Evidence Summaries

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The Children's Trust
For children with brain injury

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Child centred care at The Children's Trust
Evidence Summary
January 2019

Rationale

Child centred care places the child in the centre of all the care they receive, with the acknowledgement that children, young people and parent are partners in their care, and services should be coordinated around the child and families' needs (Department of Health, 2003). Achieving this approach is thought to offer benefits to the child's development, and the child and families' well-being and quality of life (Shevell et al. 2019).

Clinical question – How and why should child centred care be offered at the Children's Trust?

Summary of the evidence

For many years, family centred care; a model of care that is based on the understanding that every family is unique, and that parents are the constant in their child's life, has been acknowledged as the best model of care for paediatric services (Law et al. 2003, Department of Health, 2005). This model of care can only be achieved if there is open and honest communication between families and professionals, with mutual respect and acknowledgement that families are experts in their child (Kuo et al. 2012). Benefits of family centred care have been shown to include improved child development, improved child psychological adjustment, enhanced parental psychological well-being (reduced stress, anxiety, depression) and increased satisfaction with the service (Shield et al. 2019).

In more recent years there has been a change in emphasis from family centred care to child centred care, as family centred care can lead to the child's voice being lost (Ford et al. 2018; Coyne et al. 2018; Coyne et al. 2016). It is recommended that services be focused around the child as an individual, but that the child should be seen within the context of their family, and wider context in which they live (Coyne et al. 2018). However, as child centred care is a newer model of working, there is a lack of research surrounding its use (Ford et al. 2018b).

Within child centred care the principles of family-centred care, and person-centred care are combined, with the recognition that the child is the centre of everything (Ford et al. 2018). This will include processes such as:

- Organisation of multidisciplinary assessments to reduce repetition for the child
- Information provided to the child and family in accessible ways, at the most appropriate time point, and signposting to other information sources (eg books, websites or support groups).
- Collaborative goal setting processes
- Shared decision making between the child, family and clinical team, with presentation of all appropriate choices.
- Empowering the family to advocate for their child
- Having a key worker for the child and family

- Have services that are planned with children and families (Law et al. 2003)
- Have an organisational structure that seeks to promote and develop services that are designed with the families, and have the child at their centre (King and Chiarello, 2014).

Parental views

Families have reported the need to access appropriate information and support at a time, and in a format which works for them. Families have been more satisfied with the services when open and honest communication has occurred, and they have been fully involved in their child's care.

Current experiences

Our experience has been that children and families are coming to terms with a new and life changing injury and therefore need to be supported and empowered to participate in decisions around their care at a rate and pace that meets their individual needs. There are several processes at The Children's Trust that do support child centred care, and more work is required to ensure that this is maximised.

Clinical recommendation at The Children's Trust

- Offer a service that is child-centred
- Develop open communication channels with the child and family
- Utilise the different contributions from families, other important people (such as friends) and professionals, but ensure the child's voice is not lost.
- Provide accessible information at time points when the family would like it
- Use child centred processes such as MDT assessment, collaborative goal setting and shared decision making

Use of a Psychosocial Formulatory Framework at The Children's Trust
Evidence Summary
June 2017

Rationale

Rehabilitation after childhood ABI is provided by a system of rehabilitation agents. These include the injured child and the child's family, school, community and professional network. Outcome across a range of cognitive and functional domains is highly variable and influenced by child and family psychosocial function and socioeconomic status as well as biological factors associated with their injury (Wilde et al 2015). This has led to a recent consensus that long term outcome is determined by a range of practical, biological and psychosocial resources owned by the child and their rehabilitation system. These resources interact to determine the ongoing capacity of the child to learn and apply rehabilitation skills throughout their lifespan. This shapes the child's developmental recovery of skills following their ABI. A recent movement within paediatric neuropsychology takes us from a unidirectional "fix it" approach towards one that mobilises the capacity of the child's system towards a positive rehabilitative trajectory (King et al 2017)

Clinical Question

Would using a 'capacity based' framework help teams select and prioritise appropriate interventions to improve rehabilitation outcomes?

Implications:

This would involve the development of a formulatory, capacity-based framework for our inpatient neurorehabilitation service. To follow best practice this formulatory framework should be:

- **Systemic** : covering capacities of the child, their family, and school
- **Multidimensional**: to consider capacities across different dimensions including emotional adaptation, practical resources, cognitive, physical and biological
- **Developmental :**
  - To represent the dynamic process of increasing capacities post injury
  - To represent the developmental life cycle of the child and their family.
  - Indicate that rehabilitation agents may move forwards or backwards as capacities increase or reduce
  - Reflect the characteristics of our service which involves inpatient, intensive rehabilitation, often in the post acute stage of injury.
  - Pay attention to long term outcomes as well as short term. This ensures we aim to set a positive trajectory for building future capacities
- **Pragmatic** : Easily used alongside client-led goal based assessments that reflect the priorities of the child, family or school. It should help the service
  - Identify current resources within the system
  - Identify goals that reflect increasing capacities
  - Identify the balance of capacities across different agents in the system
  - Choose interventions to match current capacities and resources

    - Provide a measure of changes in capacity over the period of rehabilitation, in addition to other outcome measures
- **Amenable to update** : in line with future service developments and to reflect future outcome data within paediatric rehabilitation after acquired brain injury

Performance measures

- Framework aids overall client formulation, identification and prioritisation of interventions
- Framework identifies outcomes regarding capacity of the child and their rehabilitation system to engage in rehabilitation at TCT and after discharge
- Framework aids provide means by which to measure changes in capacity to engage in rehabilitation within child's system.

Summary of evidence

Best practice involves paediatric rehabilitation services developing a formulatory framework that reflect the capacities of the population they serve. This is used alongside a client-led goal based approach to select interventions that reflect the system's current capacities and resources, as well as their priorities (Byaard et al 2015, Gracey et al 2009). Some authors highlight cognitive capacity (Limmond et al 2014) while others consider identity and the need to develop emotional capacity and resilience (Gracey et al 2009; King et al, 2017)
Several established community paediatric rehabilitation services in the UK have undertaken this for their service

Clinical experience

New whole team approach is being received positively by MDT team members who find that the approach aids clarity.

Child and family experience

New formulation approach with family inputting to team discussions. Families and young people are positive about contributing when they are able.

Clinical recommendation at The Children's Trust

- Consider use of formulatory, capacity- based framework for children and young people on rehabilitation programme
- Educate children, young people, families and their teams about the child and their rehabilitation system
- Involve whole MDT team in formulation meeting
- Involve children, young people and families
- Monitor and evaluate use of formulation to build evidence

Goal setting at The Children's Trust
Evidence Summary
October 2017

Rationale
Goal setting is a key component of child and family centred care, to ensure care targets areas that are the priorities of the child and family (Brewer, Pollock et al. 2014). Use of goals setting is recommended by national guidelines (RCPCH, 2017), and national service frameworks (Department of Health, 2004). It is also a requirement of NHS funded rehabilitation services (NHS England, 2013). However, in reality, there are challenges with the use of goal setting in clinical practice.

Clinical question – How and why should goal setting be used at The Children's Trust?

Why use goal setting?

- Child and family centred care, which involves collaboration with, and respect for, children and families, is considered best practice (Kuo, Houtrow et al. 2012)
- Goal setting is a key component of child and family centred care, allowing areas of priority to be established (Law, Hanna et al. 2003)
- Use of goals ensures teams (including professionals and families) are working together towards the same endpoint, thus improving efficiency and effectiveness (Wade 2009).
- Goal setting promotes improved communication, clarity and understanding within the whole team (children, families, therapy, nursing, medical, psychosocial, education and play) (Brewer, Pollock et al. 2014).
- It is a requirement of government policies, and a recommendation in national guidelines (RCPCH, 2017; Department of Health, 2004).

