – imaginary in the story and represented by an actual toy provided with the pack. It is then explained that the child can, in time, be assisted to progress from a 3-dimensional prompt to a more subtle one. Stickers representing the dog are also supplied. The eventual aim is for the child to recall the prompt without a visual representation. The programme is freely available to parents/carers; there is a charge for professionals.

BACKGROUND

This programme is based on the experience of a mother who asked for assistance to identify a resource to her assist her son, who has an ABI, to self-manage his behaviour. Research showed that no such resource existed and the Child Brain Injury Trust (CBIT) commissioned the parent and two professionals working with children with ABI to produce one. Exploration of this boy's situation showed that he had developed a strong association between one of his soft toys and his ability to cope with certain situations. Based on this and previous experience, the authors planned to base the programme on an 'imaginary figure' as a prompt and a dog was chosen following consultation with CBIT parents/carers and young people forums, other parents/carers of CYP with ABI and professionals. The resulting programme was based on research and observations in clinical practice, in addition to further input from young people with ABI and their families. The layout and illustrations were carefully created to be appropriate for CYP with ABI and the final product was reviewed by young people, families and professionals.

DEFICIT ADDRESSED: C/A/PS

TARGET USER: P/F/E

KEY GOALS

- 1) To teach CYP emotional and behavioural coping strategies that can be used in specific situations with the assistance of a powerful prompt as a reminder
- 2) To work towards the CYP being able to use a prompt that is more discreet
- 3) To result in the CYP not needing the prompt to cope with specific issues

HOW THE TOOL/PROGRAMME IS USED

The explanatory/guidance book should be read by the adult initially. The storybook can be read independently by a child alongside an adult, or read to them by an adult. It can be read in small parts or as a whole at the discretion of the adult. This should be followed by an opportunity to reflect, and discuss the issues and topics raised, and by practice and reinforcement of the strategies. The soft toy provides a physical prompt to support the child in learning the strategies that are demonstrated in the book. Once the child is able to use these strategies with the prompt of the soft toy, the stickers can then be used as a more discrete prompt when they are out and about or in school. Eventually it is hoped that the child will be assisted to employ these strategies without the physical prompt of the toy or stickers. The time that this takes, and the length of time during which repetition is necessary will vary from child to child. Each chapter of the story, depicting a different situation but using the same approach, is discussed and explained in the guidance notes.

KEY OUTCOMES

- 1) To enable a child with ABI to develop strategies to self-manage specific situations and to avoid unwanted (and distressing – for the child and family) responses
- 2) To provide a resource and information for parents/carers and teachers

REFERENCE

- 1) Presented at CBIT conference

Contact for further information: www.childbraininjurytrust.org.uk

FAMILY-BASED INTERVENTION AT HOME

TOOL/PROGRAMME SUMMARY

The SARAH family-based rehabilitation methodology involves an assessment period with the child and at least one family member (usually the mother, although the father, uncles, aunts, grandparents and siblings may also be present) at scheduled hospital visits. The hospital visits include multi-disciplinary assessments of the child designed to identify areas in need of intervention and stimulation (e.g. mobility, cognition, communication, behaviour and activities of daily living). Parents attend group meetings and family training sessions and also contribute to the assessment. Visits by clinicians to the child's home provide information essential to adapting the rehabilitation programme to the everyday social and other family routines. Following this 2-week assessment period, an integrated programme of intervention and support is established, including goals in each relevant area of specialisation. The aim is to translate the treatment programme into simple activities that could be performed at home with materials available in any household.

BACKGROUND

The importance of the family's role in their child's adjustment and ongoing development after TBI has been increasingly documented in the research literature. Because of the sudden disruption of the child's developmental process, families experience significant stress and the dynamics within the family can be profoundly altered. Unresolved family stress has been shown to have a negative impact on the child's outcome. The child's long-term outcome and family adjustment are reciprocally related, yielding support for the hypothesis that the success of intervention programmes designed to assist families in their adjustment may also improve the child's outcome.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: P/F

KEY GOALS

- 1) To rehabilitate the child in their home
- 2) To involve the family in the rehabilitation

HOW THE TOOL/PROGRAMME IS USED

To facilitate family-centred intervention, SARAH staff have created numerous graphic illustrations of activities that can be selected and organised into an individualised manual for each child and family. The contents of each manual are frequently updated, based on the child's progress and feedback from the child and family. Illustrations in the manual guide parents in their selection of exercises and modification. Each child is assigned a professional who implements intensive training to teach the family the intervention and stimulation programme. The programme is implemented over a defined time period in the child's home with repeated visits to the hospital. Physical and motor functioning progress is assessed before and after treatment using the SARAH Scale of Motor Development (SARAH Scale).

KEY OUTCOMES

- 1) Home-based intervention is effective
- 2) Parents acquire the skills needed to deliver physical and cognitive interventions within the context of everyday routines of the child's life at home; family education level is not a factor
- 3) Rehabilitation is less stressful for the child as they are in their home environment

REFERENCE

- 1) Braga LW, Da Paz Junior AC, Ylvisaker M. Direct clinician-delivered versus indirect family-supported rehabilitation of children with traumatic brain injury: A randomized controlled trial. *Brain Injury* 2005; 19(10):819-831

Contact for further information: Lucia Braga: luciabraga@sarah.br

BRAIN 101: THE CONCUSSION PLAYBOOK

8

TOOL/PROGRAMME SUMMARY

Brain 101: The Concussion Playbook is a web-based intervention that includes training in sports concussion for each member of the school community, and presents guidelines on creating a concussion management team, together with strategies for supporting students in the classroom.

BACKGROUND

Many sports concussions happen during school-sponsored sports events and most state concussion laws specifically hold schools accountable for coach training and effective concussion management practices. Brain 101 was developed as a training tool for use in schools.

DEFICIT ADDRESSED: C/A

TARGET USER: P/F/E

KEY GOALS

- 1) To help schools create a comprehensive schoolwide concussion management programme with minimal expenditure
- 2) To provide engaging and effective education for teachers, coaches, parents, and students

HOW THE TOOL/PROGRAMME IS USED

The online material in Brain 101 is adjusted for each user group, concisely presented, requiring little reading time, and supported with animation and videos. Students have a 15-minute segment which is factual but simplistic, and they are encouraged to report their own injuries as well as possible injuries in their teammates. Educators are guided on what to look for in the classroom. Parents get information on concussion symptoms and steps they may use at home and in consultation with teachers to enhance recovery. Coaches see a 20-minute programme on recognising and responding to concussions and reducing risks.

KEY OUTCOMES

- 1) Student athletes and parents at Brain 101 schools have improved sports concussion knowledge, knowledge application, and behavioural intention to implement effective concussion management practice
- 2) Schools can create a comprehensive schoolwide concussion management programme

REFERENCE

- 1) Glang A, Koester MC, Chesnutt JC. The effectiveness of a web-based resource in improving post-concussion management in high schools. *J Adolesc Health*. 2015;56(1):91-97

Contact for further information: Ann Glang: aglang@uoregon.edu

<https://www.orcasinc.com/products/brain-101/index.html>

FOLLOW-UP FOR CHILDREN WITH TRAUMATIC BRAIN INJURY

TOOL/PROGRAMME SUMMARY

When children visit the emergency room of the Admiraal De Ruyter Hospital (ADRZ) in Goes, Netherlands they are registered in the Safety Information System (LIS) of Veiligheid NL. The data is filtered on a diagnosis of Traumatic Brain Injury (TBI). The names of the children diagnosed with TBI are sent to ADRZ and the hospital sends a flyer to the parents. The advice in the flyer is to contact GGD-Jeugdgezondheidszorg and mention that their child was diagnosed with a TBI. The child will then be screened during the school term to monitor the long-term consequences of TBI. When there is a problem the parents can contact a professional in the region who will then refer them to the right help and support.

BACKGROUND

The LIS in the Netherlands has continuously monitored accidents and injuries since 1997. In the local area there is a special team of professionals that register those children with mild and moderate TBI and who have disappeared from sight. To stay in contact, and to be able to screen the child's long-term consequences, they tried to identify a way to track these children. The systems and financing opportunities that were already available were used to realise this goal. In 2016 around 25% of the children diagnosed with TBI now register at the GGD-Jeugdgezondheidszorg.

DEFICIT ADDRESSED: P/A
TARGET USER: H/P

KEY GOALS

- 1) To register children with a diagnosis of TBI
- 2) To screen those children diagnosed
- 3) To follow-up and monitor the children

HOW THE TOOL/PROGRAMME IS USED

Participants from different organisations are working together to make this happen.

KEY OUTCOMES

- 1) The children are tracked and monitored
- 2) The relevant organisations are working together
- 3) The children get better help and support

REFERENCE

- 1) Revant Reigerbos: revalidatiearts Larja de letter

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www.zeeuwsezorgschakels.nl

SPEELSBREIN (PLAYFUL BRAIN) (AVAILABLE IN DUTCH) (UPDATED 2022)

TOOL/PROGRAMME SUMMARY

SpeelsBrein is an informative book for parents of children 0-4 years of age with TBI (traumatic brain Injury). The book contains psycho-education, examples of playful activities, and raises awareness on the development of neurocognition (memory, attention, executive functions and perception). In addition, a guideline for (neuro) psychologists is available with instructions on how to educate parents on playing with their child, while also addressing the different aspects of neurocognition.

The guideline consists of two parts: 1) a theoretical part on the neurocognitive development in children aged 0-4 years; and 2) a guide for psychologist/healthcare professionals on how the informative book can be used by parents. The guideline also contains instructions on how to use the SpeelsBrein book as an intervention, with a psycho-education and practical play-session component.

SpeelsBrein is currently being tailored in the Netherlands for implementation in a broader target group that includes children with brain tumours, cerebral palsy and also premature infants.

BACKGROUND

Children aged 0-4 years of age with TBI are at risk of developmental problems, for example problems with behaviour and learning, later in life. It is important that parents of these children are provided with information which makes them aware of the potential problems, and with support 'tools' that can be used to address problems if/when they arise.

DEFICIT ADDRESSED: C

TARGET USER: H/P/F

KEY GOALS

- 1) To provide psycho-education on neurocognition for parents of children with brain injury, aged 0-4 years
- 2) To provide parents with play-based tools to address neurodevelopment
- 3) To promote action-based and playful learning

HOW THE TOOL/PROGRAMME IS USED

A (neuro) psychologist provides guidance and informs parents how to use the book at home, and how to play with their child whilst simultaneously addressing key aspects of neurocognition. An intervention is included.

KEY OUTCOMES

- 1) Enhances parents' awareness of neurocognitive development in their child with TBI
- 2) Provides tools for parents to stimulate neurocognitive development at home for children aged 0-4 years

REFERENCES

- 1) SpeelsBrein (2018, 3e edition), Marleen van der Wees, Breindok, isbn 9789492649041 (www.speelsbrein.nl)
- 2) SpeelsBrein, guideline for psychologist-healthcare professionals, Marleen van der Wees (2018, 2e edition). Grant by the Dutch Brain Foundation.

Contacts for further information: Marleen van der Wees: m.vanderwees@libranet.nl | c.utens@libranet.nl

THE ACQUIRED BRAIN INJURY-CHALLENGE ASSESSMENT (ABI-CA)

TOOL/PROGRAMME SUMMARY

The ABI-CA is a dynamic assessment of advanced gross motor skills. It was designed to build upon the foundation skills of the Gross Motor Function Measure (GMFM-88). The ABI-CA is intended for use with children/young people who have an ABI, aged 7 years and over, can walk independently, but have limitations in speed and quality of movement. The ABI-CA assesses 20 advanced gross motor skills that tap into a child's co-ordination, agility, balance, fitness and strength. ABI-CA testing can be done by a paediatric physical therapist who has taken the ABI-CA training course.

The ABI-CA can be used with both inpatients and outpatients, it can assist with ascertaining areas of strength and challenge in the child's performance to enable goal setting, education with clients and families, and guide towards determining the areas of future intervention such as balance, agility, speed or co-ordination. From a goal setting and evaluation perspective, both the individual item scores and the ABI-CA total scores are of value.

BACKGROUND

The recovery of advanced motor skills for the return to recreation/sport is often an important goal of young people with ABI. The ABI-CA was developed in response to a lack of validated measures that assess high level gross motor performance post-injury, during an individual's initial recovery and the community phases of rehabilitation.

