

Guidance for the post-discharge rehabilitation of children, adolescents and young adults with acquired brain injury



Guidance for the post-discharge rehabilitation of children, adolescents and young adults with acquired brain injury

September 2018



www.edendoratrust.org



www.ipbis.org

INTRODUCTION

A great deal of best practice is available for the rehabilitation post-discharge from acute care 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 developing countries, may be aware of the wide range of tools and programmes that are available.

This toolbox, instigated by the International Paediatric Brain Injury Society (IPBIS), and produced together with The Eden Dora Trust for Children with Encephalitis, endeavours to harness and share information, for the rehabilitation post-discharge from acute care of children from birth to young adults 25 years of age with mild to severe ABI.

The tools and programmes in the toolbox were included following a summary of each being reviewed by the IPBIS Advisory Board. The toolbox contains an overview of a wide range of tools and programmes 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.

As new tools and programmes are submitted to the IPBIS they will be reviewed and, if accepted, they will be added to the toolbox biennially.

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

IPBIS Board

Who can use the document?

The document is intended for use by all rehabilitation professionals who work with children from birth to young adults 25 years of age, 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)¹.

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 template which can be accessed at www.ipbis.org/toolkit and emailed to hello@ipbis.org.

Are the tools/programmes submitted automatically included in the toolbox?

Each tool/programme is reviewed by the IPBIS Advisory Board using agreed criteria. Depending on the outcome of the review, the tool/programme is then included.

How often is the toolbox updated?

New tools/programmes will be reviewed on a biennial basis.

Do I have to belong to the IPBIS or The Eden Dora Trust 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

INDEX A: FREELY* AVAILABLE TOOLS/PROGRAMMES

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

| Tool number | Tool/programme title | Deficit addressed | | | | Target user | | | | |
|-------------|---|-------------------|---|---|----|-------------|---|---|---|-----|
| | | P | C | A | PS | H | P | F | E | CSW |
| 1 | Get schooled on concussion | | | √ | | | | | √ | |
| 2 | Reduce/Remove Educate Adjust/Accommodate Pace (REAP) | √ | √ | √ | √ | √ | √ | √ | √ | |
| 3 | Concussion and Traumatic Brain Injury – information for families | √ | √ | √ | √ | √ | √ | √ | | |
| 4 | Re-establishment of spatial functions, 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 | Playful brain | | √ | | | | √ | √ | | |
| 11 | Acquired Brain Injury Challenge Assessment (ABI-CA) | √ | | | | √ | √ | | | |
| 12 | Family Needs Questionnaire – paediatric version | | | | √ | √ | √ | √ | | √ |
| 13 | Brain Injury Family Intervention for Adolescents (BIFA) | | | √ | √ | √ | √ | √ | | √ |
| 14 | Concussion and you handbook | √ | √ | √ | √ | | √ | √ | | |
| 15 | Evaluation and family-based rehabilitation programmes | √ | √ | √ | √ | √ | √ | √ | | |
| 16 | Quality of Life after Brain Injury Questionnaire (QoLBRI) | √ | √ | √ | √ | √ | √ | | | |
| 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 | √ | √ | √ | √ | √ | √ | √ | √ | |
| 22 | Comprehensive care programme including outreach | √ | √ | √ | √ | √ | √ | √ | √ | √ |
| 23 | Acquired Brain Injury guidebook for family intervention | √ | √ | √ | √ | √ | √ | √ | √ | √ |
| 24 | Context-family based intervention | √ | √ | √ | √ | √ | √ | √ | √ | √ |
| 25 | Paediatric Acquired Brain Injury Community Outreaching Programme (PABICOP) | √ | √ | √ | √ | √ | √ | √ | √ | √ |
| 26 | Teen Online Problem Solving (TOPS) | | √ | | √ | | √ | √ | | |
| 27 | Transition from paediatric to adult services | √ | √ | | | √ | √ | | | |
| 28 | Peer events | | | | √ | | √ | | | |
| 29 | Learning parental network and learning youth network on Facebook | √ | √ | √ | √ | | √ | √ | | |
| 30 | Metacognitive dimensional 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 | √ | √ | | | √ | √ | √ | √ | |
| 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 | √ | √ | √ | √ | √ | | √ | √ | |

Notes

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

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

GET SCHOOLED ON CONCUSSION (GSOC)

1

Tool/programme summary

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): A

Target user (H/P/F/E/CSW): 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 one to four 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

References

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

REAP stands for the four essential elements of concussion treatment and management:

R- Remove/Reduce physical and cognitive, or mental demands, E – Educate the student athlete, family, educators, coaches and medical professionals on all of the potential symptoms, A- Adjust/Accommodate for the student athlete academically, P – Pace the student athlete back to learning, activity and play.