Does goal setting improve outcomes?

- In adults with stroke there is low to moderate quality evidence that goal setting can increase self-efficacy, motivation, satisfaction with and participation in rehabilitation (Rosewilliam, Roskell et al. 2011, Sugavanam, Mead et al. 2013)
- There is currently insufficient evidence to suggest that the addition of goal setting improves outcomes during rehabilitation for children with cerebral palsy (Brogren Carlberg and Löwing 2013) or adults with stroke (Rosewilliam, Roskell et al. 2011).
- No evidence whether goal setting improves the outcomes of children with ABI or PMLD

Collaborative goal setting

- Currently no evidence investigating the most effective way of goal setting with children and families following ABI, or those with PMLD.
- Children with cerebral palsy aged 5 and over have been able to set their own goals using tools such as the Perceived Efficacy and Goal Setting system (PEGS), and these goals can differ from their parents goals (Costa, Brauchle et al. 2017)
- In adult neurological rehabilitation patients varied in the amount of input they wanted into their goal setting, with some wanting to lead the discussions (Young, Manmathan et al. 2008, Laver, Halbert et al. 2010).
- Others felt unable to have an active role, and preferred professionals to take the lead, after acquiring a knowledge of what is important for them (Laver, Halbert et al. 2010, Brown, Levack et al. 2014)
- Brewer et al. (2014) also reports that parents of children accessing neurorehabilitation will vary to the extent in which they are able to participate in the process.

- Tailoring the goal setting interviews to the individual patient and family is therefore essential (Lloyd, Roberts et al. 2014)
- Training improves therapist's ability to negotiate and write meaningful goals (Krasny-Pacini, Hiebel et al. 2013)

Should goals be realistic?

- Therapists prioritise the setting of SMART (specific, measurable, achievable, realistic, timed) goals (Wade 2009)
- Specific, realistic goals are important to some patients (Young, Manmathan et al. 2008, Baird, Tempest et al. 2010, Brown, Levack et al. 2014)
- Goals that are too easily achieved were described as worthless (Baird, Tempest et al. 2010, Brown, Levack et al. 2014)
- Some patients reported wanting aspirational goals, despite being told they were unachievable (Brown, Levack et al. 2014) Hope is vital to both children and families (Bray,2015).
- Goals are interlinked with hopes, and dashing hope can have devastating consequences on emotional wellbeing (Soundy, Smith et al. 2013), whereas there is no evidence supporting that false hope is detrimental (Mudge, Stretton et al. 2014)
- However, SMART goals are needed when goals are used as an outcome for rehabilitation, which can influence professionals in their discussions (Levack, Dean et al. 2011)

Use of goals as outcome measures

- Using goals as outcomes in measures such as goal attainment scaling (GAS) can provide meaningful, relevant and sensitive outcome measures (Turner-Stokes, Williams et al. 2009, Steenbeek, Gorter et al. 2011, Krasny-Pacini, Hiebel et al. 2013)
- There is conflicting evidence regarding the reliability and validity of GAS given that goals are individually set (Krasny-Pacini, Hiebel et al. 2013)
- GAS-light is easier to use clinically (Turner-Stokes, 2009).

Evidence from clinical experience

- Goal setting interviews can be challenging for professionals
- Establishment of core goals can improve team working and direct 24 hour rehabilitation input
- Reviewing goals during the placement has supported the child's changing needs
- Tools such as Talking Mats and PEGS has assisted children to engage

Feedback from children and their families

- Informal feedback suggests that, in keeping with the literature above, some families want to actively lead in goal setting, and others need more help and support from professionals.

Clinical recommendation at The Children's Trust

- Goals should be collaboratively set with children using their established form of communication whenever possible, and their families.
- Professionals should have training in goal setting
- The whole team (child, families, and professionals) should be aware of the goals, and work towards them
- Goal setting interviews should be individually tailored to meet the needs of the child and family (using communication support and goal setting tools).
- Families' hopes should not be dashed during goal setting interviews.
- Use goals based outcome measures

Coaching for family-delivered therapy at The Children’s Trust
Evidence Summary
January 2019

Rationale: Why use parent coaching?
Supporting parents, as co-workers, to facilitate their child’s development is an effective way of working and reflects child and family centred, person centred and strength based approaches to intervention (Children and Families Act 2014). A coaching approach empowers parents, promotes self-efficacy and prepares them for discharge.

Clinical question – How and why should parent coaching be used at The Children’s Trust?

Summary of the evidence
Parents delivering therapeutic interventions, guided by professionals have been shown to be effective in improving cognitive and physical skills of children with acquired brain injury (Braga et al 2005).
Interventions designed to teach families collaborative problem solving strategies have been shown to be effective in improving behavioural, educational and everyday interaction domains of children with acquired brain injury (Wade 2003, Van’t Hooft et al 2005).
Intervention programmes designed to assist families in their adjustment can improve child outcomes (Braga 2005).

Parent coaching
Parents contribute to multi-disciplinary assessment of the child
Treatment programme translated into simple activities that can be performed on house
Illustrated, individualised manual of activities provided for each child and family
Techniques
Active listening
Use reflective statements and questions
Guided discovery – rather than present solutions guide parent to discover them
Analyse issues with parent

Feedback from children and their families

When parents feel confident to look after their child it makes going home much easier. Parents have said they would like to be co-workers with therapists and the multi-disciplinary team. Parents have told us they would like consistent and explicit explanation about clinical reasoning, purpose of activities and content of sessions. They would like clear and repeated explanations about what we are doing and why, in the moment, to help them understand the reason for a chosen activity or session content and relating these back to the joint goals set.

Clinical recommendation at The Children’s Trust

- Following the assessment phase therapists should consider how they can work with parents to enable them to deliver interventions.
- Initially this will be explaining and narrating what they are doing in sessions with a view to the parents taking a more hands on role prior to discharge.
- Parents provided with treatment programme translated into simple activities with illustrations where possible
- Towards the end of the placement parents are increasingly delivering intervention and care

Clinical Issues

- Neuroendocrine screening
- Videofluroscopy
- Headaches following mTBI
- Spasticity management
- Oral health
- Respiratory
- Concussion
- Fatigue

Neuroendocrine Screening at The Children's Trust
Evidence Summary
May 2015

Rationale

The understanding of pituitary function after brain injury is one which has been developing in the field of neurorehabilitation over recent years, yet it has remained unclear just how much of a problem it is. There are, however, case reports where diagnosis of clinically significant hypopituitarism has been missed for up to 10 years[1] in adulthood. The impact of this during childhood and adolescence should not be underestimated[2] due to the effects on the rapid development both physically and cognitively during this period.

Current practice at The Children's Trust for the surveillance of pituitary function is done via admission blood tests (random cortisol, prolactin and thyroid function) and ongoing clinical vigilance. There has not been a recent review of literature to establish whether anything different should be done.

Clinical questions –

1. How common is pituitary dysfunction in children after acquired brain injury?
2. Is there a consensus on surveillance of pituitary function following brain injury in children?
3. Can literature offer guidance for practice at The Children's Trust?

Prevalence

One grade 1b study was identified[3] in this literature review. It was a recent prospective study of 87 children and adolescents, showing good rates of participation and little loss to follow up. They identify that 8% of their participants had pituitary dysfunction after 1 year of TBI (of which 6 % was growth hormone deficient, one child had mild TSH deficiency and one ACTH deficiency).