DEFICIT ADDRESSED: P

TARGET USER: H/P

KEY GOAL

1) To assess comprehensively gross motor performance in high functioning young people with an ABI

HOW THE TOOL/PROGRAMME IS USED

The ABI-CA is administered by a paediatric physical therapist who is qualified to use the test. It requires 45-60 minutes to complete. Testing is conducted on/around a 10m long pathway. The testing equipment consists of basic gym skills items such as balls, balance beam, beanbags and stop watch. For every item, the therapist first gives directions and does a demonstration of the task and then the individual has two attempts at performing the task. The goal is to have the individual reach their peak performance while maintaining safety. The assessment is designed to be performed in a positive manner with encouragement and praise.

KEY OUTCOMES

- 1) A tool for systematic assessment of a child's motor skills for service planning, education and outcome measurement
- 2) Long-term monitoring of motor skills over the care trajectory
- 3) Enhancement of child- and family-centred care

REFERENCES

- 1) Ibey R, Chung R, Benjamin N *et al.* Development of a Challenge Assessment for high functioning children with an acquired brain injury. *Pediatr Phys Ther.* 2010;22:268-276
- 2) MacArthur C, Ventakesh S, Warren D *et al.* Refining the response scale of the ABI Challenge module to enhance its ability to measure change in children and youth with ABI. *Brain Inj.* 2013;27:1271-1280
- 3) Wong RKY, McEwan J, Finlayson D *et al.* Reliability and Validity of the Acquired Brain Injury Challenge Assessment (ABI-CA) in Children. *Brain Inj.* 2014;28(13-14):1734-1743

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Gail Kirkwood: gkirkwood@hollandbloorview.ca

FAMILY NEEDS QUESTIONNAIRE – PAEDIATRIC VERSION (FNQ-P) (UPDATED 2022)

TOOL/PROGRAMME SUMMARY

The FNQ-P is a 40-item self-report measure that provides clinicians with a tool for systematic assessment of family needs after a child sustains an Acquired Brain Injury (ABI). These needs may present during inpatient or out-patient rehabilitation, or anytime over the course of the child's subsequent development and life within their community. The FNQ-P assesses the degree to which the family's needs have been met at that point in time across six categories of need: health information, emotional support, instrumental support, community support, professional support, and involvement with care. This tool has been validated with international partners from the UK, Sweden, Lithuania, and Australia.

BACKGROUND

Researchers have identified a strong relationship between unmet family needs and increased family burden as well as a bi-directional relationship between child and family outcomes after ABI. However, the lack of validated measures to assess family needs after a child sustains an ABI is a critical clinical and research gap.

DEFICIT ADDRESSED: PS
TARGET USER: H/P/F/CSW

KEY GOALS

- 1) To give families a voice about the needs that are important to them
- 2) To facilitate service and transition planning through the systematic assessment of family needs
- 3) To provide a roadmap for families around the changing needs over time
- 4) To provide a framework for routine data collection and long-term monitoring of family needs over time (for programme planning and evaluation, and intervention and family-based research)

HOW THE TOOL/PROGRAMME IS USED

The FNQ-P can be used in inpatient settings to obtain information shortly after the child's admission to facilitate service planning during the child's inpatient rehabilitation stay. It can be re-administered in the weeks leading to discharge to facilitate transition planning to home and community. In outpatient and community settings, the FNQ-P can be completed during the intake or assessment phase to expedite identification of a family's greatest needs. This can facilitate discussion of potential resources and referrals that may help to address families' needs and priorities. The tool can also be administered longitudinally to track changing family needs over time.

Individual item scores can be used to determine unmet family needs, which can assist with service planning around families' identified priorities. Total FNQ-P scores or mean scores for each of the six categories of family needs can be used to track changing needs over time. On a broader scale, FNQ-P scores can be used to identify areas of unmet needs to facilitate program planning and evaluation. Multicentre use of the FNQ-P in paediatric ABI research is also supported as translated versions of the FNQ-P have already been developed through our validation study.

KEY OUTCOMES

- 1) A tool for systematic assessment of family needs for service planning and outcome measurement
- 2) Long-term monitoring of family needs over the care trajectory
- 3) Improved psychosocial support for families of children with ABI
- 4) Enhanced family-centred care

FAMILY NEEDS QUESTIONNAIRE – PAEDIATRIC VERSION (FNQ-P) (UPDATED 2022) (continued)

REFERENCES

- 1) Gan C, Van't Hooft I, Brookes N *et al.* First stage international validation of the Pediatric Family Needs Questionnaire (FNQ-P), *Brain Injury* 2020; 34(8):1074-1083. DOI:10.1080/02699052.2020.1782474
- 2) Gan C, Wright V, Van Hooft I *et al.* Validation of the Pediatric Family Needs Questionnaire: A Partnership Approach Across Five Countries. Accepted Abstracts from the International Brain Injury Association's 12th World Congress on Brain Injury, *Brain Injury* 2017; 31:6-7, 870-871. DOI:10.1080/02699052.2017.1312145
- 3) Gan C, Provvidenza C, Townley A *et al.* Meeting the needs of families after pediatric brain injury: Do you know what you don't know? Accepted Abstracts from the International Brain Injury Association's 13th World Congress on Brain Injury, *Brain Injury* 2019; 33:sup1,23. DOI:10.1080/02699052.2019.1608749
- 4) Gan C and Wright V. Development of the family needs questionnaire – paediatric version [FNQ-P] – Phase I. *Brain Injury* 2019; 33(5):623-632. DOI:10.1080/02699052.2019.1566836

For further information and to download the FNQ-P tool and FNQ-P manual for free, please go to the FNQ-P website. <https://hollandbloorview.ca/research-education/bloorview-research-institute/outcome-measures/family-needs-questionnaire>

Translated versions of FNQ-P in Swedish, Spanish, and Norwegian are also available for free download through the FNQ-P website.

BRAIN INJURY FAMILY INTERVENTION FOR ADOLESCENTS (BIFI-A) (UPDATED 2022)

TOOL/PROGRAMME SUMMARY

BIFI-A is an empirically-based family intervention designed to facilitate adjustment for adolescents with Acquired Brain Injury (ABI) and the family system. BIFI-A is a manual, face-to-face intervention that incorporates a broad curriculum of education about ABI, emotional support, and skill building. Topics include: What happens after brain injury, common changes after brain injury, brain injury happens to the whole family, what happens after brain injury, brain injury happens to the whole family, being a teen and achieving independence, emotional and physical recovery, coping with loss and change, managing intense emotions, managing stress and taking care of self, setting SMART goals and tracking progress, learning patience and solving problems, school, transitions and preparing for adulthood. BIFI-A is available in Swedish and Chinese. A Norwegian version will be available later in 2022.

BIFI-A has been designated a Leading Practice through Accreditation Canada. <https://healthstandards.org/leading-practice/brain-injury-family-intervention-for-adolescents-bifi-a/>

BACKGROUND

The negative impact of ABI on families is well documented; yet there are few practice guidelines on how to support families of adolescents with ABI. Providing clinicians with tools to support families is essential as research shows a reciprocal relationship between child and family outcomes after ABI.

DEFICIT ADDRESSED: A/PS

TARGET USER: H/P/F/CSW

KEY GOALS

- 1) To provide adolescents/families with information about common challenges after brain injury
- 2) To help family members better understand how the brain injury has affected each family member and the family as a whole
- 3) To teach adolescents/families a variety of strategies which will enable them to more effectively problem solve and achieve personal goals
- 4) To teach coping strategies that facilitate the process of emotional recovery
- 5) To instil hope and build resilience by identifying progress and personal strengths, and helping families access community resources
- 6) To teach family members effective communication skills and develop a strong long-term support system
- 7) To provide adolescents/families with a good foundation of knowledge and strategies that they can build on to live successfully in the community

HOW THE TOOL/PROGRAMME IS USED

BIFI-A is an interactive programme designed to engage all members of the family including parents, siblings or the extended family. The detailed manual includes a scripted protocol, step-by-step procedures, ready-to-use handouts, and tools for effective clinical implementation. Family members learn about what happens after ABI, being a teenager and achieving independence, school transitions, and preparing for adulthood. Through family discussion, supportive interventions are incorporated to enhance emotional adjustment, coping with loss and change, and managing intense emotions. Families are provided with tools for goal setting, stress management, and problem-solving. The focus on strengths and successes helps to enhance family resilience.

A 2-day Brain Injury Family Intervention training programme has been developed to help professionals learn skills in family assessment, engagement, intervention, and effective implementation of the BIFI-A curriculum. More than 450 rehabilitation professionals from Canada, US, Sweden, and Norway have attended our training programme. Evaluation of our training workshops has shown statistically significant improvements in participants' ratings of knowledge, confidence, and skills in working effectively with families after brain injury. Virtual training has also been developed for a team from Hong Kong.

KEY OUTCOMES

- 1) Improved clinical knowledge and skills in working with families of adolescents with ABI
- 2) Enhanced clinical care and resource information for adolescents with ABI and their families
- 3) Improved knowledge, enhanced skills and psychosocial support for families of adolescents with ABI

BRAIN INJURY FAMILY INTERVENTION FOR ADOLESCENTS (BIFI-A) (UPDATED 2022) (continued)

REFERENCES

- 1) Gan C and Ballantyne M. Brain injury family intervention for adolescents: A solution-focused approach. *NeuroRehabilitation* 2016;38:231-241, doi: 10.3233/NRE-160135
- 2) Gan C, Gargaro J, Kreutzer J, Boschen K *et al.* Development and preliminary evaluation of a structured family system intervention for adolescents with brain injury and their families. *Brain Injury* 2010; 24(4):651-663

<https://hollandbloorview.ca/services/programs-services/brain-injury-rehab/BIFI-A>

TOOL/PROGRAMME SUMMARY

The Concussion and You handbook provides information on returning to the various aspects of daily life after a concussion. Geared towards children and families, the handbook provides:

- Information about concussion and its potential effect on the mind and body
- Strategies to help with recovery, including:
 - Energy conservation
 - Sleep
 - Nutrition
 - Relaxation
 - Return to school
 - Return to physical activity and sport
- Self-management tools to assist with the recovery process
- Recovery timeline incorporating strategies and tools to help children and families see how recovery phases fit together

BACKGROUND

The handbook helps children and families with concussion management and recovery by providing simple and relevant management techniques. The handbook was informed by leaders in youth concussion from the Holland Bloorview Kids Rehabilitation Hospital Concussion Centre, representing a multidisciplinary healthcare team (medicine [paediatrician, neurologist], occupational therapy, neuropsychology, social work).

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: P/F

KEY GOALS

- 1) To increase knowledge about concussion and the recovery process
- 2) To provide concussion strategies, tools and resources
- 3) To enable self-management of concussion by children and families

HOW THE TOOL/PROGRAMME IS USED

The handbook is user-friendly and easy to understand by the reader. The information, combined with the self-management tools and recovery timeline allows children and their families to create a self-management strategy that is tailored to the needs and environment of the child and family.

All children and families that access Concussion Services at Holland Bloorview Kids Rehabilitation Hospital are referred to the handbook to provide them with education on concussion and self-management strategies. As part of the Concussion Centres' services, free education and support sessions for children and their families are provided. An orientation to, and review, of the 'Concussion and You' handbook is provided during the education sessions.

KEY OUTCOMES

- 1) Increased knowledge about concussion and concussion management
- 2) Creating a concussion management plan tailored to the needs of the child

REFERENCES

- 1) Hunt AW, De Feo L, Macintyre J *et al.* Development and feasibility of an evidence-informed self-management education program in pediatric concussion rehabilitation. *BMC Health Serv Res* 2016;16:400. Published online 2016 Aug 17. doi: 10.1186/s12913-016-1664-3

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Christine Provvidenza: cprovvidenza@@hollandbloorview.ca | <https://hollandbloorview.ca/concussion-handbook>

EVALUATION AND INDIVIDUALISED FAMILY-BASED REHABILITATION PROGRAMME

TOOL/PROGRAMME SUMMARY

An experienced transdisciplinary team evaluates the child with an Acquired Brain Injury (ABI) and plans an internal and intensive 8-week rehabilitation programme, followed by an external programme, 3 times a week. The programme includes cognitive stimulation, language evaluation, communication/alternative communication, social and academic support, family orientation and cognitive coaching about strategies to deal with patient's behaviour. A range of tools are used for experiencing daily life activities, psychomotricity, stimulating motor abilities, locomotion, balance and coordination, sports, including 'Smartlab' (neurorehabilitation lab: virtual reality resources, electronic games) and comprehensive assistive technology (orthosis and wheelchair adaptations).