REAP is a 20 page manual for community-based concussion management. The manual outlines the four teams (family, medical, school academic, and school physical team) that make up the essential core of coordination and collaboration for the three plus weeks when managing concussion in children and adolescents. The text is colour-coded to identify information and advice directed specifically to each team. The manual includes a symptom checklist and a Teacher Feedback Form.

Background

REAP was written as the result of a Second Impact Syndrome case in 2004. The author was the psychologist at the school attended by the student who lost his life as a result of concussion. REAP is a practical and community-based guide to help direct collaboration between the school, physician and family.

Deficit addressed (P/C/A/PS): P/C/A/PS

Target user (H/P/F/E/CSW): H/P/F/E

Key goals

- 1) To provide information about concussion in an easy to understand, family friendly language
- 2) To enable each team to know and understand their specific role in concussion management, and understand what members of the other teams should be doing simultaneously
- 3) To emphasise that first and foremost, REMOVE student immediately from risk of further head injury

How the tool/programme is used

REAP has been used as an educational tool in teaching to coaches, healthcare professionals, parents and educators. It contains resources for Colorado but has been customised for New York, New Jersey, Florida, Hawaii, Washington, Nebraska, Iowa and Alabama. REAP has been translated into Spanish.

Key outcomes

- 1) Basic understanding of how the four teams must work together
- 2) An expectation that the four teams will pass the student back and forth to each other as required throughout concussion recovery
- 3) Guidance on support for the student from each team (different support by different teams) throughout recovery
- 4) Acknowledgement that all four teams should have confirming data and be in consensus about the safest time to begin to return a student athlete back to play

References

Four consensus papers have been used to guide REAP. REAP is currently being updated with the latest information from the 5th consensus paper.

Contact for further information

Karen McAvoy: karenmcavoy11@gmail.com

<https://rockymountainhospitalforchildren.com/service/concussion-management-reap-guidelines>

CONCUSSION AND TRAUMATIC BRAIN INJURY: INFORMATION FOR FAMILIES

3

Tool/programme summary

The DVD entitled 'Concussion and Traumatic Brain Injury: Information for Families' is a compilation of four 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 this DVD was then produced.

Deficit addressed (P/C/A/PS): P/C/A/PS

Target user (H/P/F/E/CSW): 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

Reference

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

4

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 (P/C/A/PS): C/A

Target user (H/P/F/E/CSW): 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 for neuropsychological rehabilitation was designed. 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.buap.mx www.neuropsicologia.org.mx www.colegiokepler.edu.mx

COUNSELLOR-ASSISTED PROBLEM SOLVING (CAPS)

5

Tool/programme summary

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 (P/C/A/PS): PS

Target user (H/P/F/E/CSW): H/P/F

Key goal

- 1) To improve behaviour

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

Wade SL, Stancin T, Kirkwood MW, Brown TM, McMullen KM, Taylor HG. 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 (P/C/A/PS): C/A/PS

Target user (H/P/F/E/CSW): 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

Presented at CBIT conference.

Contact for further information

www.childbraininjurytrust.org.uk

FAMILY-BASED INTERVENTION AT HOME

7

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): P/C/A/PS

Target user (H/P/F/E/CSW): 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

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 (P/C/A/PS): C/A

Target user (H/P/F/E/CSW): 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

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 <http://brain101.orcasinc.com/1000/#>

FOLLOW-UP FOR CHILDREN WITH TRAUMATIC BRAIN INJURY

9

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/C/A/PS): P/A

Target user (H/P/F/E/CSW): 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

Revant Reigerbos: revalidatiearts Larja de letter

Contact for further information

Cisca Zuurveld czuurveld@zeeuwsezorgschakels.nl www.zeeuwsezorgschakels.nl

SPEELSBREIN (PLAYFUL BRAIN) (available in Dutch)

10

Tool/programme summary

SpeelsBrein is an informative book for parents of children 0-4 years of age with Traumatic Brain Injury (TBI). The book contains psycho-education, examples of playful activities, and raises awareness of the development of neurocognition (memory, attention and executive functions) and perception. In addition a guideline for (neuro) psychologists is available to help to educate parents how to play with their child, and simultaneously how to address 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 on how the informative book can be used by parents.