Other studies were of grade 2b in nature and provide limited data with questionable reliability. Nine studied children and adolescents, and report prevalence between 0%[4] and 39%[5] (see table 1). These studies were either small in sample size, were retrospectively carried out or both. These studies have multiple differences in sampling techniques, definition of the disorder, time since injury and duration of study, amongst other differences, which makes comparison between them difficult.

%	Affected/ sample
0%[4]	0/36
4%[6]	2/41
5%[7]	1/20 *
8%[8]	16/198
10%[9]	7/70
16%[10]	5/32
28%[11]	6/21
34.7%[12]	8/24
39%[5]	13/33

*Associated with a pre-existing condition

Table 1: Reported prevalence

Recent studies into the adult population have found hypopituitarism in between 1%[13] and 33%[14], which appear broadly similar to those investigating children. These studies have a different set of challenges to those with children, for example accounting for the natural changes in gonadotroph levels with increasing age, as well as being unable to use height velocity as a measurement of GH action.

Expert opinions reviewing current literature seem to support the proposal that early studies have over-estimated the clinical problem[15], particularly in the paediatric population, although others[16, 17] refute this and perceive the problem as significant. Still others simply reflect on the large variance of prevalence in studies[18.]

Surveillance

No consensus was found on who, what and when screening of pituitary function should occur.

Studies showing a low prevalence of pituitary dysfunction tended to recommend that screening should not be universally undertaken of all people following a TBI[4, 7, 13, 19 and 20].

Other studies state that routine endocrine screening should be undertaken for all children following a TBI, although they frequently do not specify a method of doing so[3, 6, 11, 16, and 17].

The previously described 1b study 3) found sufficient abnormality in pituitary function to recommend systematic hormonal assessment in children and adolescents 12 months after severe traumatic brain injury, and prolonged endocrine follow up. They highlight that abnormalities in height velocity may not be noted by 12 months after injury, and that longer term monitoring would be required.

Screening can be done using blood tests (basal or stimulation) or clinically (through histories/ symptoms and measured parameters) but this is not always specified in recommendations. The 2005 consensus statement for adults[21] suggest basal testing at 3 and 12 months post injury, which has also been suggested for use in children[17], with stimulation testing conducted only when abnormalities are found. Both of these recommendations are based on grade 5 evidence, and additionally the consensus statement was prepared now ten years ago, before recent literature reducing estimates prevalence of post traumatic hypopituitarism.

The most commonly suggested approach in a paediatric population is to regularly measure height velocity, pubertal status and weight gain with serum hormone testing only if abnormalities occur or if the child becomes symptomatic of hormone deficiency[4, 5, 8, 9, 10, 15, and 22]. This approach may be more challenging to implement with post-pubertal adolescents who have already achieved full or near full height, although other parameters could still be monitored.

Clinical recommendation at The Children's Trust

There is not enough evidence to recommend a change from the current practise.

Based on what evidence is available and clinical expertise within organisation, the following suggestions have been made as a guide:

- Continue baseline hormone screen with admission bloods
- Ensure all children are monitored with regards to height velocity, weight, BMI, pubertal stage regularly, as part of their routine care
- Consider further endocrine causes for abnormality in any of the above
- Communicate the need for ongoing monitoring of height, weight and puberty to clinicians involved on discharge, and suggest consideration of pituitary dysfunction if abnormalities are noted.

Videofluroscopic Swallow Study at The Children's Trust
Evidence summary
October 2017

Rationale

Videofluroscopic swallow study or modified barium swallow has been considered the diagnostic instrumental tool study of choice to evaluate oropharyngeal swallowing anatomy and physiology for many years now. Videofluroscopy is a dynamic continuous radiological examination of the anatomy and function of the oral cavity, pharynx, and upper oesophageal airway opening that includes lateral and frontal views while swallowing a high-density barium or non-ionizing contrast bolus of different consistencies. (Rommel, 2017). The use of VFSS at The Children's Trust has helped to support the identification and further management of aspiration in children and young people. This method of assessment has been used hand in hand with other assessments and never in isolation.

Clinical question-
Should we use Videofluroscopic Swallow Studies (VFSS) to assess dysphagia in children and young people at The Children's Trust?

Evidence

- No studies have discussed VFSS specifically in relation to children and young people with ABI or neurodiability, so therefore evidence investigating other groups of children is being used.
- Case history information should be gathered from the children/ young person's carers or family members along with any medical notes or report. This detailed history should include physiological abnormalities of the swallow, digestive, respiratory and neurological systems (**Arvesdon, 2008**)
- Best test to determine the presence of aspiration and penetration, but it may not always be needed as part of a swallowing assessment. It should be only used when there is uncertainty of penetration of aspiration (**DeMatteo et al. 2005**)
- A VFSS provides dynamic imaging which shows the mouth (oral phase), the back of the throat (pharyngeal phase), and top of the stomach (oesophageal phase) during swallowing and as such is regarded as the gold standard for identifying aspiration. **Arvedson 2008**
- Using instrumental techniques in addition to clinical examination provides a more precise understanding of the biomechanics of the child's swallow which then will lead to a more targeted therapeutic intervention **Rommel 2017**
- The main reason for VFFS referral is aspiration risk **Rommel 2017**
- Although it is regarded as an important assessment in identifying aspiration, inter – rater reliability between professionals such as speech and language therapists and radiologists is variable **Cockerill et al 2016**
- When using VFSS with children SLT's have a much higher inter rater reliability when assessing fluids as opposed to solids**. de Matteo et al 2005**
- VFSS has limitations, such as the need for ionizing radiation and thereby the reluctance to repeat the procedure, the child unfriendly environment of the radiology suite, and the mainly qualitative nature of information obtained" **Rommel 2017**
- VFSS exposes children to ionizing radiation and therefore should be used minimally. **Celeste et al 2012**
- VFSS can only produce a snapshot of a person's swallow function, despite the fact that this function can vary from day to day. **Celeste et al 2012**

- It can be a terrifying and uncomfortable experience. **Celeste et al 2012**
- VFSS should not be carried out for behaviour feeding problems or children who cannot sit still. **Hiorns & Ryan 2006.**
- According to **Kim et al 2012** during a study including 295 patients it was found that radiation exposure during a VFSS is lower than that of a routine chest CT. It would take more than 40 VFSS' annually to exceed the annual radiation exposure dose limit, therefore making VFSS' relatively safe in terms of radiation exposure risk.

Guidance derived from clinical experience at TCT

VFSS at The Children's Trust has been used in the following instances:

- If clinical signs of aspiration have been observed and changes to texture modification and positioning have been trialled with continuing signs of aspiration observed.
- Should further information than that which a clinical bedside assessment provides be needed.
- Should a young person be at significant risk of danger of long term consequences if they aspirate.
- To offer further investigations following suspicion of silent aspiration i.e. repeated chest infections but not showing signs of aspiration during the clinical bedside evaluation.

However there have been occasions when a more in depth MDT discussion has been required to address the complex needs of this population. Occasions such as:

- If it is already clear that the young person is not managing and modification to texture, positioning and equipment can be made.
- If the young person is not thought to tolerate the process e.g. emotional or behavioural difficulties
- If the young person has had prior exposure to radiation therapy and is not medically stable.
- If the young person is not currently eating or is on small amounts of tasters e.g. lip swipes.
- As this does not follow a young person's typical feeding environment or routine it may not be a true reflection of their skills. This should be considered when deciding to refer for a videofluroscopy.

Child and family experiences

Some children and young people find the experience intrusive and overwhelming and as a result may find it difficult to participate and engage in the procedure. Other children and young people are able to successfully participate in the procedure with the support of a family member or familiar member of staff. The taste, smell and consistency of the barium can pose as a barrier to the young person engaging in the assessment.