BACKGROUND

The SARAH Network of Rehabilitation Hospitals (Brazil) has vast experience with a context-sensitive family based approach, whose basic principles are based on an individualised programme according to the child's developmental stage, realistic and viable objectives, and a contextualised programme that includes assistance, support and information for the family, who are considered experts on their child.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: H/P/F

KEY GOALS

- 1) To provide a detailed evaluation and description of each recovery stage
- 2) To plan an individual programme for the child and family to achieve the highest level of independence and autonomy possible, integration in the community and improved quality of life
- 3) To assess the treatment efficacy for Acquired Brain Injury
- 4) To identify the correlation between evolutive radiological, neurophysiological, functional, psychological aspects, genetic and inflammatory blood markers
- 5) To identify predictive and prognostic factors related to neurological recovery (like gender, age at time of accident, brain damage severity, APOE genotype, family's compliance to rehabilitation programme and previous psychiatric diagnosis, child's cognitive and behavioural background)

HOW THE PROGRAMME IS USED EVALUATION PROTOCOL

- 1) Medical report and neurological examination.
- 2) Sequential brain images e.g. MRI, Diffusion, Tractography and Spectroscopy (biannual while changes are noticed).
- 3) Videoelectroencephalogram (annual).
- 4) Visual Evoked Potential responses to calculate the Inter-hemispheric transfer time (annual while changes are noticed).
- 5) Blood markers (APOE, BDNF).
- 6) Cognitive (Wechsler Intelligence Scale Cognitive IV): baseline, complete 90 mins test initially. After 6 months or after intervention: second and last time; about 30 mins test: (Processing Speed Index and Working memory Index).
- 7) Executive Functions (BRIEF- P : Behavior Rating Inventory of Executive Function): repeated as many times as necessary.
- 8) Behaviour evaluation: Child Behavior Checklist (CBCL – available of the internet).
- 9) Gross Motor Function Scales- GMFM); available on internet.
- 10) Manual function - PEGBOARD (reduced version of the Peg Moving Task - PMT-5) and Grooved Pegboard.
- 11) Gait analysis (annual).
- 12) Posturography (if balance is not normal, the test could be repeated 6 months after the intervention).
- 13) Pictures and videos register patient's improvement and their families impressions.

The first appointment is assisted by a rehabilitation/developmental paediatrician, physiotherapist and psychologist. Radiological evaluations and other medical needs are discussed with neurosurgeons, radiologists and orthopaedics, to decide on surgical interventions (intracranial haemorrhage, shunts etc.), pain or spasticity control (botulinum toxin etc.) and concluding with the clinical stability for the rehabilitation programme. The rehabilitation programme is prescribed and closely followed by the professionals, with active family participation.

KEY OUTCOMES

- 1) Achieve the highest level of independence and autonomy possible, as well as integration in the community and improvement of quality of life
- 2) Family are involved at all stages and provided with explanations about global stimulation and behaviour management strategies
- 3) Awareness of possible behavioural changes even into adulthood
- 4) Follow-up ensures a better understanding of the variables involved in the recovery process

EVALUATION AND INDIVIDUALISED FAMILY-BASED REHABILITATION PROGRAMME (continued)

REFERENCES

- 1) McKinlay A, Linden M, DePompel R *et al.* Service provision for children and young people with acquired brain injury: Practice recommendations. *Brain Injury* 2016;30(13-14):1656-1664
- 2) Braga LW. Family Participation in the Rehabilitation of the Child with Traumatic Brain Injury. *Brain Impairment* 2004;5(1):115
- 3) Braga LW, Método SARAH – Reabilitação Baseada na Família e no contexto da criança com lesão cerebral, Ed. Santos
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- 9) Berg M, Frooslie KF, Hussain A. Applicability of Pediatric Evaluation of Disability Inventory in Norway. *Scand J Occup Ther.* 2003;10(3):118-26
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- 12) Nordmark E, Orban K, Hägglund G *et al.* The American Paediatric Evaluation of Disability – Inventory (PEDI): applicability of PEDI in Sweden for children aged 2.0-6.9 years. *Scand J Rehabil Med.* 1999;31(2):95-100
- 13) GMFM- 88 and GMFM -66 scoring; 2013 Diane Russel and Peter Rosenbaun, Mc Master University, 2013
- 14) Kelly 2014; Curran 2015 Gross motor function measure (GMFM66) trajectories in children recovering after severe TBI; *Developmental Medicine and Child Neurology*

Contacts for further information:

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QUALITY OF LIFE AFTER BRAIN INJURY QUESTIONNAIRE (QOLIBRI)

TOOL/PROGRAMME SUMMARY

The Quality of Life after brain injury questionnaire (QoLIBRI) was specifically developed to assess the health-related quality of life (HRQoL) of individuals after Traumatic Brain Injury (TBI). It is a comprehensive questionnaire with 37 items covering 6 dimensions of HRQoL after TBI i.e cognition, self, daily life and autonomy, social relationships, emotions and physical problems. The first 4 scales assess 'satisfaction' and the final 2 scales 'feeling bothered' with key aspects of life. The questionnaire provides a quality of life profile together with a total score. It is easy to complete, and can be completed in 7-10 minutes. It is suitable for use in clinical settings, research studies, and population surveys.

BACKGROUND

HRQoL refers specifically to the effects of illness or other health conditions on QoL, and is a particularly important concept in chronic health conditions. The QOLIBRI is designed to capture changes in QoL in areas commonly affected by brain injury. An international multi-disciplinary group was formed in 1999 (the TBI Consensus Group, later the QOLIBRI Task Force) to develop a patient-based TBI specific questionnaire.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: H/P

KEY GOALS

- 1) To measure health improvement or decline
- 2) To follow-up the consequences of TBI
- 3) To conduct epidemiological studies monitoring QoL after TBI
- 4) To assess treatment effectiveness
- 5) To improve patient-doctor communication
- 6) To increase awareness of patients' HRQoL among relatives and carers

HOW THE TOOL/PROGRAMME IS USED

QOLIBRI scores are reported on a 0-100 scale, where 0=worst possible QoL and 100=best possible QoL. Responses to the 'satisfaction' items (i.e. items on the cognition, self, daily life and autonomy, and social relationships scales) are coded on a 1-5 scale, where 1= not at all satisfied and 5=very satisfied.

Responses to the 'bothered' items (i.e. items on the emotions and physical problems scales) are reverse scored to correspond with the satisfaction items, where 1=very bothered and 5=not at all bothered. The responses on each scale are added up to give a total, and then divided by the number of responses to give a scale mean. The scale means have a maximum possible range of 1-5. The mean can be computed when there are some missing responses, but should not be calculated if more than one third of responses on the scale are missing. In a similar manner the QOLIBRI total score is calculated by adding up all the responses, and then dividing by the actual number of responses. Again, a total score should not be calculated if more than one third of responses are missing. The scale means are converted to the 0-100 scale by subtracting 1 from the mean and then multiplying by 25. This produces scale scores which have a lowest possible value of 0 (worst possible QoL) and a maximum value of 100 (best possible QoL).

KEY OUTCOMES

- 1) Measurement of health improvement or decline
- 2) Assessment of treatment effectiveness
- 3) Improved understanding of the patient's HRQoL amongst parents and families

REFERENCE

1) von Steinbüchel N, Wilson L, Gibbons H *et al.* Quality of Life after Brain Injury (QOLIBRI): Scale validity and correlates of quality of life. *Journal of Neurotrauma* 2010;27:1157-1165

Contact for further information: The QOLIBRI questionnaire is free to use for researchers and non-profit organisations. There is a charge for commercial use. <http://www.qolibrinet.com>

LEARNET PROBLEM-SOLVING SYSTEM

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TOOL/PROGRAMME SUMMARY

LEARNet is a resource produced by the Brain Injury Association of New York State (BIANY). It includes a problem-solving system designed to help teachers identify useful procedures for helping students with brain injury in school and at home. There is a video introduction to the programme, a list of possible problems and tutorials to facilitate solving the problems.

BACKGROUND

Helping children and adolescents with a brain injury is a challenge that requires creativity and often the help of a specialist. Experience and research has shown that educator training presented in live workshop formats has little impact on a change in classroom practices or the enhancement of teacher competency. Lack of impact is a combined result of relatively few educators receiving training, relatively little transfer from the training context to classroom application, rapid shifts in staff within the educational system, and isolation of the family. Project LEARN and the LEARNet website makes available 'anytime access' with Acquired Brain Injury (ABI)/Traumatic Brain Injury (TBI) consulting services to all schools and families.

DEFICIT ADDRESSED: A

TARGET USER: P/F/E

KEY GOAL

1) To provide effective intervention and learning support plans for students with ABI/TBI

HOW THE TOOL/PROGRAMME IS USED

The video provides an introduction to the programme for the student/family. The problems can be identified and tutorials are available to then provide guidance to address the problems. The organisation of the material is user friendly, written in an understandable manner and contains a wealth of information, as much or as little as the user wants to deal with at the time.

KEY OUTCOMES

- 1) An effective resource for teachers and families
- 2) Tailored problem-solving resources

Contact for further information: www.projectlearnet.org

TOOL/PROGRAMME SUMMARY

The Brain Injury Hub is a comprehensive website providing information about brain injury for parents, families and teachers. Users can find information on Acquired Brain Injury (ABI), the effects of ABI, being in hospital, rehabilitation, being back at home, returning to education, the transition to adulthood, real stories of childhood brain injury and practical help for carers.

BACKGROUND

This website was developed as a way of sharing expertise about brain injury. It provides the information in an understandable language for parents, teachers and families to help them on their on-going journey following a child's brain injury. The Brain Injury Hub was developed by The Children's Trust, the UK's leading charity for children with brain injury. Clinicians from The Children's Trust have contributed extensively to this website and used their vast knowledge, expertise and experience on working closely with children with a brain injury to provide tips, strategies and practical information.

DEFICIT ADDRESSED: P/C/A/PS
TARGET USER: H/P/F/E/CSW

KEY GOALS

- 1) To inform about ABI and its ongoing consequences
- 2) To provide practical help

HOW THE TOOL/PROGRAMME IS USED

The website is freely available and users can explore the site and download information as required.

KEY OUTCOME

- 1) Provision of easily accessible, reliable and practical information

Contact for further information: www.braininjuryhub.co.uk | www.thechildrenstrust.org.uk

MY BRAIN AND ME

TOOL/PROGRAMME SUMMARY

My Brain and Me is a software application or 'app' for young people with Acquired Brain Injury (ABI). It works as a mood diary and information resource. Users can keep in touch with how they are feeling by logging their entries in the diary under the section 'Mood'. The app also provides tips for young people for when they are feeling down or anxious. In the 'Brain' section, users will be able to learn about the different parts of the brain and how they affect day-to-day life. Users can also access the 'Friends' section where contacts and emergency phone numbers are saved. The app comes with saved numbers of charities and organisations that can help support young people with ABI and users can add to the section by saving their own emergency contacts.

BACKGROUND

The Brain and Spine Foundation developed the resource because ABI affects children both physically and cognitively; individuals will experience different practical and emotional needs over time and they need to be able to learn how to manage them.

DEFICIT ADDRESSED: P/C
TARGET USER: P

KEY GOAL

1) To provide a resource to support young people with ABI

HOW THE TOOL/PROGRAMME IS USED

The app is free and available to download for iOS devices on App Store and for Android on Google Play – contact the web address below. The user then interacts with the app as required.

KEY OUTCOME

1) On-the-go support for young people with ABI

Contact for further information: info@brainandspine.org.uk

BRAIN INJURY ALERT

TOOL/PROGRAMME SUMMARY

The Brain Injury Alert is a tool to assist in the identification of the signs of Acquired Brain Injury (ABI) in children; it is not a diagnostic tool. It consists of 19 cognitive, behavioural and socio-emotional questions, with four response categories each: 1) yes, this problem is present and it impedes the child's development; 2) yes, but it doesn't impede development; 3) no, problem not present; 4) don't know.

When three or more items are scored with answer category 1, referral to detailed diagnostics is recommended.

BACKGROUND

The Brain Injury Alert was developed by Rasquin SMC, Ritzen WJM, Winkens I, van Heugten, CM. Published by Vilans, Utrecht 2008.

DEFICIT ADDRESSED: C/PS

TARGET USER: H/P/F/E

KEY GOAL

1) To identify possible ABI in a child

HOW THE TOOL/PROGRAMME IS USED

The tool has been validated and can easily be completed in 12-15 minutes.