Background

Children aged 0-4 years of age with TBI are at risk of developmental problems in later life. It is important that the parents of these children are provided with information and support 'tools' in order to be aware of the potential problems and are able to address them.

Deficit addressed (P/C/A/PS): C

Target user (H/P/F/E/CSW): P/F

Key goals

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

How the tool/programme is used

Parents receive a book with examples of games that can be played at home, and information about the development of neurocognition in young children. A (neuro) psychologist provides guidance and informs parents how to use the book at home, and how to play with their child and simultaneously address the aspects of neurocognition and perception.

Key outcome

- 1) Enhances parents' awareness for neurocognitive development in their child with TBI

Reference

Currently under development (expected March 2018)

Contacts for further information

m.vanderwees@libranet.nl

c.utens@libranet.nl

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

11

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/C/A/PS): P

Target user (H/P/F/E/CSW): 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.

Contacts for further information

Virginia Wright: vwright@hollandbloorview.ca

Gail Kirkwood: gkirkwood@hollandbloorview.ca

FAMILY NEEDS QUESTIONNAIRE – PEDIATRIC VERSION (FNQ-P)**12****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 (P/C/A/PS): PS

Target user (H/P/F/E/CSW): 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

References

- 1) Gan C, Wright V, Sheffe S. (2015) Development of the Pediatric Family Needs Questionnaire – A partnership approach. Paper presented at the First International Conference on Acquired Brain Injury – Top scoring abstracts category, Liverpool, UK. ([manuscript in progress](#)).
- 2) Gan C, Wright V, Van Hooft I et al. (2017). Validation of the Pediatric Family Needs Questionnaire: A Partnership Approach Across Five Countries. International Brain Injury Association Conference, New Orleans, US. ([manuscript in progress](#)).
- 3) Gan C, Van Hooft I, Brookes N et al. An International Perspectives on Family Needs After Pediatric ABI, Symposium Chair – Symposium to be presented at the 2nd IPBIS Conference in Rome Italy, September 2017.

Contact for further information

Caron Gan: cgan@hollandbloorview.ca

BRAIN INJURY FAMILY INTERVENTION FOR ADOLESCENTS (BIFI-A)**13****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.

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 (P/C/A/PS): A/PS

Target user (H/P/F/E/CSW): 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. A focus on strengths and successes helps to enhance family resilience.

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

References

- Gan C. (2015) – “Strengths-Based Family Intervention After Pediatric ABI” – Invited speaker, Pre-Conference Workshop on Family Resilience After ABI, First International Conference on Acquired Brain Injury, Liverpool, UK.
- Gan C. (2014) – Adaptation of Swedish version of Brain Injury Family for Adolescents – 2-Day Intensive Training - Astrid Lindgren Children’s Hospital, Karolinska University Hospital, Stockholm, Sweden.
- Gan G and Kreutzer J. (2014) - “Outcomes of brain injury family intervention training for professionals” – Poster presented at the International Brain Injury Association 10th World Congress, San Francisco, CA.
- 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.

BIFI-A has also been designated a Leading Practice through Accreditation Canada.