Clinical recommendation at The Children's Trust

- Assess the child/ young person's swallow using non-instrumental techniques first.
- Do not refer for VFSS if there are modifications which can be made, a young person is not medically stable, only having small quantities of food such as lip swipes or if the young person has behaviour difficulties.
- Consider discussion with the MDT and referring for VFSS if there is a concern of aspiration risk and all other modifications have been made.
- Consider the exposure of ionizing radiation to a young person undergoing VFSS and assessments and interventions which are in their best interest. Make use of VFSS as an instrumental technique of swallow assessment having considered these limitations.

Managing headaches following mild traumatic brain injury
Evidence Summary
January 2019

Rationale

Headaches are one of the most common physical symptoms following a traumatic brain injury (TBI) (Kacperski & Arthur, 2016; Wantanbe et al, 2012) and post-traumatic headaches (PTHAs) have been described as the most disabling symptom of post-concussion syndrome (PCS) (Kuczynski et al, 2013). Of a sample of over 400 children and young people presenting at an emergency department with mild traumatic brain injury (mTBI), 29.3% reported PCS at a three month follow up (Babcock et al, 2013). The most frequent symptom of PCS reported was headaches and additionally one of the most common predictors of PCS following mTBI was headache on admission. Persistence of headaches can result in difficulty with concentration, attention and reduced participation in school and the in the community. Reduced participation in school and other age appropriate activities can cause significant challenges for children at a critical time (Choe & Blume, 2016).

Clinical question – What advice or guidance can be provided by Brain Injury Community Service in relation to the management of headaches in children with mild TBI (mTBI)?

Assessment

- Establish the history of the injury and include exploration of any other pre-existing factors (e.g. headaches/migraines, family history of headaches, anxiety, previous head injuries).
- Establish whether the child has a whiplash injury or neck pain, if so the child/young person should be referred to the GP (General Practitioner)
- Ask questions directly to the child and/or parent:
  - *“What helps your headache? What makes the headache better? And what makes it worse? What time of day does it happen? How long do they last?”.* This may help identify any potential triggers, such as a particular classroom/subject or a change in environment (Kacperski and Arthur, 2016)
  - *“Where is the pain located? Describe the type of pain.”*
  - *“Is there any associated nausea, photo/phono-phobia – is this influenced by movement/exercise/lights/noise?”*
- Establish whether the child has had a visual assessment in the last year, if not parents should be advised to attend the opticians
- Establish whether the child has a good sleep pattern, advice should be given regarding sleep hygiene
- Establish whether the child is drinking enough fluid on a daily basis. Further advice can be obtained here: https://www.healthykids.nsw.gov.au/kids-teens/choose-water-as-a-drink-kids
- Quantify patient experience of pain using a ruler pain scale of 0-10, or using a Face Pain rating scale, such as Wong-Baker (2014).
- Track the headache with a headache diary in order to identify any patterns or possible triggers for headaches and review with the parent or child.

Generic management

- Non-pharmacological treatment includes provision of advice on a healthy life style with emphasis on regular meals, sleep, exercise and rest. Children should be advised to take good amounts of water and avoid caffeine-containing drinks (Abuarafeh & Howells, 2014).
- Powell (2014) advised post traumatic headaches are likely to be related to stress, tension or by doing too much. Therefore, a multi-disciplinary approach may be necessary to provide support across environments, for example school staff and family supporting implementation of rest and psychology services to advise on strategies to manage pain and relaxation techniques.
- Day et al (2014) found that mindfulness based cognitive therapy (MBCT) is a feasible, tolerable and acceptable intervention for headache pain and therefore this may be considered as a management strategy.

- Provide information on or refer to local psychological services should there be evidence of other issues such as anxiety, depression, anger and personality change contributing to the headaches (Lew et al, 2006).
- Over the counter medication such as ibuprofen can be effective for pain relief, however should be taken no more than 3 days per week and no more than twice in a day. Care should be taken to avoid development of medication overuse headaches (Kacperski & Arthur, 2016)
- Onward referral to a paediatrician may be considered if headaches continue to impact a child's participation in school, home and the community.

Performance measures

- Self-report of frequency and severity of headaches, including use of 0-10 scales or Face Pain scales.
- Parental and child or young person report of analgesia use.
- Self, family and school report of participation at home, school and in the community. This may be done anecdotally or through using outcome measures such as the Child and Adolescent Scale of Participation (CASP) (Bedell, 2009).

Summary of the research evidence

- Headaches are one of the most common physical symptoms following a traumatic brain injury (Wantanabe et al, 2012).
- Headaches can be accompanied by other symptoms e.g. dizziness, mood disturbances and sleep problems, as part of PCS (Blume, 2015).
- Headaches are commonly reported as one of most disabling symptoms of PCS (Kuczynski et al, 2013).
- Headaches can impact upon participation levels in school and the community (Choe and Blume, 2016).
- PTHAs can be persistent, with 18-33% continuing after a year (Lew et al, 2006).
- Girls are more likely than boys, and adolescents more likely than younger children, to experience PTHAs (Blume et al, 2012).
- The term "chronic PTHA" may be used when the headache persists for more than 3 months (Olesen, 2005).
- There is currently a lack of evidence to support which are the most effective treatment strategies for headaches after a brain injury (Lucas, 2011). However, Day et al (2014) found that MBCT can be a feasible intervention for headache pain. Additionally, Gurr & Coetzer (2005) reported that cognitive behavioural therapy (CBT) can help to reduce tension type headaches following TBI.

Currently there appears to be little evidence to suggest the most effective treatment for PTHAs. The advice reported in this evidence summary is based on a common sense approach at resolving a primary type headache and further research is required to determine the efficacy of available headache treatments following a TBI.

Evidence based on clinical experience at TCT

Identification of factors that may contribute to headaches following a holistic assessment is important in order to develop a management plan. It can be beneficial to make onward referrals to a medical team/psychology department for further guidance if the headaches continue to impact function and participation.

Child/young people and family view

Headaches are commonly reported as a cause for concern during screening and assessment visits

Clinical recommendation at The Children's Trust

- Assess the headaches, including frequency and severity, and the impact this is having on the child's functioning and participation across environments.
- Provide generic advice for the child, young person and family on prevention and treatment.
- Review management with the child, young person or parent to assess for improvement
- Make appropriate onward referrals if the headaches persist.

Spasticity management at The Children's Trust
Evidence Summary
January 2019

Rationale

Many children and young people have difficulties with hypertonicity (high muscle tone) after their brain injury. Spasticity is one type of hypertonia which is defined as "Disordered sensorimotor control, resulting, resulting from an upper motor neuron lesion (UMN), presenting as an intermittent or sustained involuntary activations of muscles'" (Pandyan et al. 2005). Spasticity can affect the child/young person's ability to move or be moved and positioned, and their comfort and way they look. As a result this can affect all aspects of the child's daily life.

Clinical question – How should spasticity in children and young people be managed at The Children's Trust?

Assessment

- Children and young people with spasticity should be assessed using the CPIPS (CPIP UK, 2016) and CPUPS (CPUP, 2011) assessments
- Activity and participation measures should also be completed using, selected via the gross motor/upper limb outcome pathways.
- Goals based measures should also be used.
- Pain should be monitored through the use of a pain tool

Management

- There are evidence based guidelines completed by the National Institute of Clinical Excellence (NICE) that make recommendations for the pharmacological and physical management of spasticity (Spasticity in under 19s: Management- Clinical guideline [CG145], updated 2016). These include guidance for use of botulinum toxin injections, systemic medications, orthoses, active physical interventions and surgical interventions. An interactive pathway and the full guidance can be found here https://pathways.nice.org.uk/pathways/spasticity-in-children-and-young-people.
- Children's Trust guidelines for specific therapeutic interventions (e.g. the upper limb pathway and postural management, gait re-education, strengthening, balance training) should be followed where appropriate.