KEY OUTCOME

1) Enhanced identification of ABI in children

REFERENCES

- 1) Rasquin S, Winkens I, van Heugten C *et al.* Development and validity of the Brain Injury Alert, screening tool for cognitive, emotional and social problems after paediatric acquired brain injury. *Brain Inj* 2011;25(7-8):777-86. doi: 10.3109/02699052.2011.580311. Epub 2011 May 11
- 2) 2011;25(7-8):777-86. doi: 10.3109/02699052.2011.580311. Epub 2011 May 11
- 3) <https://www.ncbi.nlm.nih.gov/pubmed/21561290>

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RETURN TO SCHOOL PATHWAY AND GUIDANCE DOCUMENT

TOOL/PROGRAMME SUMMARY

This is a collaborative return to school pathway and guidance document developed in Nottingham (UK) by the local Educational Psychology (EP) service, the paediatric neuropsychology service at a regional centre, and a young man, Sam White, and his parents. Contributions were sought from key agencies involved in supporting children and young people (CYP) with an Acquired Brain Injury (ABI), including neuro-oncology/BI keyworkers and teaching staff.

BACKGROUND

Clinical work and small-scale research with families of CYP diagnosed with an ABI highlighted significant issues with returning to school. Return to school was often delayed and extremely stressful for CYP, families felt schools were frequently underprepared and slow to respond to the CYP's needs and teachers reported lacking knowledge and understanding about brain injuries and the potential impact on a CYP's learning and engagement. Educational psychologists were often unaware of these CYPs. The need for a return to school pathway and guidance document was identified. The pathway was named after Sam.

DEFICIT ADDRESSED: P/C/A/PS
TARGET USER: H/P/F/E

THE SAM WHITE RETURN TO EDUCATION PATHWAY

INITIATION OF PATHWAY:

CYP with admitted to regional centre with ABI – triggers referral to pathway and assessment by key workers and neuropsychology team. Consent for EP involvement gained.

INVOLVEMENT OF LOCAL EP TEAM:

Keyworkers informs Specialist Practitioner EP who contacts the school and local EP.

REGULAR DISCHARGE PLANNING AND SUPPORT MEETINGS:

MDT meetings arranged to support discharge and return home/to school. Attended from outsets by EP, school and other specialist services.

COLLABORATIVE RETURN TO EDUCATION PLAN MADE:

Return to education plan instigated, in line with guidelines and utilising all required agencies. Training accessed and bids for funding made, as required.

RETURN TO EDUCATION BY CYP:

CYP returns to school/collage with plan and any necessary adjustments already in place.

SUPPORT EVOLVES WITH THE CYP:

Progress monitored each team, and at key stages and transition.
 Annual review at county 'springboard' meeting.
 Level of support adjusted accordingly and services accessed/re-accessed as necessary.

KEY GOALS

- 1) To outline the involvement and responsibilities of key agencies, and highlight the roles of the EP service, paediatric neuropsychologists, and keyworkers in supporting the process
- 2) To provide information for schools for preparing staff, pupils and the environment for the CYP's return
- 3) To offer positive practice examples and a checklist for school actions
- 4) To ensure CYP with an ABI are not forgotten by the education system

HOW THE TOOL/PROGRAMME IS USED

All CYP treated at the regional centre for moderate/severe ABI are automatically placed on the pathway and all aspects followed through.

KEY OUTCOMES

- 1) A proactive, rather than reactive, approach is beneficial for the CYP
- 2) Pathway promotes good practice and inter-agency collaboration, while also acting as a safety-net for families where school-return has been more challenging
- 3) Training sessions and dissemination at conferences has led to other UK areas starting to develop similar pathways

REFERENCE

- 1) Presented at the 2nd International Conference on Paediatric Acquired Brain Injury, Rome 2017

Contact for further information: Emily Bennett: emily.bennett@nuh.nhs.uk

<https://www.thesamwhitelegacy.org.uk/wp-content/uploads/2017/03/PDF-Making-a-Successful-Return-to-Education-After-an-Acquired-Brain-Injury-ABI-02-17.pdf>

COMPREHENSIVE CARE PROGRAMME (INCLUDING OUTREACH)

TOOL/PROGRAMME SUMMARY

This programme was developed in Saint Maurice, France and features an inpatient and outpatient rehabilitation facility, where comprehensive multidisciplinary rehabilitation and specialised schooling are provided to children with acquired neurological injury (mostly but not exclusively brain). There are 30 beds and in addition the department can see 30 outpatients daily. Referral is mostly from the acute care hospitals. Adequate preparation for discharge is essential, long-term follow-up is organised, and an outreach programme has been developed to deal with the complex delayed psychosocial issues. All children with Acquired Brain Injury (ABI) are eligible to benefit from the programme which is publicly funded.

BACKGROUND

ABI is a leading cause of death and lifelong acquired disability in children and remains a significant public health issue. Deficits may only become fully apparent when developmental demands increase, and once cognitive processes are expected to be fully developed. It is therefore necessary to provide organised long-term follow-up for children post-ABI. Despite these recommendations, it has been shown that only a small proportion of children receive the necessary specialised rehabilitation and adequate follow-up after ABI.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: H/P/F/E/CSW

KEY GOALS

- 1) To systematically provide an individualised care and school plan for each child with various levels of intervention available long term
- 2) To promote each child's successful re-integration in school and in the community

HOW THE TOOL/PROGRAMME IS USED

An in- and out-patient rehabilitation facility has been established with multi-disciplinary rehabilitation. There is specialised schooling for CYP aged 3-15 years. Forty-five to 60 patients present each day with long-term follow-up in the clinics until their transition to adult services. Many have additional ongoing rehabilitation in the community and only get follow-up in clinics if their issues are not too complex to deal with. Only those that cannot be seen and dealt with 'only' in outpatients clinics and need multidisciplinary interventions, contacts with schools, attending school meetings, etc., are referred to the outreach team. The latter has been developed to deal with complex delayed psycho-social issues.

KEY OUTCOMES

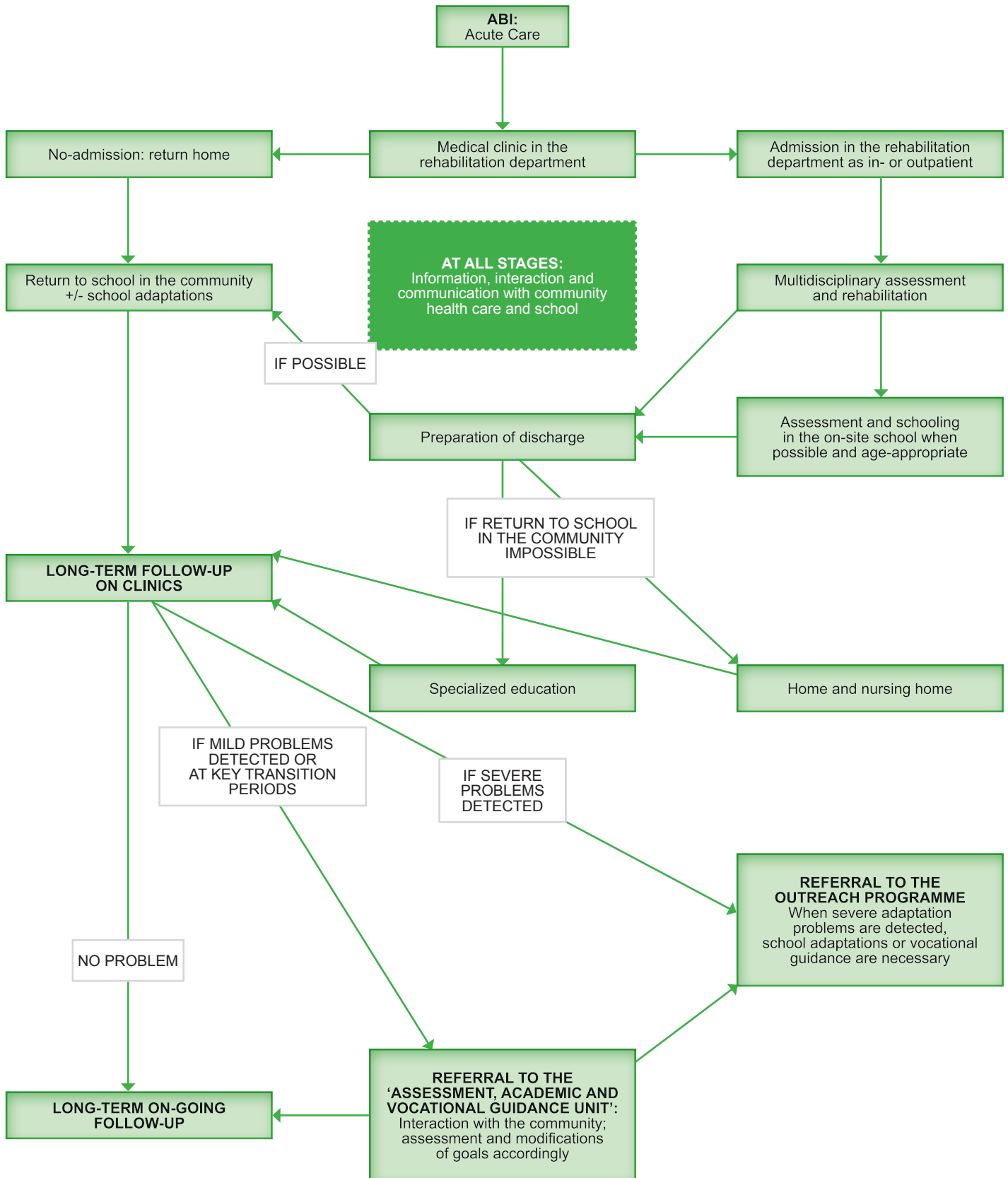
- 1) Outcomes are selected for each individual according to what is clinically relevant
- 2) Provides comprehensive long-term multidisciplinary assessment and rehabilitation, with a focus on the child and family, as well as schooling until transition to the adult service
- 3) Ensures best possible re-integration into school and transition

REFERENCE

- 1) Chevignard M, Toure H, Brugel DG *et al.* A comprehensive model of care for rehabilitation of children with acquired brain injuries. *Child: Care, Health and Development* 2009;36(1):31-43. Presented at 2nd International Conference on Paediatric Brain Injury, Rome 2017

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POST-INJURY CARE PATHWAY FOR A CHILD WITH ABI



ACQUIRED BRAIN INJURY GUIDEBOOK FOR FAMILY INTERVENTION (AVAILABLE IN DUTCH)

TOOL/PROGRAMME SUMMARY

This is a guidebook for the treatment and support for families who have a child with ABI. It is also aimed at managers as well as health professionals.

BACKGROUND

The tool was developed following a: 1) a literature study, 2) regional symposia, 3) consensus meetings of professionals, 4) working with the tool with 40 families.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: H/P/F/CSW

KEY GOAL

1) To ensure high quality, specific treatment and support for families with a child with ABI in all phases of ABI (from acute to chronic)

HOW THE TOOL/PROGRAMME IS USED

The book is a reference tool for all involved to read.

KEY OUTCOMES

- 2) Improved family life
- 3) Increased knowledge of ABI for parents and siblings
- 4) Improved self-rated proficiency by parents and professionals working with children who have ABI

REFERENCE

- 1) Eric Hermans and Rianne Gijzen. 'Gewikt en gewogen'. (Report of a pilot in 40 families)

Contact for further information: Rianne Gijzen: r.gijzen@vilans.nl | www.vilans.nl

CONTEXT-FAMILY BASED APPROACH

TOOL/PROGRAMME SUMMARY

The context-family based approach is multidisciplinary approach and involves collaborative assessments of each individual child and a rehabilitation plan rooted in the child's particular needs and interests. The family accompanies each stage of the rehabilitation process, starting with the first evaluation. They are offered ongoing support through group meetings and extensive information about their child's condition. Parents or familial caregivers are trained in the administration of context-sensitive stimulation and rehabilitation activities, to be performed at home, in the daily context of home life. They are provided with manuals containing written and illustrated guidelines, adjusted frequently as the child grows and develops.

BACKGROUND

The SARAH Network of Rehabilitation Hospitals in Brazil created, validated, and refined an ecological rehabilitation approach centred on the family. This methodology has been in effect for over 30 years. It includes a manual with illustrated stimulation activities for each stage of the child's motor and cognitive development, visuo-motor coordination, language skills, and independence in activities of daily living (ADLs). The philosophical principles, methods, ways of stimulating the rehabilitation of the child, are found in the book (see reference below) and evidence of the methods demonstrated in a Randomised Controlled Trial (see reference below).