<https://healthstandards.org/leading-practice/brain-injury-family-intervention-for-adolescents-bifi-a/>

Contact for further information

Caron Gan: cgan@hollandbloorview.ca

CONCUSSION AND YOU HANDBOOK

14

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): P/C/A/PS

Target user (H/P/F/E/CSW): 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

Reference

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

Contacts for further information

Nick Reed: nreed@hollandbloorview.ca

Christine Provvidenza: cprovvidenza@hollandbloorview.ca

<http://hollandbloorview.ca/Assets/Concussion%20handbook%20Nov.2015.pdf>

EVALUATION AND INDIVIDUALISED FAMILY-BASED REHABILITATION PROGRAMME

15

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 SARA 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): P/C/A/PS

Target user (H/P/F/E/CSW): 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

References

- 1) McKinlay A, Linden M, DePompe 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.
- 4) Haley SM, Coster WJ, Ludlow LH et al. Pediatric evaluation of disability inventory: development, standardization, and administration manual. Boston: New England Medical Center; 1992.
- 5) Haley SM, Coster WJ, Ludlow LH et al. Paediatric Evaluation of Disability Inventory - PEDI; Inventário de Avaliação Pediátrica de Incapacidade; Versão 1.0 Brasileira.
- 6) Ylvisaker, Mark Ed. Traumatic brain injury rehabilitation: Children and adolescents . Butterworth-Heinemann, 1998.
- 7) Sparrow SS, Cicchetti DV, Balla DA. Vineland Adaptive Behavior Scales, Second Edition.
- 8) McCauley S et al, Recommendations for the use of common outcome measures in pediatric traumatic brain injury research. *Journal Neurotrauma* 2012;29:678-705.
- 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.
- 10) Mancini MC. Inventário de Avaliação Pediátrica de Incapacidade (PEDI): manual da versão brasileira adaptada. Belo Horizonte: UFMG; 2005.
- 11) Wassenberg-Severijnen JE, Custers JWH, Hox JJ et al. Reliability of the Dutch Pediatric Evaluation of Disability Inventory (PEDI). *Clin Rehabil* 2003;17(4):457- 62.
- 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

Lucia Braga: lucia.braga@sarah.br Eliane Cespedas Paes Huard: elianecphuard@gmail.com
www.sarah.br

QUALITY OF LIFE AFTER BRAIN INJURY QUESTIONNAIRE (QoLIBRI)

16

Tool/programme summary

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 four scales assess 'satisfaction' and the final two 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): P/C/A/PS

Target user (H/P/F/E/CSW): 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

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

17

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 (P/C/A/PS): A

Target user (H/P/F/E/CSW): 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

Reference

Contact for further information

www.projectlearnnet.org

BRAIN INJURY HUB**18****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): P/C/A/PS

Target user (H/P/F/E/CSW): 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

Reference**Contact for further information**

www.braininjuryhub.co.uk

www.thechildrenstrust.org.uk

MY BRAIN AND ME

19

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/A/PS): P/C

Target user (H/P/F/E/CSW): 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

Reference

Contact for further information

info@brainandspine.org.uk

BRAIN INJURY ALERT**20****Tool/programme summary**

The Brain Injury Alert is a tool to assist in the identification of the signs of brain injury 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 (P/C/A/PS): C/PS

Target user (H/P/F/E/CSW): H/P/F/E

Key goal

- 1) To identify possible Acquired Brain Injury (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 outcomes

- 1) Enhanced identification of ABI in children

Reference

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. <https://www.ncbi.nlm.nih.gov/pubmed/21561290>