Children, young people and Parental views

- Managing spasticity, for the way it looks, feels and affects function (active or as a recipient of care) is important to both children and young people, and their families
- Use of different modalities (eg Botulinum Toxin or medications) can be acceptable to different families- a full explanation of benefits and risks for each intervention needs to be given so that an informed decision is made.
- Spasticity affects children and young people differently, and the priorities and goals of each family differ.

Current experiences

- Best results are achieved when doctors, therapists and nursing staff work jointly with the child and family to make decisions regarding spasticity management.
- The child/young person's tonal pattern is likely to change throughout their placement so regular review is required, and appropriate preparation for discharge is needed.

Clinical recommendation at The Children's Trust

- Assess children/young people with spasticity at an impairment, activity and participation level, with their goals and priorities established.
- Manage spasticity based on the NICE guidelines for spasticity in under 19's (2016).
- Regularly review children and young people with spasticity with a coordinated team approach, including families, therapists, doctors and nursing staff, and management adjusted according to the NICE guidelines.

Oral Health Care at The Children’s Trust
Evidence based summary

Rationale

Oral healthcare is an important part of all children and young people’s (CYP) overall health, nutritional status and wellbeing. An assessment of oral health is the starting point for assessing a child’s oral health needs and developing an appropriate individual oral health care plan. Oral health care is an essential part of all CYP’s personal care routine and involves more than just brushing teeth. It also includes the maintenance of healthy gums, lips, mouth and face. Current evidence confirms that oral health is not being adequately or routinely assessed in hospital or care homes with few having appropriate policies in place for routine oral health practices (PHE/DH 2017, HE England 2018). Furthermore, it has been found that nursing and care staff carrying out mouth care have limited or no previous training to accurately assess a patient’s oral health status resulting in a lack of standardization in the delivery of best practice oral health care (Stout et al 2009). Poor standards of oral health care not only result in pain and discomfort due to halitosis, gum disease and dental caries but can also lead to more serious health complications including nutritional deficiency and infection. CYP with neurogenic impairment or profound and multiple learning disabilities (PMLD) often experience more problems with oral health than the general population (RCS 2012). This is principally associated with the challenges of cognition, coexisting medical issues, side effects of medication (such as dry mouth), facial and mouth developmental abnormalities, eating and swallowing difficulties.

Clinical question –
Are we providing best practice oral health care to all children and young people cared for at The Children’s Trust?

Assessment

- Checking the condition of the mouth involves regular recorded mouth care assessments.
- Assessments should be based on the framework recommended by Health Education England, Mouth Care Matters - *Mouth care risk assessment* (HE England 2018).
- Assessments scored at a ‘high level’ of risk will require a Doctor or Dental team referral.
- An evidence based individualised daily *Oral Health Care Plan* should be developed in conjunction with the CYP, parents/guardians, nursing and allied health professional including speech & language and occupational therapists.
- A baseline oral health screening assessment based on the Health Education England, Mouth Care Matters, *Mouth care screening tool w*ill enable staff to;
    - ✓ Inspect and record the current condition of the mouth, lips, tongue, teeth gums, cheeks, palate and under the tongue and scored in accordance with the red, amber, green (RAG) rating of risk for developing further problems.
    - ✓ Record the level of assistance required to deliver oral care to the CYP.
    - ✓ Identify the need for regular weekly mouth care assessments if scoring in the amber or red categories.

Intervention

- Day to day mouth care is the responsibility of all nursing and care staff in the (absence of parents/guardian) and is key to having a healthy mouth.
- Staff need to consider how oral health care should be delivered using an evidence based approach to mouth care knowledge, skills, tools and products and level of support required.
- Practical mouth care for CYP at TCT should involve identifying, analyzing and breaking down oral care tasks in order to manage any specific oral care problems including;
    - ✓ mouth or face sensitivity,
    - ✓ gagging or retching
    - ✓ toothbrush biting
    - ✓ strong tongue thrust
    - ✓ reduced or limited cooperation.

- Practical tooth brushing should reflect EVB oral health care guideline recommendations to ensure;
    - ✓ The correct size, shape and type toothbrush and or cheek/tongue brush is selected [NB. toothbrushes can be adapted in many ways for example 2 or 3 headed or electric toothbrushes may be more effective depending on individual need]
    - ✓ Fluoride toothpaste is used (NB can be foaming or non-foaming, mint or other flavor),
    - ✓ A full explanation is given prior to starting oral health care [NB. assisting or cleaning another person's teeth and gums is invasive and intrusive and can be frightening],
    - ✓ The CYP is appropriately located, comfortable with their head well supported prior to any starting oral health care,
    - ✓ Teeth and gums to be cleaned at least twice per day for 2 minutes,
    - ✓ A planned order of teeth brushing should be used [NB. generally brush from back to front using of 'short scrub motions' paying attention to gum margins, gently hold and brush tongue]
    - ✓ Encouraging spitting out rather than rinsing [NB. do not completely rinse away fluoride toothpaste to ensure adequate teeth protection]
    - ✓ Gloves (if worn) to be discarded after oral health care has been given to the CYP procedure to prevent cross infection.

Child/young person and family view

Families are concerned about oral health. They often ask if oral health procedures have been completed as part of daily care routines.

Clinical recommendations at The Children's Trust

- Complete a baseline *Oral Health Screening* within 24 hours of admission
- Complete weekly evaluation of *Oral Health Assessment* with actions when children and young people score an amber or red flag at screening
- Offer oral healthcare as per best practice guidelines and training.
- Use an MDT approach to ensure oral health care is optimized.

Manual Respiratory Physiotherapy Techniques at The Children’s Trust
Evidence Summary
November 2018

This is an evidence based summary for use by appropriately trained clinicians. This does not replace a full clinical assessment and should be considered in such light.

Rationale

Children with neurological disorders are at increased risk of developing chest infections and respiratory compromise. This is a result of difficulties with tone, muscle strength, spinal changes and associated changes to patterns of breathing, ineffective cough, swallowing difficulties and risks of aspiration (Proesmans 2016). The aim of this document is to improve the consistency of the use of manual airway clearance techniques at The Children’s Trust for children and young people who are at risk of respiratory compromise. An evidence based approach to the respiratory management of this group of children is essential to maintain physical wellbeing and quality of life (Winfield et al 2014).

Clinical question – How should manual respiratory physiotherapy techniques (MRPT) be used in children who are unable to clear their own secretions at the Children’s Trust?

Summary of the evidence

There has been very little research into the use of MRPT in children with ABI or with severe global developmental delay. A Cochrane review on respiratory management of children with severe global developmental delay did not find any research studies on MRPT in this population (Winfield et al. 2014).

There has been no research conducted in the use of MRPT in neuromuscular disorders. However, manual techniques are widely used by professionals to help mobilise secretions (Chatwin et al. 2018). International consensus guidelines rated MRPT to be moderately or minimally effective in patients with neuromuscular disorders, but felt they were low cost and may have clinical utility, particularly if supported by NIV (Toussanit et al. 2018).

In conditions such as Cystic Fibrosis, MRPT and positioning has been found to be as effective as other airway clearance techniques (Lee et al 2017). Techniques in regards to strength and frequency should be modified to consider age and factors such as reflux and bone density (Lee et al 2017). Respiratory care should involve a comprehensive assessment and development of an individualized management plan.

Parental and CYP views
Children, young people and their families sometimes find the techniques distressing.

Current experiences
There is currently a wide variety in the amount or the type of clearance technique that are used at The Children’s Trust as there is no clear evidence to guide this. Local consensus agreed that the minimal amount that is effective to clear the secretions should be used.