DEFICIT ADDRESSED: P/C/A/PS
TARGET USER: H/P/F/E/CSW

KEY GOALS

- 1) To improve the cognitive and motor function of children with brain injury
- 2) To train and prepare the family to administer the neurostimulation and neurorehabilitation exercises at home with the child
- 3) To positively alter the rehabilitation experience for both the child and family, while maximising professional support through more streamlined day-to-day involvement

HOW THE TOOL/PROGRAMME IS USED

Healthcare professionals, parents, family caregivers, and community professionals are all trained in the ecological integration of situations that target the child's motor, cognitive, communication and ADL independence which leads to more frequent and natural neurodevelopment stimulation.

An integrated multidisciplinary assessment of the child with brain injury was conducted with the family and professionals. Short-, medium-, and long-term goals were agreed and an individualised rehabilitation programme designed and implemented with stimulation activities centred on the family context. Choose activities (illustrations) targeting each specific developmental stage and short-term goals, train the family to exercise these activities at home with the child, transferring them to their daily life routines. Perform periodic reassessments of the child, help the family evaluate the results obtained with the stimulation activities, update the rehabilitation programme, train the family for the next stage of activities, all with longitudinal follow-up of the child and family by the multidisciplinary professional team.

KEY OUTCOMES

- 1) In one year the study demonstrated significantly better motor development than in group exclusively stimulated by professionals
- 2) In one year, there was significantly better cognitive development than in group exclusively stimulated by professionals
- 3) The child's development was not influenced by the parents' educational abilities

REFERENCES

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- 2) Braga LW, Da Paz Jr AC, Ylvisaker M. Direct clinician-delivered versus indirect family- supported rehabilitation of children with traumatic brain injury: a randomized controlled trial. *Brain Inj.* 2005;19(10):819-831
- 3) Braga LW. Should we empower the family? *Dev Neurorehabil.* 2009;12(4):179-80 [Editorial]

PAEDIATRIC ACQUIRED BRAIN INJURY COMMUNITY OUTREACH PROGRAMME (PABICOP)

TOOL/PROGRAMME SUMMARY

The Paediatric Acquired Brain Injury Community Outreach Programme (PABICOP) is a model of care developed to provide a comprehensive continuum of care to children and young people (CYP) with Acquired Brain Injury (ABI) throughout childhood and adolescence. Case-specific consultations, school and community liaison and educational sessions are the principal services provided. It is a coordinated, family/community-focused programme aimed at enhancing outcomes for children and youth with ABI and their families.

BACKGROUND

The programme was developed by the late Dr Jane Gillett, paediatric neurologist and founder of the IPBIS, and is carried out at the Thames Valley Children's Centre in London Ontario (Canada). The philosophy of this programme is that it is holistic, parent and family-centred, and it incorporates and involves the community at large in the ongoing care and management of the CYP with ABI, while supporting the family. It also includes the ideas of continuity, accessibility, knowledge, collaboration, empowerment and advocacy.

DEFICIT ADDRESSED: P/C/A/PS
TARGET USER: H/P/F/E/CSW

KEY GOALS

- 1) To improve knowledge among parents/caregivers about the characteristics of ABI and effective strategies to deal with the associated problems
- 2) To facilitate a sense of empowerment in the rehabilitation process for parents/caregivers
- 3) To increase the extent to which the CYP has been successfully integrated back into the family and the community

HOW THE TOOL/PROGRAMME IS USED

A CYP can be referred to PABICOP for assistance with the effects of a remote brain injury, including medical, psychological and educational issues. The criteria used for a referral include the following: 1) loss of consciousness no matter how brief, 2) confusion at the scene or shortly thereafter, 3) amnesia as a result of the event. The PABICOP multidisciplinary team works with community clinics. Depending on the severity of the brain injury various forms of multidisciplinary follow-up are arranged. The first follow-up clinic appointment is usually at 3 months. The families are encouraged to invite anyone who they feel should be at the clinic; they are actively encouraged to bring all the important people in their CYP's life to the clinic. A PABICOP-like pilot project has been carried out in The Netherlands.

KEY OUTCOMES

Children with ABI and their families receiving services from the PABICOP programme fared significantly better than a comparison group receiving standard care with respect to:

- 1) Enhancing parent/ caregivers' knowledge of ABI
- 2) Integrating children back into the family and community

REFERENCES

- 1) Gillett J. The Pediatric Acquired Brain Injury Community Outreach Program (PABICOP) – An innovative comprehensive model of care for children and youth with an acquired brain Injury. *NeuroRehabilitation* 2004;19:207-218
- 2) McDougall J, Servais M, Sommerfreund J *et al.* An evaluation of the paediatric acquired brain injury community outreach programme (PABICOP) *Brain Injury* 2006;20(11):1189-1205

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TEEN ONLINE PROBLEM SOLVING (TOPS)

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TOOL/PROGRAMME SUMMARY

Teen Online Problem Solving (TOPS) comprises core website modules that provide training in problem-solving, planning/organisation, self-regulation, anger management, verbal/nonverbal communication, and social problem-solving.

BACKGROUND

Traumatic Brain Injury (TBI) is a leading cause of acquired disability in childhood, and incidence peaks during adolescence. Consequences include persistent changes in cognitive abilities, executive functions, behaviour, and social competence. Families are also adversely affected, particularly after severe TBI. Injuries during adolescence may contribute to difficulties negotiating normative developmental transitions such as dating, driving a car, and getting a job. Parental concerns, coupled with the deterioration in the teen's problem-solving skills and self-regulation, can result in increased conflict and additional deterioration in teen behaviour. Few evidence-based treatments exist to facilitate adolescent and family adaptation after TBI, and TOPS was developed to address this.

DEFICIT ADDRESSED: C/PS
TARGET USER: P/F

KEY GOAL

1) To provide training on problem-solving, planning/organisation, self-regulation, anger management, verbal/nonverbal communication, and social problem-solving for adolescents and their families

HOW THE TOOL/PROGRAMME IS USED

A therapist identifies goals that the teen and family wanted to address and trains the family on navigating the TOPS website and the use of video conferencing software. Subsequent sessions can be conducted remotely by using online video conferencing or, if video conferencing is not possible, over the telephone. The teen and his or her primary caregiver complete the initial face-to-face session and subsequent video conferences together with the therapist. After completion of each web module, the family meet with the therapist via video conference. The therapist reviews the website content and works with the family to apply the problem-solving process with the goal of generating a plan to address a problem or goal identified by the family, giving the family experience in implementing the self-regulation skills taught through the self-guided web pages.

KEY OUTCOMES

- 1) Improvement in parent-teen conflict generally
- 2) Improvement in parent and self-reported teen behaviour problems
- 3) Decreased parent-teen conflict

REFERENCE

1) Wade SL, Walz NC, Carey J *et al.* Effect on Behavior Problems of Teen Online Problem-Solving for Adolescent Traumatic Brain Injury. *Pediatrics*. 2011;128(4):947-953

Contact for further information: Shari Wade: shari.wade@cchmc.org

TRANSITION PROGRAMME FROM PAEDIATRIC TO ADULT SERVICES

TOOL/PROGRAMME SUMMARY

Guidelines were developed in Australia to formalise the transition from paediatric to adult healthcare services.

BACKGROUND

The transition between paediatric and adult care for adolescents with disability is challenging and often poorly managed. People who have sustained an Acquired Brain Injury (ABI) in childhood have similar aspirations to those without disabilities, but they have more difficulty accessing services. Young people who do not engage in a transition process succumb to poorer outcomes such as unemployment or limited employment choices and access to vocational training, poor self-esteem and self-confidence, lacking in self-care abilities, financial issues, drug, alcohol and gambling addictions, crime involvement, and mental health issues. If transition clinics exist there may be no formal procedure for supporting the young person through the system.

DEFICIT ADDRESSED: P/C

TARGET USER: H/P

KEY GOAL

1) To ensure a smooth and seamless transition from the paediatric to adult healthcare service

HOW THE TOOL/PROGRAMME IS USED

Following the development of the formalised guidelines in the form of a flow chart (see below), all eligible young people commence the transition process. Formal transition meetings occur at key developmental or educational stages. The first transition meeting includes receiving an explanation of the transition process and an information pack, as well as a Home, Education/Employment, Eating, Activities, Drugs, Sexuality, Suicide/Depression, and Safety (HEEADSSS) assessment. Goals are identified and an Individual Transition Plan (ITP) is developed. The adult team case manager (and adult therapists as required) are introduced to the young person at 16 years of age and the case management role may be shared depending on the needs of the client. Prior to this, the paediatric clients are given informal opportunities to meet with them. The client is fully transferred over to the adult team on completion of secondary schooling. Between the formal transition meetings regular liaison occurs with the client and their family, and others involved in their rehabilitation programme to continuously monitor their progress, evaluate current strategies, and review goals.

KEY OUTCOMES

- 1) Increased retention of young people with ABI as they transition to adult services
- 2) Adult team members develop more awareness of the issues associated with adolescence
- 3) Increased collaboration between paediatric and adult teams
- 4) Increased successful transitions
- 5) Young people show greater confidence and increased responsibility for their rehabilitation.

REFERENCE

- 1) Presented at 2nd International Conference on Paediatric Acquired Brain Injury, Rome, 2017

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PEER EVENTS

TOOL/PROGRAMME SUMMARY

An event is organised with a group of friends chosen by the patient to facilitate shared learning and social activity. All are invited to a session at a nearby non-hospital facility. The therapy team offers brain injury education appropriate to the age group, information about how they could help their friend, a forum for questions and/or anxieties, sharing thoughts and feelings and a supported social activity. Feedback questionnaires are distributed after each session.

BACKGROUND

It is well documented that the peer relationships of children and adolescents are important for the development of social competence and confidence, and for mental health and wellbeing. Following ABI problems with disinhibition, impulsiveness, poor social judgement, lack of emotional response and slowed processing can all contribute to difficulties maintaining relationships with peers as well as difficulties in acquiring new ones.

Evidence shows that when children and young people attempt to reconnect with their pre-injury peers the result is often a gradual loss of friendships and increasing isolation. Loneliness has been reported as one of the dominant concerns for individuals living with a brain injury. Social function was identified at King's College London, UK to be the greatest ongoing burden of disability and a peer event initiative was developed within the acute neurorehabilitation service.

DEFICIT ADDRESSED: C/PS

TARGET USER: P

KEY GOALS

- 1) To improve the social interaction and integration of children and adolescents following ABI
- 2) To promote better social competence and confidence
- 3) To reduce the likelihood of peer rejection
- 4) To enhance understanding and involvement of close friends in the CYP's brain injury and recovery

HOW THE TOOL/PROGRAMME IS USED

The event is organised as part of the CYP's ongoing rehabilitation.

KEY OUTCOMES

- 1) Improved understanding of brain injury by the patient's friends
- 2) Identification of practical and realistic support that could be provided
- 3) Patients and their families report positive outcomes
- 4) Addresses the ongoing burden of social integration difficulties in children and young people following neurorehabilitation for brain injury in their initial transition into the community and school

REFERENCES

- 1) Presented at the 2nd international Conference on Paediatric Acquired Brain Injury, Rome, 2017
- 2) Presented at the 3rd International Conference on Paediatric Acquired Brain Injury, Belfast, 2018

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LEARNING PARENTAL NETWORK AND LEARNING YOUTH NETWORK ON FACEBOOK

TOOL/PROGRAMME SUMMARY

In closed Facebook accounts, parents and teenagers with an Acquired Brain injury (ABI) are able to discuss and share their experiences while having access to professional knowledge and support if required. Parents can discuss any subject they like and at the same time they have the opportunity to access tips, advice and links that are posted by the BarnRehab Skåne (BRH) team in Sweden.

The BRH team consists of an occupational therapist, psychologist, special educational needs teacher and counsellor. They can also access information about different activities at BRH and sign up for these activities.

BACKGROUND

Families of children and teenagers with ABI often have concerns about how life will develop with regard to school, leisure time, social interaction, adulthood and future working life. They need ongoing advice from professionals. Parents and teenagers often also want to get in touch with other families who are in the same situation. BRH is a resource centre within the Region Skåne's Child and Youth Rehabilitation and specialises in rehabilitation after ABI. It started two different Facebook groups to create learning and information networks for teenagers with ABI, and for their parents.