Contact for further information

Rianne Gijzen: r.gijzen@vilans.nl

RETURN TO SCHOOL PATHWAY AND GUIDANCE DOCUMENT

21

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): P/C/A/PS

Target user (H/P/F/E/CSW): H/P/F/E

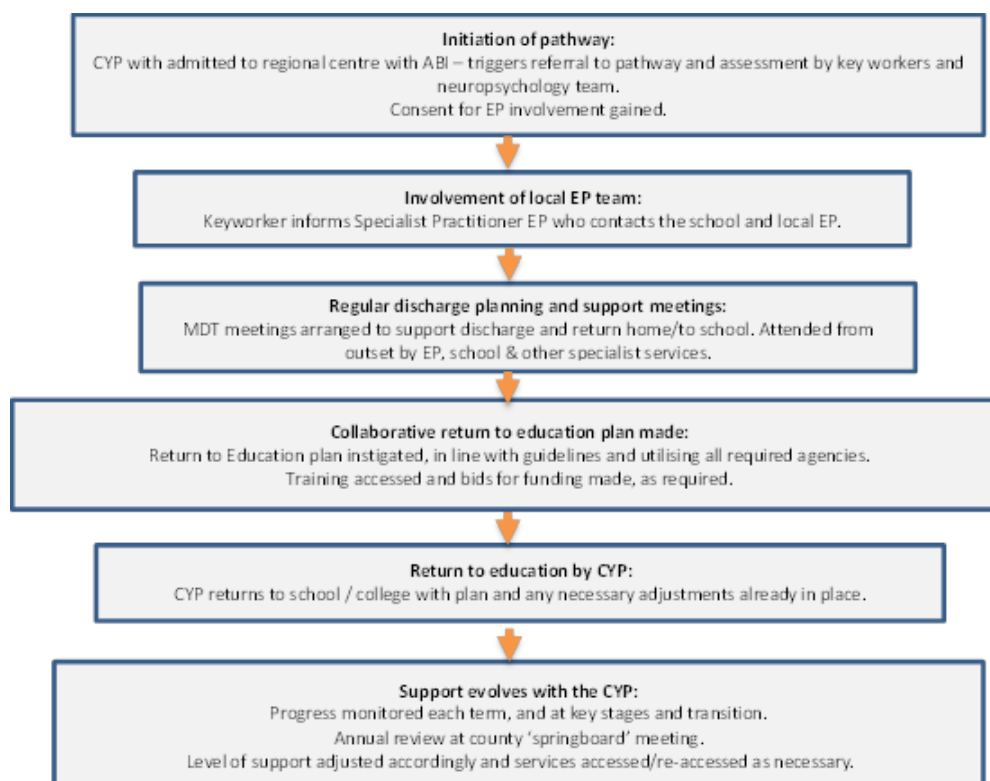
Key goals

- 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.

The Sam White Return to Education Pathway



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

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

Contact for further information

Emily Bennett: Emily.bennett@nuh.nhs.uk

<http://www.thesamwhitelegacy.org.uk/wp-content/uploads/2016/09/Making-a-Successful-Return-to-Education-after-an-Acquired-Brain-Injury-29-03-16-5359.pdf>

COMPREHENSIVE CARE PROGRAMME (INCLUDING OUTREACH)

22

Tool/programme summary

This programme was developed in Saint Maurice, France and features an in- 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): P/C/A/PS