At times children have required more than one programme depending on how well they are at the time.

Considerations for MRPT

- Consent should be always be sought, where possible from the CYP, and parents or appropriate advocate. In emergency situations it is understood that staff may need to react in the child’s best interests, and this should be documented.
- All clinicians who are performing these techniques should be aware of the individual child’s signs and symptoms of deterioration, and how to respond to these in a timely manner.
- Consideration should be given to child indications of tolerance to techniques. Families should be guided through this process.
- Thought should be given as to how to best incorporate MRPT into a child’s day, to maximise the effectiveness of the intervention whilst minimising the impact on other activities.
- Thought should be given to the environment where the technique is used and the presence of other CYP and parents.
- Care should be given about the language used when describing the techniques. It should age appropriate, supportive and specific to the child (for example the use of touch cues).

Clinical recommendations for The Children’s Trust

- The respiratory team should establish a chest management programme for all CYP who have long term problems with clearing secretions.
- Use clinical reasoning and consider the factors listed above to guide the chest management dosage and techniques.
- Be aware of the sometimes distressing nature of these techniques and therefore the minimal amount that is clinically effective should be used.
- Respond to any deterioration during the procedure in an appropriate and timely manner
- The respiratory team should regularly evaluate and review programs to ensure the current needs are being addressed.

Concussion - Evidence Summary October 2017

Rationale

Each year, 1.4 million people attend emergency departments (ED) in England and Wales with a recent head injury; between 33% and 50% of these are children aged under 15 years (NICE guidelines 2014). Of the large number of head injury presentations to ED, 90% of injuries are considered to be mild (Kay & Teasdale, 2001). However, increasingly there has been noted to be a lack of consensus of terms used to describe such injuries. Therefore, there remains discrepancies in information provided and approaches to management (Sharp & Jenkins, 2015).

Implications

Clinical question – How can The Children's Trust support CYP with concussion?

Terminology

There is no universal consensus regarding the definition of concussion; some clinicians use the terms 'concussion' and 'mTBI' interchangeably, whilst others propose they should be viewed as distinct entities (Bodin et al, 2012; Bradley-Klug et al, 2015; Kristman et al, 2014). Sharp & Jenkins (2015) argue that there is no clear pathological definition to distinguish concussion from other types of TBI and the injuries leading to concussion are biomechanically similar to other types of TBI. Clinicians may use the term 'concussion' because it is less alarming to parents, with the intent of implying that the injury has no significant long-term health consequences (DeMatteo et al, 2010). However, a significant minority of individuals with mTBI (up to a third) report symptoms persisting beyond six months (Hou et al, 2012; Stulemeijer et al, 2008). The implication that a brain injury did not occur can result in poor follow up with health care professionals (DeMatteo et al, 2010; Sharp & Jenkins, 2015).

Activity Levels Post Injury

Literature reviews of mTBI have found a lack of research addressing return to activity principles (Burke et al, 2015). Many guidelines advocate rest following mTBI, though there is a growing amount of evidence to support activity post-injury (Buckley et al, 2016; DeMatteo et al 2015b; DiFazio et al, 2016; Grool et al 2016; Howell et al, 2016; Thomas et al, 2015; Wells et al, 2016). For those who are slower to recover, engagement in an active rehabilitation programme including light aerobic exercise can have a positive impact on function and symptoms (Gagnon et al, 2016; Kurowski et al, 2017; Swanson et al, 2014). These findings are based on small sample sizes and are not generalizable. However, the evidence base that exercise is beneficial for neurorehabilitation is growing (Wells et al, 2016). Most findings describe physical activities and not address cognitive demands. Silverberg et al (2016) found that although symptom spikes may not be detrimental and resolved quickly, the risk was enlarged by an abrupt increase in mental activity i.e. return to school (RTS). DeMatteo et al (2015a) developed a protocol for RTS following concussion, advocating for initial cognitive rest and a timely, graded return with individualised modifications, to ensure normality and social support. Similarly, Wells et al (2016) state that removal from regular routine, i.e. school, is itself a stressor and can cause fear and anxiety, thus increasing post-concussive symptoms (PCS). Bradley-Klug et al (2015) argue that for these protocols to be successful, information sharing between professionals and family is key to ensure a consistent approach across environments.

Symptoms and Management of mTBI

Sleep disturbance

Sleep difficulties can be a common effect of mTBI (Schimdt et al, 2015; Theadom et al, 2016; Towns et al, 2015), however sleep outcomes may not differ significantly from non-injured controls beyond 3 months (Schmidt et al, 2015) or 6 months (Landry-Roy et al, 2017). Theadom et al (2016) found that sleep difficulties post mTBI can be predictive of longer term outcomes, yet Towns et al (2015) found psychological distress was a larger predictor. Landry-

Roy et al (2017) found that premorbid and injury related factors placed some CYP at risk for poorer sleep after mTBI, hence a detailed history is important.

Education

Parents, educators and CYP can lack concussion knowledge and require more comprehensive education programmes to increase knowledge and change attitudes i.e. increased self-reporting of symptoms (Eagles et al, 2016; Glang et al, 2015; Graff & Caperell, 2016; Kearney, 2017; Kroshus et al, 2016; LaBond et al, 2014; Weerdenburg et al, 2016). Developmentally appropriate concussion education programming has been suggested for children as young as six (Kroshus et al, 2016). Studies have found both online education programmes (Glang et al, 2015; Graff & Caperell, 2016) and face to face delivery (Eagles et al, 2016; Hunt et al, 2016) to be effective in increasing concussion knowledge, however multiple sessions may be required for retention (Cusimano et al, 2014).

Psychological Needs

Evidence suggests CYP may be more prone to psychological sequelae following their injury (Mrazik et al, 2016; McCarty et al, 2016; McCauley et al, 2014; Keightley et al, 2014, Jimenez et al, 2017). However, Jimenez et al (2017) found that most post-injury mental health services (86%) were accessed by CYP who previously had mental health disorders. Currently, there is insufficient literature to make any recommendations on psychotherapeutic treatment for paediatric mTBI (Bergersen et al, 2017).

Summary of the Evidence

Terminology

- Consider use of term ‘mTBI’ rather than ‘concussion’.

Activity Levels Post-Injury

- Graded, light, physical activity may reduce symptoms acutely and longer-term.
- There is less research reviewing effects of early cognitive demands on symptoms; studies advocate a timely return to school with individualised modifications to reduce school absence periods whilst promoting brain recovery.
- Active rehabilitation programmes may be beneficial in reducing PCS but more research is required.

Management

- Sleep difficulties can be common after mTBI and may be linked to increased PCS.
- CYP, families and educators can increase their mTBI knowledge through delivery of education sessions online or face to face; multiple sessions may be required.
- Psychosocial needs following mTBI may be increased; more research is needed.

Clinical recommendation at The Children’s Trust

- Consider using the term ‘mild traumatic brain injury’ instead of ‘concussion’, to encourage understanding that an injury to the brain has occurred, with possible long term impact and need for specialist input.
- Advocate graded return to activities and encourage individual modifications based on need.
- Highlight the possible benefits of light physical activity i.e. walking, as tolerated. Follow return to sport guidelines for consideration regarding more active leisure.
- Offer education programmes and resources for children, families and educators to increase concussion knowledge and tailor child sessions based on developmental stage.
- Be aware of the possible psychosocial impact of mTBI and support families with appropriate referrals.
- Be aware of possible sleep difficulties; include sleep in child history and review sleep hygiene post-injury.
- Signpost CYP and their families to the Brain Injury Hub for further information.