DEFICIT ADDRESSED: P/C/A/PS
TARGET USER: P/F

KEY GOALS

- 1) To provide easily accessible professional information and support to families and children with ABI
- 2) To allow interaction with other families and peers

HOW THE TOOL/PROGRAMME IS USED

Families and teenagers sign up to the relevant Facebook network. BRH has a team who actively participate in this network by publishing posts every week and contributes with information and support as required.

KEY OUTCOMES

- 1) Parents appreciate the discussions and obtain new ideas on how to support their children in their everyday life
- 2) Professionals experience a positive response from parents and teenagers
- 3) Positive and useful experience for both parents, teenagers and professionals

REFERENCE

- 1) Presented at 2nd International Conference on Paediatric Acquired Brain Injury, Rome, 2017

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METACOGNITIVE DIMENSION PROGRAMME FOR PRE-ADOLESCENTS AND ADOLESCENTS (MCD)

TOOL/PROGRAMME SUMMARY

This programme helps pre-adolescents and adolescents develop the executive and metacognitive functions that will improve their self-control and self-regulation abilities, thereby reducing behavioral problems, impulsivity, and irritability. This approach involves college students who act as more able peers to stimulate the executive and self-control functions through interactive activities that are guided and supervised by a multiprofessional team.

BACKGROUND

The University of California in San Diego developed an after-school educational programme aimed at enriching the environment of socio-economically challenged young people through supervised interactions with college students. This project is based on Vygotsky's Zone of Proximal Development concept where the more capable peers engage with the challenged young people which improves their cognitive development. Based on this peer-centered experience, which is very important during pre-adolescence and adolescence and, therefore, more ecological, the SARAH Network pioneered a programme in 2007 involving the interaction between pre-adolescents and college students, albeit, with a different focus. The programme was designed not only to enrich the child's environment, but also, and primarily, to help develop metacognitive functions such as self-control and self-regulation, which contribute to improved behavior and other functions linked to the frontal lobe.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: H/P/F/E/CSW and undergraduate college students

KEY GOALS

- 1) To develop the executive functions of self-control and self-regulation, as well as metacognition
- 2) To improve behavior and social relationships
- 3) To reduce impulsivity and conflict-involvement (criminality)

HOW THE TOOL/PROGRAMME IS USED

Undergraduate college students majoring in psychology undergo a selection process and, once chosen, are trained in various topics, such as: Acquired Brain Injury (ABI), brain maturation, cognitive development, executive functions, metacognition, zone of proximal development, and goal management training. The pre-adolescents come to the Rehabilitation Centre in groups of 8, twice a week, for 2 hours, to experience the interactions with the undergraduates. They engage in activities involving various modalities, such as virtual reality, sports, games, art and computers. These activities are carried out in an ecological manner – and targeted towards helping the pre-adolescents to stop ongoing behavior, rethink and re-adjust their goals by using professionally supervised metacognitive strategies. The parents are also trained to give continuity to this type of goal management training in their daily lives.

Children, students, parents and the team, together establish goals based on each child's history, context and interests. During their supervised interactions, the adolescent/undergraduate pair engage in activities that are enjoyable and, consequently, sustainable, thereby promoting practical training on self-instructions and self-monitoring exercises. The students also use external cues and stories promoting discussion about executive dysfunction in their daily lives. Games in pairs or groups stimulate sharing rules, which implies in controlling their own behavior and preparing the preadolescents to deal with social and interactional rules. At the end of each session, the adolescent and undergraduate groups discuss their processes and gains among themselves as well as with the multidisciplinary supervisory team.

KEY OUTCOMES

- 1) Improved self-esteem and self-concept/image
- 2) Increased metacognitive strategies and self-regulation
- 3) Improved behavior and social relationships/exchanges

REFERENCES

- 1) Braga LW, Cole M. Creating an idioculture to promote the development of children with cerebral palsy. *Educação e Pesquisa*. 2016;36:131-141. Available from: http://www.scielo.br/pdf/ep/v36nspe/en_v36nspea11.pdf
- 2) Braga LW, Rossi L, Moretto AL *et al*. Empowering preadolescents with ABI through metacognition: preliminary results of a randomized clinical trial. *NeuroRehabilitation* 2012;30(3):205-212

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QUALITY CRITERIA AND A REFERRAL GUIDE: CARE FOR CHILDREN WITH BRAIN TUMOURS (AVAILABLE IN DUTCH)

TOOL/PROGRAMME SUMMARY

The Association of Parents of Children with Cancer (VOKK) and the Foundation for Paediatric Oncology (SKION) have developed quality criteria for the care of children with brain tumours. The criteria reflect what parents and children think is important. In addition a referral guide has been produced which provides information about where families can get treatment, help and support during the acute, post- acute and chronic phase.

BACKGROUND

More than 80% of children with a brain tumour have the sequelae caused by the tumour or the treatment. The illness as well as the treatment can cause brain injury, and for many parents it is very frustrating and time consuming to identify the most appropriate care at a time when the family burden is already high.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: H/P/F/E/CSW

KEY GOALS

- 1) To provide a dialogue on the quality of care between families and professionals
- 2) To ensure patient-focused improvements in care
- 3) To provide information for families and professionals on the available support and care

HOW THE TOOL/PROGRAMME IS USED

In one region of the country the quality criteria and the referral guide have been implemented in a pilot project. The priorities for the improvement of care were: 1) improvement of expertise in general and of school support in particular, and 2) to bring about a regional specification of the referral guide.

KEY OUTCOMES

- 1) Organisations involved in the treatment and care for these children are better connected
- 2) Connections have been established with the regionally operating brain injury teams
- 3) Improvements in care and support have been achieved

REFERENCES

- 1) Quality criteria: <http://vokk.nl/index.cfm?action=doelloket.home&category=227>
- 2) Referral Guide: <http://hersentumoren.vokk.nl>

Contact for further information: Rianne Gijzen: r.gijzen@vilans.nl

STANDARD OF CARE FOR PAEDIATRIC TRAUMATIC BRAIN INJURY (AVAILABLE IN DUTCH)

TOOL/PROGRAMME SUMMARY

The Standard of Care describes what treatment and care parents and children may expect following Traumatic Brain Injury (TBI). It is developed on the basis of literature and existing good practices in The Netherlands and supported by professionals from all disciplines involved. It describes how care can be organised in an optimal and holistic way, in order to make sure that children and parents get the best treatment and support during all phases.

BACKGROUND

The Standard of Care was developed from the observation that a seamless continuum of care did not exist and that care was fragmented.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: H/P/F/E/CSW

KEY GOALS

- 1) To support professionals in maximising optimal care for children and their families
- 2) To inform families about the care they may expect
- 3) To help care providers to collaborate with others for the benefit of children with TBI and families

HOW THE TOOL/PROGRAMME IS USED

From November 2016 until May 2018 the Standard of Care is being implemented in four pilot regions in The Netherlands. In the pilot regions professionals from various disciplines and organisations will identify key problems in their regions and try to achieve improvements on the basis of the Standard of Care.

KEY OUTCOMES

- 1) The results are not known because pilots with implementation of the Standard are still ongoing.

REFERENCE

- 1) Hersenstichting (2016). Zorgstandaard Traumatisch Hersenletsel Kinderen & Jongeren. https://www.zorgstandaardnah.nl/Zorgstandaard_THL_Kinderen_Jongeren/zorgstandaard_kinderen

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GRADUATED RETURN TO SCHOOL/RETURN TO PLAY GUIDELINES

TOOL/PROGRAMME SUMMARY

The guidelines are based on the Centre for Disease Control and Prevention (CDC, USA) Heads Up programme to educate people on how to recognise, respond to and minimise the risk of concussion or other serious brain injury. It provides a step-wise progression of managing a graduated return to school prior to play, and assists parents and children in working with schools and their physicians to safely return to activity following concussion.

BACKGROUND

The guidelines, together with the tools developed by Dr Gerrard Gioia, and the Defense and Veterans Brain Injury Centre Parent's Guide to Returning Your Child to School after Concussion, were operationalised in order to develop a stepwise progression.

DEFICIT ADDRESSED: P/C

TARGET USER: H/P/F/E

KEY GOALS

- 1) To educate parents on stepwise programme of symptom resolution
- 2) To guide a return to school and accommodate discussion
- 3) To ensure medical oversight and clearance before a return to play

HOW THE TOOL/PROGRAMME IS USED

The guidelines are presented along with educational presentation on concussion to school nurses, teachers, coaches, athletic trainers, parents and child athletes at the beginning of the school year, and again in the spring to ensure understanding to support recovery.

Parents, school staff and children are educated in the school environment regarding concussion risk, prevention, and care prior to engaging in school sports activities. Parents and students are educated on symptoms of concussion as well as concussion management and recovery, to ensure a safe, slow and systematic return to increased activity is consistent with the child's recovery.

KEY OUTCOMES

- 1) Improved parent and child health literacy on concussion management
- 2) Support for school staff and parents on co-ordinating a return to activity
- 3) Create a dialogue and discussion with the medical provider for clinical management and return to activity

REFERENCES

- 1) Gioia G. Medical-school partnership in guiding return to school following mild traumatic brain injury in youth. *J Child Neurol* 2016;31(1):93-108
- 2) De Maio VJ., Joseph DO, Tibbo-Valeriotte H *et al.* Variability in discharge instructions and activity restrictions for patients in a children's ED post-concussion. *Pediatric Emergency Care* 2014;30(1):20-25
- 3) DeMatteo C, Stazyk K, Giglia L *et al.* A balanced protocol for return to school for children and youth following concussive injury. *Clinical Pediatrics* 2015;54(8):783-792. doi:10.1177/0009922814567305
- 4) Presented at the 2nd International Conference on Paediatric Acquired Brain Injury

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CHILD AND ADOLESCENT SCALE OF PARTICIPATION (CASP) (AVAILABLE IN SPANISH, FRENCH, GERMAN, HEBREW, AND MANDARIN)

TOOL/PROGRAMME SUMMARY

CASP measures the extent to which school-age children (5 years and older) with Acquired Brain Injury (ABI) participate in home, school, and community activities compared to children of the same age as reported by family caregivers.

The CASP consists of 20 ordinal-scaled items and four subsections: 1) Home Participation (6 items), 2) Community Participation (4 items), 3) School Participation (5 items), and 4) Home and Community Living Activities (5 items). The 20 items are rated on a four-point scale: Age Expected (full participation), Somewhat Restricted, Very Restricted, Unable. A 'Not Applicable' response is selected when the item reflects an activity in which the child would not be expected to participate in due to age (e.g., work). Each CASP item examines a broad type of activity or life situation. Most items include examples of activities that fall within the broad life situation. Item, subsection, and total summary scores can be examined for use in research and practice. Higher scores reflect greater age-expected participation. The CASP also includes open-ended five questions that ask about effective strategies and supports and barriers that affect participation.

There is a version available for young people.

BACKGROUND

CASP was designed as part of the Child and Family Follow-up Survey (CFFS) to monitor outcomes and needs of children with ABI. The content and methods used in the CASP and CFFS were informed by the International Classification of Functioning (WHO, 2001), research addressing the participation of children/young people (CYP) with a range of disabilities, and factors related to the child, family and physical and social environment that support and/or hinder participation. In addition feedback was obtained by parents of CYP with ABI and clinical and measurement experts to develop and refine the CASP and CFFS.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: H/P/F/E/CSW

KEY GOAL

1) To assess participation in home, school and community activities

HOW THE TOOL/PROGRAMME IS USED

The CASP is either self-administered (in person or mail survey) or interviewer administered (in-person or by telephone). It should take no more than 10 minutes. The website below provides information about the scoring and analysis.

KEY OUTCOME

1) Facilitates the development of effective strategies to promote participation of CYP in home, school and community activities

REFERENCES

- 1) Bedell G. Developing a follow-up survey focused on participation of children and youth with acquired brain injuries after inpatient rehabilitation. *NeuroRehabilitation* 2004;19:191-205
- 2) Bedell G. Further validation of the Child and Adolescent Scale of Participation (CASP). *Developmental Neurorehabilitation* 2009;12:342-351

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<http://sites.tufts.edu/garybedell/measurement-tools/>

CHILD AND ADOLESCENT SCALE OF ENVIRONMENT (CASE)

TOOL/PROGRAMME SUMMARY

CASE measures the perceived impact of problems experienced with the physical, social and attitudinal environment features of the child's home, school and community. The CASE also examines problems related to the quality or availability of services or assistance that the child receives or might need. Each CASE item or problem is rated on a 3-point ordinal scale: 1) No problem; 2) Little problem; 3) Big problem. There is a 'not applicable' response as well. For example, the items referring to school or work would not be applicable for those not attending school, or a structured program or work setting. When the CASE is used separately from the Child and Family Follow-up Survey (CFFS), parents/guardians are also asked to identify the physical or social aspects of the environment or qualities about the services that their child receives that are supportive or helpful to their child.