Target user (H/P/F/E/CSW): 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

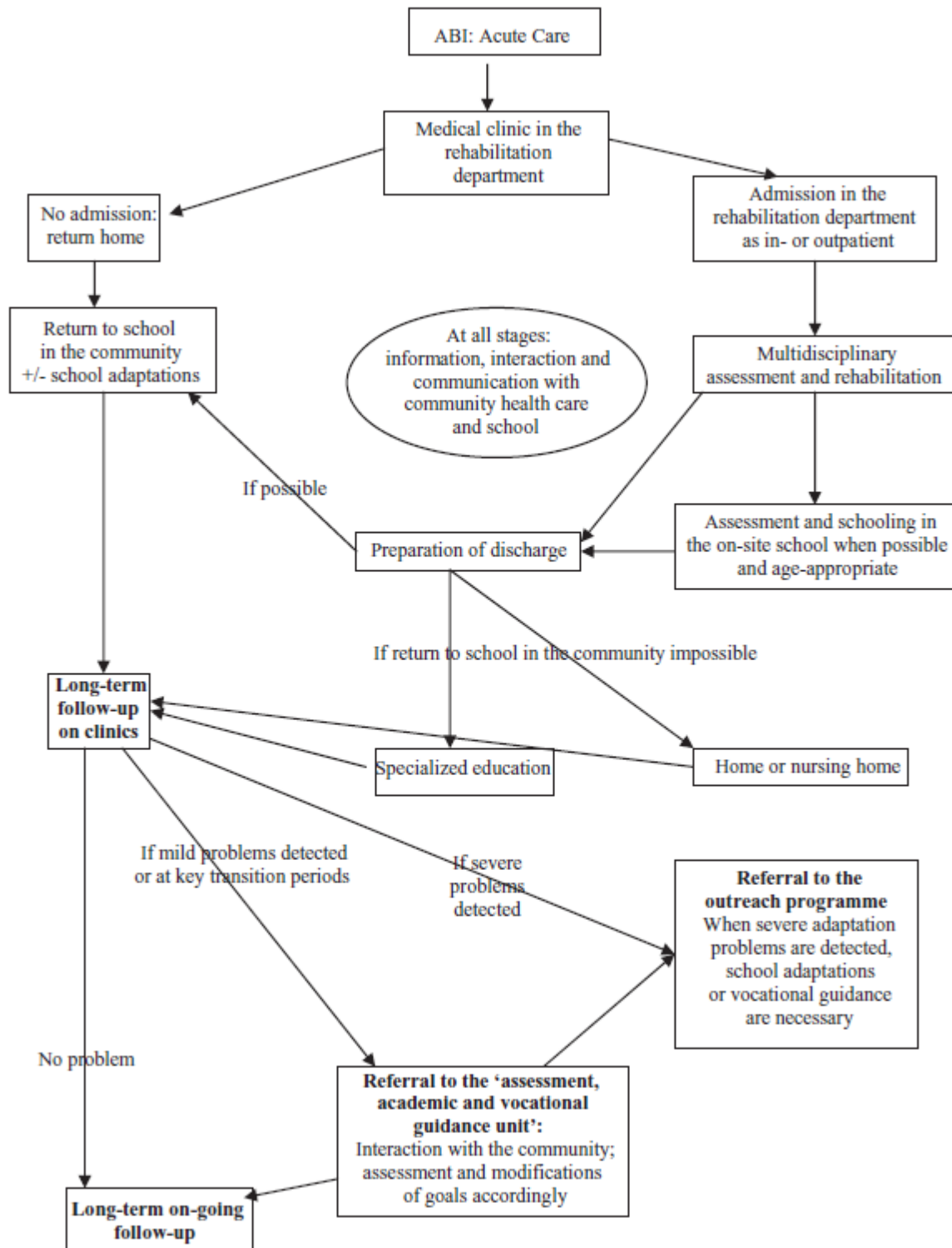
References

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

Contact for further information

Mathilde Chevignard: m.chevignard@hopitaux-st-maurice.fr

Flow chart indicating various steps followed by the child with ABI post-injury



Acquired Brain Injury Guidebook for Family Intervention (available in Dutch)

23

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): P/C/A/PS

Target user (H/P/F/E/CSW): 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

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-SENSITIVE, FAMILY-BASED APPROACH

24

Tool/programme summary

This is a multidisciplinary approach that 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 centered 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): P/C/A/PS

Target user (H/P/F/E/CSW): 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 centered 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

- 1) Braga LW, Campos da Paz Jr A, editors. The child with traumatic brain injury or cerebral palsy: a context-family based approach to development. CRC Press. ISBN 9781841845036 - CAT# DU5035
- 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].

Contact for further information

Lucia Braga: luciabraga@sarah.br www.sarah.br

PAEDIATRIC ACQUIRED BRAIN INJURY COMMUNITY OUTREACHING PROGRAMME (PABICOP)

25

Tool/programme summary

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): P/C/A/PS

Target user (H/P/F/E/CSW): 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. A n evaluation of the paediatric acquired brain injury community outreach programme (PABICOP) *Brain Injury* 2006;20(11):1189–1205.

Contact for further information

Sara Somers: Sara.Somers@tvcc.on.ca www.tvcc.on.ca

TEEN ONLINE PROBLEM SOLVING (TOPS)

26

Tool/programme summary

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 (P/C/A/PS): C/PS

Target user (H/P/F/E/CSW): 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

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

27

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 as 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/A/PS): P/C

Target user (H/P/F/E/CSW): 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

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

Contact for further information

Jasmine Xavier: jasmine.xavier@health.nsw.gov.au

PEER EVENTS

28

Tool/programme summary

An event is organised with a group of friends chosen by the child/young person (CYP) with an Acquired Brain Injury (ABI) and all are invited to an afternoon 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, 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 CYP 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 CYP 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 (P/C/A/PS): PS

Target user (H/P/F/E/CSW): 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 for CYP with an ABI
- 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 better understanding of ABI by friends of the child
- 2) Identification of practical and realistic support that could be provided
- 3) Patients and their families report positive outcomes from these events

Reference

Presented at the 2nd international Conference on Paediatric Acquired Brain Injury, Rome, 2017

Contact for further information

Miranda Loveday: Miranda.loveday@kch.nhs.uk

LEARNING PARENTAL NETWORK AND LEARNING YOUTH NETWORK ON FACEBOOK

29

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): P/C/A/PS

Target user (H/P/F/E/CSW): 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

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

Contact for further information

Sofie Nilsson, Barn Rehab Skane, Sweden +0046 46-770900

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

30

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): P/C/A/PS

Target user (H/P/F/E/CSW): 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):205-12.