Fatigue management at The Children's Trust
Evidence Summary
Reviewed July 2018

Rationale

Fatigue is a sense of physical tiredness and lack of energy greater than expected for the degree of effort required for a usual task (Freal et al 1984). It is a type of tiredness that is pervasive and can result independently or from physical and cognitive effort. Fatigue has been recognised as a long term problem affecting participation following brain injury in children and young people (Limond et al 2009; Renstrom et al 2012; Wales 2014, Crichton et al 2017).

Clinical question – how do we assess and support fatigue as part of the rehabilitation programme at The Children's Trust?

Assessment

Children	**Adults**
PedsQL fatigue - Multidimensional Fatigue Scale (Varni)	Diaries - Rochester fatigue diary
General analogue scale e.g. 1-10 or smiley faces	FSS - Fatigue Severity Scale (Krupp et al 1989)
Questioning e.g. how tired do you feel?	FAS - Fatigue Assessment Scale (Michielen 2003)
	Chalder Fatigue Scale (Chalder 1993)
	Epworth Sleepiness Scale http://epworthsleepinessscale.com/about-epworthsleepiness/
Additional MDT assessments; pain, constipation, mood, anxiety	
Parents/families FIS - Fatigue Impact Scale (Fisk 1994)	

Interventions	**Strategies**
➢ Relaxing evening and bed time routine	➢ Sleep diary monitoring
➢ Relaxation	➢ Relaxation
➢ Information/education	➢ Energy conservation
➢ Ongoing review of fatigue/activity diaries	

Performance measures

Ability to manage a whole day of rehabilitation / at school
Ability to manage all childhood tasks across the day
Complete PedsQL (outcomes)

Summary of the evidence

There are emerging evidence within fatigue and paediatric ABI which indicates fatigue is a long-term issue following ABI (Limond 2009; Renstrom 2012; Wales 2014). Research is still lacking for specific intervention to address these issues

It has been suggested that the severity of all areas of fatigue is associated with the severity of the injury (Crichton 2017). Research distinguishes between sleep/rest and cognitive fatigue. Tiredness is reported in groups of severe TBI, but not in groups of moderate/mild TBI (Renstrom et al 2012). Cognitive fatigue in particular has been observed to worsen over time with no evidence observed for recovery (Crichton A et al 2017).

Further research found an association between Socioeconomic Status and higher levels of parent reported fatigue in older children with non-traumatic brain injury (Van Markus-Doornbosch, 2016)

Parental views

Variable feedback from parents which is often linked to limited understanding and knowledge around fatigue and how this can impact on a child/young person's activities

Current experiences

Anecdotal cases of using diaries and adjusting timetables has enabled children to access therapy more productively.
Fatigue has been observed to increase as demands increase during period of rehab and as physical skills increase

Clinical recommendation at The Children's Trust

- If reported by parents, child or clinicians then complete: PedsQL Multidimensional Fatigue Scale
- Set GAS goal acknowledging impact of fatigue
- Educate parents and young people in generic fatigue management principles
- Commence interventions above and review.
- Gather case note evidence to support service development

Functional: Cognition

- Cognitive rehabilitation
- Errorless Learning
- Cognitive Orientation to Occupational Performance

Cognitive rehabilitation at The Children's Trust
Evidence Summary
Updated December 2016

Rationale

Cognitive rehabilitation is a systematic intervention to improve cognitive ability or to compensate for cognitive and/or behavioural difficulties following brain injury (Slomine and Locascio 2009). An increase in cognitive ability or an increase use of cognitive strategies should in turn lead to an improvement in daily functioning. There is a lack of studies evaluating the outcomes of cognitive remediation with children with acquired brain injury, although there is a recent increase in interest in this clinical area, especially in the domain of attention training

Clinical question – is there evidence to support the effectiveness of cognitive rehabilitation for children with acquired brain injury in a rehabilitation setting?

Implications

Assessment

1. Neuropsychological assessment
2. Assessment of Motor and Process Skills (AMPS)
3. Children's Cooking Task (Chevignard et al 2009)
4. Goal based evaluation (e.g. Goal attainment Scaling – GAS)
5. Parent/carer feedback (qualitative and quantitative)

Interventions

Online problem solving programme (Wade et al, 2009)

Not commercially available - ?email author shari.wade@cchmc.org

Attention-specific neuropsychological training (Galbiati et al 2009)

4 times a week for 45 minutes for 6 months

a. Tabletop tasks – interpreting picture, Q&A, opinions (Marzocchi, Molin & Poli, 2000) 15 min
b. Computerized tasks – Rehacom program * (Schuhfried, 1996), Attenzione & concentrazione program * (DiNuovo, 1992) 30 mins

Common Effective ingredients in attention training domain (see appendix 1 for literature review)

- Combination of process-specific approach and metacognitive strategies
- Involvement of coach (e.g. teacher/parent)
- Everyday intervention/routine
- Homework/Practice
- Repetition weeks of previously learnt skills
- Clinical input to formulate more individualised approach
- Addressing motivation within intervention

Strategies

Key instructional practices that can promote learning for individuals with acquired memory impairments(Ehlhardt et al 2008)	**Instructional Practices – common components** (Glang et al 2008) Mainly extrapolated from typically developing children)
• Clear delineation of intervention targets and/or use of task analyses when training multi-step procedures • Constraining errors and controlling client output while acquiring new or relearning information and procedures	• Systematic, explicit instruction & practice • Consistent instructional routines • Effective task analysis • Systematic introduction & modelling of component skills • Use of scaffolding/guided practice

• Providing sufficient practice • Distributing practice • Use of stimulus variation (eg multiple exemplars) • Use of strategies to promote more effortful processing (eg verbal elaboration; imagery) • Selection and training of ecologically valid targets	• Rapid instructional pacing • Teaching to mastery (criterion referenced instruction) • Consistently high rates of success • Teaching of generalizable strategies • Planned & programmed generalisation • Frequent & cumulative review

Performance measures

- Change in formal test scores, neuropsychological assessment, SFA, AMPS, Children's Cooking Task (eg Chevingard, 2009)
- Measurable clinical observations eg time on task, engaging in strategy use, independent use of strategies, reduction in behavioural agitation and episodes, improve in functional ability

Summary of the evidence

Slomine and Locascio (2009) re-examined the evidence and theoretical constructs in five key areas of cognitive rehabilitation and presented

1. Attention and working memory

    "Overall there is ***solid support*** *for the use of attention training in children with ABI"*

2. Memory

    "There are ***limited*** *data from the APT literature demonstrating that strategy practice improves memory"*

    (APT=attention process training)

    "Some evidence demonstrates that training in the use of external cues is efficacious for children after ABI"

3. Unilateral neglect

    "..few studies examining cognitive rehabilitation of neglect in children with ABI"

4. Executive functioning

    *"****Insufficient*** *evidence to make clinical recommendations for children"*

    Several theoretical papers and many case reports on aspects of executive functioning – problem solving, self-monitoring, use of Direct Instruction

5. Educating and Involving the Family

    "The results of multiple well-designed intervention studies that include families of children with ABI provide ***strong support*** *for educating, involving, and working with the family in order to ameliorate cognitive and behavioural problems in these children"*

Clinical experience and child/family feedback

Tailor made attention homework programmes and individual programmes of strategy use have been well received by children, young people and families. Cognitive rehabilitation groups are being trialled at The Children's Trust.

Clinical recommendation at The Children's Trust

- Carry out baseline assessment of cognitive and functional ability
- Set rehabilitation goal
- Offer attention training intervention programme
- Introduce strategies at developmentally appropriate level
- Work in partnership with families
- Collect data to contribute to evidence base in this area

Errorless learning at The Children's Trust
Evidence Summary
Updated September 2017

Rationale

Errorless learning is an approach that targets the learning phase of a new skill and aims to increase learning potential by eliminating the interference of errors.