BACKGROUND

CASE was originally developed as part of the Child and Family Follow-up Survey (CFFS) to monitor outcomes and needs of children with ABI. It examines the perceived impact (not frequency) of environmental problems encountered by the child and family.

The content and methods used to develop the CASE and other CFFS measures were informed by the International Classification of Functioning (WHO, 2001), research addressing the participation of children and young people (CYP) with a range of disabilities, and four factors related to the child, family and physical and social environment that support and/or hinder participation. In addition, feedback was obtained by parents of CYP with Acquired Brain Injury (ABI) and clinical and measurement experts.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: H/P/F/E/PS

KEY GOAL

1) To measure the perceived impact of problems experienced with the physical, social and attitudinal environment features of the child's home, school and community

HOW THE TOOL/PROGRAMME IS USED

CASE can be used separately from the CFFS, but is most often used as part of the CFFS or along with two other measures that are included in the CFFS: The Child and Adolescent Scale of Participation (CASP) and Child and Adolescent Factors Inventory (CAFI).

The CASE is either self-administered (in person or mail survey) or interviewer administered (in-person or by telephone). It should take no more than five minutes. The website below provides information about the scoring and analysis.

KEY OUTCOME

1) Facilitates the development of effective strategies to promote participation of CYP with ABI in home, school and community activities

REFERENCE

1) Bedell G, McDougall J. The Child and Adolescent Scale of Environment (CASE): Further validation with youth who have chronic conditions. *Dev Neurorehab* 2015;18(6):375-382

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<http://sites.tufts.edu/garybedell/measurement-tools/>

TOOL/PROGRAMME SUMMARY

The CAFI is an inventory of problems in physical, cognitive and psychosocial functioning and other symptoms encountered by children and young people (CYP) with Acquired Brain Injury (ABI) as well as other childhood disabilities. It was initially designed as part of The Child and Family Follow-up Survey (CFFS), but can be used separate from the CFFS in research and practice. It is most often used in combination with the Child and Adolescent Scale of Participation (CASP) and the Child and Adolescent Scale of Environment (CASE).

CAFI consists of a list of 15 potential problems that the child may be experiencing as a result of his or her diagnosis or condition related to health and cognitive, psychological, physical and sensory functioning.

Each item or problem is rated on a 3-point ordinal scale: 1) No problem; 2) Little problem; 3) Big problem. There is one additional question that asks whether the child has any health or medical restrictions on his or her daily activities, and if so, to describe the specific restrictions.

BACKGROUND

CAFI was initially developed as part of the CFFS to monitor the outcomes and needs of CYP with ABI. CAFI can be used separately from the CFFS, but is most often used as part of the CFFS or along with two other measures CASP and CASE. The content and methods used in the CAFI and CFFS were informed by the International Classification of Functioning (WHO 2001), research addressing participation of CYP with a range of disabilities and factors related to the child, family and physical and social environment that support and/or hinder participation. In addition, feedback was obtained by parents of CYP with ABI.

DEFICIT ADDRESSED: P/C/PS

TARGET USER: H/P/F

KEY GOAL

1) To assess the problems encountered by CYP with ABI

HOW THE TOOL/PROGRAMME IS USED

The CAFI is either self-administered (in person or mail survey) or interviewer administered (in-person or by telephone). It should take no more than 5 minutes. The website below provides information about the scoring and analysis.

KEY OUTCOME

1) Assessment of problems which then facilitates support planning

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<http://sites.tufts.edu/garybedell/measurement-tools/>

TOOL/PROGRAMME SUMMARY

The CFFS was initially designed to monitor outcomes and needs of children and young people (CYP) with Acquired Brain Injury (ABI). The content and methods used in the CFFS were informed by the International Classification of Functioning (WHO 2001), research addressing the participation of CYP with a range of disabilities, and factors related to the child, family and physical and social environment that support and/or hinder participation. In addition, feedback was obtained by parents of CYP with ABI and clinical and measurement experts. The CFFS consists of five sections with closed and open-ended questions. It can be completed by, or administered to, the child's family caregiver (parents or primary guardians).

BACKGROUND

This parent-guardian report survey was originally designed to assess the needs of children and youth with ABI as well as their families, after the children were discharged from inpatient rehabilitation. The survey asks questions about the child and family and about the type and quality of services received after discharged. The CFFS includes three other measures Child and Adolescent Scale of Participation, Child and Adolescent Scale of Environment and Child and Adolescent Factors Inventory and all can be used separately from the CFFS in research or practice.

DEFICIT ADDRESSED: P/C/A

TARGET USER: H/P/F

KEY GOALS

- 1) To assess needs
- 2) To monitor outcomes

HOW THE TOOL/PROGRAMME IS USED

The CFFS is either self-administered (in person or mail survey) or interviewer administered (in-person or by telephone). It should take no more than 30 minutes. The website below provides information about the scoring and analysis.

KEY OUTCOMES

- 1) Individualised intervention planning
- 2) Programme evaluation
- 3) Multisite and population-based research

REFERENCE

- 1) Bedell, G. Developing a follow-up survey focused on participation of children and youth with acquired brain injuries after inpatient rehabilitation. *NeuroRehabilitation* 2004;19:191-205

Contact for further information: Gary Bedell: gary.bedell@tufts.edu

<http://sites.tufts.edu/garybedell/measurement-tools/>

TOOL/PROGRAMME SUMMARY

HEADS UP is a series of educational initiatives, developed by the Centers for Disease Control and Prevention (CDC), Atlanta, GA USA, that all have a common goal: protect children and teens by raising awareness and informing action to improve prevention, recognition, and response to concussion and other serious brain injuries. Initially, HEADS UP materials addressed health care professionals and their important role in diagnosing and managing concussions. More recently HEADS UP initiatives focus on sports programmes and schools as key places to share concussion information with coaches, parents, and school professionals. HEADS UP educational materials are designed help support individuals and organizations with their concussion efforts and are available in a variety of formats.

Since the launch of the first Heads Up initiative, CDC distributed more than 6 million HEADS UP print resources nationwide. HEADS UP resources were distributed and promoted through a range of channels, including the CDC website, partner organisations' websites, email lists, newsletters, events, conferences, and various social media platforms. The most popular HEADS UP print materials include two concussion awareness fact sheets for parents and a fact sheet for young athletes, which are part of the HEADS UP: Concussion in Youth Sports initiative. Combined, almost 3 million of these three fact sheets have been distributed (1,077,293 fact sheets for parents; 1,067,105 parent/athlete information sheets; and 873,880 fact sheets for athletes).

BACKGROUND

Over the last 10 years, the CDC's Heads Up campaign has grown into a cohesive suite of educational initiatives that share a common goal: to help protect children and adolescents from concussions and other serious brain injuries by raising awareness, enhancing knowledge, and informing action to improve prevention, recognition, and response to concussions.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: H/F/E and sports personnel

KEY GOALS

- 1) Raise awareness about concussion and other serious brain injuries
- 2) Enhance knowledge about concussions and other serious brain injuries
- 3) Prevent, recognise and respond to concussions and other serious brain injuries

HOW THE TOOL/PROGRAMME IS USED

All materials developed by CDC for the HEADS UP initiative are available for public use and distributed free of charge at-<https://www.cdc.gov/headsup/about/index.html>. The tools are used to inform the public as well as specific audiences- healthcare providers, school providers, parents, and youth sports.

KEY OUTCOMES

- 1) Prevent concussions and other types of serious brain injuries in children
- 2) Work with partner organisations to disseminate and integrate educational messages into existing systems and programmes

REFERENCE

- 1) Sarmiento K, Hoffman R, Dmitrovsky Z and Lee R. A 10-year review of the Centers for Disease Control and Preventions' Heads Up Initiatives: Bringing concussion awareness to the forefront. Journal of Safety Research 2014;50:143-147

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<https://www.cdc.gov/headsup/about/index.html>

TOOLBOX 2018

INDEX B: PAID FOR TOOLS/PROGRAMMES

The tools and programmes are indexed according to the deficit(s) addressed:

P/C/A/PS: Tool/programme addresses **P**hysical, **C**ognitive, **A**cademic and/or **P**sychosocial deficits

and the target users:

H/P/F/E/CSW: Tool/programme will be used by the **H**ealthcare professional, **P**atient and/or **F**amily, **E**ducator, **C**ommunity **S**ervice **W**orker

The following tools and programmes have to be paid for. Web address and/or contact detail are provided so that further information can easily be obtained. It is assumed that the reader will select and use a particular tool or programme according to their own requirements.

Tool No.	Tool/programme title	Deficit addressed				Target user				
		P	C	A	PS	H	P	F	E	CSW
1	Captains Log cognitive training software		√				√			
2	Brain Injury: Strategies for Teams and Re-education for Students (BrainSTARS)	√	√	√	√	√	√	√	√	√
3	Recognising My Progress (with cognitive difficulties)		√				√		√	
4	Brain Injury Screening Questionnaire (BISQ)	√	√	√	√	√	√			
5	Behaviour Rating Inventory of Executive Function (BRIEF)		√				√	√	√	
6	Child Behaviour Checklist				√	√	√	√		

CAPTAIN'S LOG COGNITIVE TRAINING SOFTWARE

1

TOOL/PROGRAMME SUMMARY

Captain's Log software is a computerised cognitive rehabilitation training package consisting of 50 multi-level brain-training exercises designed to help develop and remediate a wide range of cognitive skills.

The software is a mental workout for students with Attention Deficit Hyperactivity Disorder/Attention Deficit Disorder, learning disabilities, brain injuries, or other cognitive difficulties. It is multilevel, comprehensive and systematic, as it is based on a structured hierarchy of cognitive skills and continually builds on what has been learned.

BACKGROUND

Cerebral malaria is the most severe form of malaria affecting 575,000 African children under 5 years of age of which 110,000 die. Neuro-cognitive morbidity also presents a significant problem with more than 200,000 child survivors of cerebral malaria estimated to have long term cognitive impairment.

Retrospective studies have shown that cerebral malaria child survivors have cognitive deficits in several areas including language, memory, attention, visual spatial skills and somatosensory discrimination with some lasting up to nine years post illness. Captain's Log software was used in the cognitive rehabilitation of these children.

DEFICIT ADDRESSED: C
TARGET USER: P

KEY GOAL

1) To improve cognitive function including visuomotor processing, working memory, learning and internalising problems and behaviour

HOW THE TOOL/PROGRAMME IS USED

The 50 multilevel programmes in the Captain's Log system are organised into three training sets:

- Attention Skills Training Set
- Problem Solving and Memory Skills Training Set
- Working Memory Training Set

Neuropsychologists assess the children to determine which exercises need to be included from each set in the Captain's Log. This will depend on their verbal skills, grasp of English, familiarity with computers etc. The Captain's Log is then programmed to run for a set time each session starting at the simplest level and the difficulty is increased depending on the child's performance. The number of sessions is determined by the therapist.

KEY OUTCOME

1) Improved cognitive function

REFERENCE

1) Bangirana P, Giordani B, Chandy JC *et al*. Immediate neuropsychological and behavioral benefits of computerized cognitive rehabilitation in Ugandan pediatric cerebral malaria survivors. *J Dev Behav Pediatr*. 2009;30(4):310-318

Contact for further information: <http://www.braintrain.com/captains-log-for-educators/>

TOOL/PROGRAMME SUMMARY

BrainSTARS (Brain Injury: Strategies for Teams and Re-education for Students) is a manual developed in the USA and is available in Dutch and Spanish. It provides parents and school personnel with basic Acquired Brain Injury (ABI) education and decision trees for the symptom-based assessment of problems and recommended interventions. The authors review background information about brain injuries, child neurodevelopment, abilities affected by brain injuries, provide strategies and approaches to intervention, and discuss obtaining help in the community to assist children with brain injuries. Practical interventions are provided that target domains that can be impaired by a brain injury.

BACKGROUND

BrainSTARS is an individualised consultation programme that included a comprehensive manual on paediatric ABI. It was written by a team of professionals who have worked for many years with children and young adults (CYP) who have brain injury. The manual was written because paediatric brain injury is very confusing for parents and teachers and the authors wanted to ensure that the parents of CYP and their teachers are well-educated so that they can work well together to provide the best chance for a child's recovery.