Contact for further information

Lucia Braga: luciabraga@sarah.br www.sarah.br

QUALITY CRITERIA AND A REFERRAL GUIDE: CARE FOR CHILDREN WITH BRAIN TUMOURS (available in Dutch)

31

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 suffer from 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): P/C/A/PS

Target user (H/P/F/E/CSW): 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)

32

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): P/C/A/PS

Target user (H/P/F/E/CSW): 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

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

Contact for further information

Rianne Gijzen: r.gijzen@vilans.nl

GRADUATED RETURN TO SCHOOL/RETURN TO PLAY GUIDELINES

33

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/A/PS): P/C

Target user (H/P/F/E/CSW): 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

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.

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.

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

Presented at the 2nd International Conference on Paediatric Acquired Brain Injury

Contact for further information

Kendra Jorgensen-Wagers: Kendra.I.jorgensen-wagers.ctr@mail.mil

CHILD AND ADOLESCENT SCALE OF PARTICIPATION (CASP) (available in Spanish, French, German, Hebrew, and Mandarin)

34

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): P/C/A/PS

Target user (H/P/F/E/CSW): 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

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.

Bedell G. Further validation of the Child and Adolescent Scale of Participation (CASP). *Developmental Neurorehabilitation* 2009;12:342-351.

Contact for further information

Gary Bedell: Gary.bedell@tufts.edu

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

CHILD AND ADOLESCENT SCALE OF ENVIRONMENT (CASE)**35****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): P/C/A/PS

Target user (H/P/F/E/CSW): 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

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.

Contact for further information

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

CHILD AND ADOLESCENT FACTORS INVENTORY (CAFI)**36****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/A/PS): P/C/PS

Target user (H/P/F/E/CSW): 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

Reference**Contact for further information**

Gary Bedell: Gary.bedell@tufts.edu <http://sites.tufts.edu/garybedell/measurement-tools/>

CHILD AND FAMILY FOLLOW-UP SURVEY (CFFS)**37****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/PS): P/C/A

Target user (H/P/F/E/CSW): 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

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/>

HEADS UP

38

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):P/C/A/PS

Target user (H/P/F/E/CSW): 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

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.

Contact for further information

Juliet Haarbauer-Krupa: JHaarbauerKrupa@cdc.gov
<https://www.cdc.gov/headsup/about/index.html>

INDEX B: TOOLS/PROGRAMMES THAT HAVE TO BE PAID FOR

| Tool number | 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 | | | | √ | √ | √ | √ | | |

Notes

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

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 Worker

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 (P/C/A/PS): C

Target user (H/P/F/E/CSW): 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

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/>

BRAINSTARS

2

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): P/C/A/PS

Target user (H/P/F/E/CSW): 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-assurance 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) 3

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 (P/C/A/PS): C

Target user (H/P/F/E/CSW): 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

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): P/C/A/PS

Target user (H/P/F/E/CSW): 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

<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)

5

Tool/programme summary

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 one of two different versions and assesses behaviours related to executive functions in eight 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 (P/C/A/PS): C

Target user (H/P/F/E/CSW): 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

- Gioia GA, Isquith PK, Guy SC et al. Behavior Rating Inventory of Executive Function. Lutz, FL: Psychological Assessment Resources, Inc. 2000.
- 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 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 (P/C/A/PS): PS

Target user (H/P/F/E/CSW): 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

Achenbach TM. (1991). Manual for the child behavior checklist/4-18 and 1991 profile. Burlington, VT: University of Vermont, Department of Psychiatry.

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.

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>



www.edendoratrust.org



www.ipbis.org