The BrainSTARS manual was funded by a grant from the US Department of Education. It was field-tested and several versions of it were piloted with families and school personnel over a period of four years. The manual was reviewed by a panel of national USA experts in paediatric ABI, critiqued and field-tested by 17 family-school teams. Central in BrainSTARS is the A-B-C Method (Antecedents-Behaviour- Consequences) model of behaviour change.

DEFICIT ADDRESSED: P/C/A/PS

TARGET USER: H/P/F/E/CSW

KEY GOALS

- 1) To provide psychological-based education on ABI
- 2) To enhance collaboration between all those who are involved with CYP who have ABI
- 3) To understand and improve the child's behavior

HOW THE TOOL/PROGRAMME IS USED

The recommendation is to organise three meetings of 1.5 hours each with everyone who is involved in working with the child who has ABI, chaired by someone who knows the method very well. There should be four weeks between each meeting.

KEY OUTCOMES

- 1) Significant improvement in self- rated proficiency by parents, teachers and school personnel in working with children who have an ABI
- 2) Significant improvement in ratings of children's school performance by parents, teachers and school personnel
- 3) In a small scale pilot in The Netherlands it was concluded that use of BrainSTARS had a positive influence on development of the child with ABI, contributed to a more regular family life, enhanced knowledge of ABI and self-assuredness in parents, and improved collaboration between home and school

REFERENCES

- 1) Dise-Lewis JE, Lewis HC, Reichardt CS. BrainSTARS: Pilot data on a team-based intervention program for students who have acquired brain injury. *J Head Trauma Rehabil* 2009;24(3):166-177
- 2) Davis AS. BrainSTARS – brain injury: strategies for teams and re-education for students. *Journal of school Psychology* 2004;42:87-92

Contact for further information: Rianne Gijzen: r.gijzen@vilans.nl | Chris Moores: chris.moores@childrenscolorado.org
A short video on how to use the BrainSTARS manual is available: www.youtube.com/BrainSTARSprogram

RECOGNISING MY PROGRESS (WITH COGNITIVE DIFFICULTIES)

TOOL/PROGRAMME SUMMARY

Recognising My Progress is a book for teachers with information and suggestions for both students and teachers to facilitate thoughts and work out measures together to help the student. It comprises a rating scale and assessment bank together with suggested questions; the purpose of the material is to make the actual progress made by the person with Acquired Brain Injury (ABI) visible to him/her and others. If no progress has been made within the specified areas, the material can provoke discussion around the possible causes of the lack of progress and the pupil's needs. This 24-page book can be purchased in Swedish or English.

BACKGROUND

The initial progress after the acute phase of brain injury can be difficult to see, because survivors often compare themselves with the way they were before the illness or accident. Sometimes the individual family and caregivers do not see progress because the sadness and frustration is so great. Difficulties after A thoughts and work out measures together to help the student BI can mean that the individual is extremely tired, slow and/or has difficulties concentrating. People around the person can sometimes mistakenly perceive these difficulties as the person being unwilling or lazy. Therefore, it is very important that people are given information about the difficulties the person is experiencing. It is also important that the survivor is given the possibility to become aware of his/her own progress and needs. This resource is a method for children and young people (CYP) with brain injury to estimate their strengths and needs. 'Recognising My Progress' was developed by Christina Eklund in a collaboration with students with ABI.

DEFICIT ADDRESSED: C
TARGET USER: P/E

KEY GOAL

- 1) To identify the CYP's cognitive difficulties and needs

HOW THE TOOL/PROGRAMME IS USED

The rating scale and the assessment bank along with suggested questions make it easier for both students and teachers to express thoughts and work out measures together to help the student. This may involve one or more meetings over time.

KEY OUTCOMES

- 1) Enables the CYP with an ABI to understand their needs and difficulties
- 2) Facilitates academic progress

REFERENCE

- 1) Presented at 2nd International Conference on Paediatric Acquired Brain Injury, Rome 2017

Contact for further information: Cristina Eklund: cristina.eklund@akademiska.se

BRAIN INJURY SCREENING QUESTIONNAIRE (BISQ)

4

TOOL/PROGRAMME SUMMARY

The BISQ is divided into three parts: Traumatic Brain Injury (TBI) history, symptoms, and other health conditions. Part I queries lifetime TBI by asking a series of questions. Part II is an inventory of 100 cognitive, physical, emotional, and behavioural symptoms that can be used to characterise transient or chronic symptoms after brain injury. Part III is designed to help clarify the relationship of reported symptoms to prior brain injury. When parts I, II, and III are used as a part of a clinical evaluation, inferences about the extent to which a person's current symptoms are attributable to TBI history can be made. The BISQ can be used as a self-report measure or can be completed by a proxy. It is available in English, Spanish, Chinese, and Greek. The full BISQ takes 10 to 15 minutes to complete.

BACKGROUND

Identification of TBI is particularly important when the injury results in continuing symptoms (chronic TBI) that can lead to reduced productivity, poor community integration, and other social problems. History of TBI is rarely queried in primary care or other health service and educational settings, and its symptoms (if reported) may be inappropriately attributed to other causes such as ageing, depression, or, in schools, to learning or emotional disabilities. Failure to recognise the aetiology of these symptoms precludes appropriate treatment or symptom management. Self-reports elicited through structured screening tools is increasingly recognised as the best, or perhaps only, way to estimate TBI incidence and chronic TBI prevalence. The BISQ was developed with the goal of creating a TBI screening tool that could be used to document lifetime history of self-reported TBI and the presence of current symptoms, if any, as well as to rule out alternative explanations for reported symptoms.

DEFICIT ADDRESSED: P/C/A/PS
TARGET USER: H/P

KEY GOALS

- 1) To assess a history of TBI
- 2) To assess current symptoms of TBI

HOW THE TOOL/PROGRAMME IS USED

Part I provides structured and detailed cueing by asking respondents whether they have ever experienced a blow to the head in 19 specific situations in which a blow may have occurred. The provision of structured recall cues is intended to serve as a memory jog and has been shown to enhance recall of situations in which a TBI event may have occurred. For every event endorsed, the informant is asked whether he or she experienced either a loss of consciousness or a period of being dazed and confused and, if so, for how long. Next, respondents are asked whether they have ever been hospitalised or treated in an Emergency Department for any of 13 specific medical events to document alternative explanations for clinically significant symptoms. People who report no TBI events on part I are considered a negative screen and are not asked to complete parts II or III.

The list of symptoms in Part II cover a comprehensive range of symptoms. Respondents are asked to rate on a 4-point Likert scale the extent to which each symptom has been a problem for them in the past month. Part III is designed to help clarify the relationship of reported symptoms to prior brain injury and asks for age at the first and most recent blow to the head resulting in alteration in mental status, as well as the presence of other health conditions that may contribute to or explain the symptoms a person reports, including use of certain medications, developmental delays, or neurological conditions.

KEY OUTCOMES

- 1) For individuals, screening for TBI events and chronic TBI results in ability to provide treatment
- 2) Accurate documentation of TBI history in the medical or academic record can inform health-related decision making at the time of screening or years down the road

REFERENCE

- 1) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4985006/#R20>

Contact for further information:

BISQ is sometimes sold to agencies/organisations that want to screen people for brain injury.

To request a copy of the BISQ visit: www.tbicentral.org

BEHAVIOUR RATING INVENTORY OF EXECUTIVE FUNCTION (BRIEF)

TOOL/PROGRAMME SUMMARY

The Behaviour Rating Inventory of Executive Function (BRIEF) is an easy to administer and score individualised, norm-referenced measure of executive function behaviours, designed for students from 5-18 years of age. BRIEF is a questionnaire that is completed by parents or teachers using 1 of 2 different versions and assesses behaviours related to executive functions in 8 scales (Inhibit, Shift, Emotional Control, Initiate, Working Memory, Plan/Organise, Organisation of Materials, and Monitor). The results of the scales are combined to generate two index scores, Behavioural Regulation/BRI (based on three scales) and Metacognition/MI (based on five scales), along with an overall composite score, the Global Executive Composite/GEC. Standardisation of the BRIEF included individuals with a variety of developmental or neurological conditions, allowing for use of the inventory with a broad range of students.

There are two versions of the original BRIEF (the Parent form and the Teacher form) and several variations of each version of the BRIEF, which are designed for different age ranges. A Self-Report Form, the Behaviour Rating Inventory of Executive Function – Self-Report Version (Guy *et al* 2005) is also available for use with students 13-18 years of age.

BACKGROUND

Executive functions (EF) are cognitive processes that are controlled and coordinated during complex tasks. EF has become increasingly popular in the context of clinical evaluation, and in the school setting. If children are unable to perform basic classroom functions, such as inhibiting responses, regulating behaviour, or predicting outcomes, their academic success is likely to be compromised. BRIEF was designed to assess the behavioural characteristics related to EF deficits in young individuals in school and home environments. Gioia *et al* (2000) created items for the BRIEF based on their clinical experience as well as a review of neuropsychological literature.

DEFICIT ADDRESSED: C

TARGET USER: P/F/E

KEY GOAL

1) To measure commonly agreed domains of EF in children

HOW THE TOOL/PROGRAMME IS USED

The questionnaire is completed by the target user and analysed. It takes 10-15 minutes to administer and 15-20 minutes to score.

KEY OUTCOME

1) Ecologically valid model of executive function and deficits

REFERENCES

- 1) Gioia GA, Isquith PK, Guy SC *et al*. Behavior Rating Inventory of Executive Function. Lutz, FL: Psychological Assessment Resources, Inc. 2000
- 2) Guy SC, Isquith PK, Gioia GA. Behavior Rating Inventory of Executive Function® – Self-Report Version. Lutz, FL: Psychological Assessment Resources, Inc. 2005

Contact for further information:

www.researchgate.net/publication/237256589_Behavior_Rating_Inventory_of_Executive_Function_BRIEF

CHILD BEHAVIOUR CHECKLIST (CBCL)

6

TOOL/PROGRAMME SUMMARY

The Child Behaviour Checklist (CBCL) is a widely used questionnaire to assess behavioural and emotional problems. It is a widely used caregiver report and used in both research and clinical practice with young people.

The CBCL has been translated into more than 90 languages, and normative data are available integrating information from multiple societies. Because a core set of the items has been included in every version of the CBCL since the 1980s, it provides a meter stick for measuring the change in behaviour problems over time or across societies.

The CBCL allows data to be obtained from multiple sources (i.e. child, parent, and teacher) and it is available in several versions including:

- 1) Parent report (CBCL/1-5, for those aged 1-5 years)
- 2) Parent report (CBCL/6-18, for those aged 6-18 years)
- 3) Teacher report (TRF for 6-18 year olds)
- 4) Adolescent self-report (YSR, for 11-18 year olds)

BACKGROUND

It is generally accepted that assessment of psychological problems in children and adolescents should not be delayed until these problems reach more serious levels and more intensive and expensive interventions are required. Mental health professionals need reliable and valid screening methods for behavioural and emotional problems in children. Screening through observation or interview can be time intensive and these methods are generally neither very reliable nor cost-effective. The CBCL was developed as a general assessment instrument to measure child behavioural/emotional problems and competencies.

DEFICIT ADDRESSED: PS

TARGET USER: H/P/F

KEY GOALS

- 1) To assess behavioural and emotional problems
- 2) To monitor behavioural change over time

HOW THE TOOL/PROGRAMME IS USED

The CBCL is questionnaire-based and requires completion by the parent, adolescent and/or teacher.

KEY OUTCOMES

- 1) Detailed assessment of problems over time
- 2) Enables the appropriate management programme to be developed and instigated

REFERENCES

- 1) Achenbach TM. (1991). Manual for the child behavior checklist/4-18 and 1991 profile. Burlington, VT: University of Vermont, Department of Psychiatry
- 2) Achenbach TM, Becker A, Döpfner M *et al.* Multicultural assessment of child and adolescent psychopathology with ASEBA and SDQ instruments: Research findings, applications, and future directions. *Journal of Child Psychology and Psychiatry* 2008;49:251-275
- 3) Achenbach T.M, and Rescorla LA (2001). Manual for the ASEBA school-age forms & profiles. Burlington, VT: University of Vermont, Research Center for Children, Youth, & Families

Contact for further information: For sample forms visit <http://www.aseba.org/forms.html>