Information to be learned is presented with a high degree of structure and prompting. This ensures that no errors occur and that the subject only encodes the information to be learned in contrast to trial and error learning (T&E) where guessing is encouraged (Tailby and Haslam 2003). There is a large and established evidence base for efficacy in a range of client groups dementia, Alzheimers, schizophrenia, learning disability and more recently adult brain injury.

Errorless learning is indicated following a brain injury where implicit memory is retained but episodic memory is affected.

Clinical question – Will all children with an ABI benefit from an errorless learning approach?

Assessment of memory and orientation

- Childrens Orientation Amnesia Test (COAT)
- Westmead PTA
- Children's Memory Scale (CMS) – must be administered by psychologist
- Rivermead Behavioural Memory Test (RBMT)

Interventions

- Error free environment ○ Children not to be questioned for recall eg "do you remember me?" "do you remember what we did yesterday". Instead "my name is ** and I saw you here yesterday when we did ** "
  - ○ Children to have a limited and structured routine to learn 2 or 3 places and 5 key staff initially
  - ○ Children to be assessed for individual memory strategies eg memo board, homework book, diary
- Errorless learning ○ Task analysis
  - ○ Task stages identified and written in procedure ○ Repetition of task – could be up to 20+ learning trials ○ Therapist to be anticipate errors ○ Learning trials separated by sleep

Strategies

- Name badges
- Reduce number of names and places to be learned
- Signage
- Memo boards
- Diaries
- Repeated practice following task breakdown

Performance measures

- Number of names learned
- Knowledge of strategies

- Orientation to time and person
- Able to find way from house to therapy centre

Summary of the evidence

3 main studies

Landis et al 2006 (n=34). Mild, mod and severe TBI age 6-18yrs learning facts eg a plant eating animal or insect is a (herbivore)

Findings did not support errorless learning as a generalized intervention for learning difficulties after TBI or identify specific age- or injury-severity groups that benefited from this technique.

Haslam et al 2012 (n=30) (15 ABI children;15controls)

Errorless learning vs errorless learning with self-generation vs errorful learning

Learn 3 word lists under different conditions and then distract and recall after 20 minute delay.

No effect for controls but ABI group significantly better under errorless conditions

Warmington et al 2013 – experiment with 49 typically developing children. Task involved word learning and included errorless learning vs errorful learning. Errorless learning significantly better learning outcomes

Low level evidence to support errorless learning routinely in functional task

Guidance derived from clinical experience at The Children's Trust

Poster presentation Wales (2007). Case study - route learning task for adolescent following traumatic brain injury. Independence after 19 learning trails. Clinical evidence from further case studies at The Children's Trust, Tadworth.

Child and family views

Children reported to have reduced anxiety with recognition of key places and people.

Clinical recommendation at The Children's Trust

Assess memory and functional independence

Do not routinely offer errorless learning

Consider an error free environment for all children with amnesia

Set rehabilitation goal with child, young person and family

Consider errorless learning in a controlled manner for particular task/skill learning

Collect outcome data systematically to build evidence for this intervention

Use of The Cognitive Orientation to daily Occupational Performance

Evidence Summary

October 2017

Rationale

CO-OP is a highly individualized, client centred, performance-based, problem solving approach that enables skill acquisition through a process of strategy use and guided discovery (Polatajko and Mandich 2004). CO-OP was developed to meet families and therapists requests for an intervention that would enable children to become competent in everyday activities they are expected to, want to or need to perform. CO-OP is a complex integrated approach based on cognitive behavioural learning theory and motor learning theory.

CO-OP is congruent with the ICF, is goal focused and child and family centred. A main focus of CO-OP is teaching clients how to solve their own problems with a global cognitive strategy of GOAL PLAN DO CHECK (GPDC). CO-OP also advocates learning through a process of guided discovery involving supported trial and error and review.

> Clinical question - Is there evidence to support the use of a CO-OP approach in the treatment of children and young people following acquired brain injury?

Assessment

- *Semi-structured interview with client and family*
- *Canadian Occupational Performance Measure (COPM)*
- *PACS/PEGS*
- *Complete daily log*

Goal Setting

- *Establish baseline performance using the Performance Quality Rating Scale (PQRS)*
- *Look at performance break down/problems*
- *Complete Dynamic Performance Analysis (DPA)*

Interventions

- *Teaching of a Global Cognitive strategy: Goal, Plan Do, Check (GPDC)*
- *After teaching get the child/young person to teach you a task*
- *Activity specific*
- *Top-down approach*
- *Focusing on actual performance*

Strategies

- *Focus on the activity and THE PLAN rather than the impairment*
- *Good understanding of the activity and the disability will support with providing good guided discovery. (use visual mnemonics).*
- *Distraction*
- *Relaxation*
- *Verbal guidance*

Performance measures

- *Baseline of task performance (PQRS)*
- *What is going wrong?*
  - Individual
  - Environment
  - Task
- *Outcomes (COPM)*

Summary of the evidence

CO-OP is based on contemporary motor-learning and cognitive-behavioural theory (Henshaw et al 2011), and there is emerging evidence from a series of studies for its use in children with developmental co-ordination disorder (Polatajko et al 2001). CO-OP has also shown to be effective in children with a variety of disabilities (Bernie & Rodger 2004; Miller et al 2001, Rodger et al 2008).

There is some evidence specifically in support of the use of CO-OP with children and adults with acquired brain injury (Dawson et al 2009, Missiuana et al 2010) however much of this evidence is based on single case or small studies where significant reported limitations include reduced ability to generalise to the wider population. In addition, much of the evidence for its use in ABI and stroke is in more mild cases; these studies tend also to be in the post-acute phase rather than in intensive rehabilitation programmes and primarily focus on the adult population. A single study (Wolf et al 2016) found improved outcomes using CO-OP, over traditional therapy in adults in early phase recovery from stroke.

A single published study using CO-OP with children following acquired brain injury indicates that CO-OP could be valuable but that adaptations are likely to be required (Missiuna et al, 2010). Missiuna et al found therapists carrying out the sessions struggled with identifying what part of a cognitive task was difficult for the child when completing the dynamic performance analysis. They also identified difficulties with retaining the cognitive strategy GPDC. Four particular principles were identified as being useful when working with children with ABI, these were: *making it fun*, *taking one thing at a time, working towards independence* and *guided discovery*. The other two principles *framing it in the GPDC structure* and *promote good strategy* use were not as important as the children with ABI were found not to remember or apply the cognitive strategy from one session to the next and required assistance to formulate cognitive strategies used.

Clinical experience

The findings from the above study are consistent with the clinical experience of CO-OP trained Occupational Therapists at The Children's Trust. In this study, there was no evidence of the children's ability to recall or apply the executive problem solving strategy- GPDC, however the importance of parental involvement to enable strategy use was highlighted

Child/young people and family view

So far young people and families have expressed mixed feelings to this approach.

Clinical recommendation at The Children's Trust

- Assess child/young person occupational performance
- Follow The Children's Trust CO-OP Decision Tree to identify if this approach would be a suitable approach
- Work with guidance from CO-OP trained therapists.
- Include parents in the process wherever possible.
- Collect outcome data to further the evidence base in this clinical field.
- Due to the limited evidence this document should be reviewed within one year to ensure up to date evidence is included.

Functional: psychological

- Narrative therapy
- Cognitive Behavioural Therapy

Narrative Therapy at The Children's Trust
Evidence Summary
February 2019

Rationale

Narrative therapy is a therapeutic approach which places the individual as the expert of their own lives and views the problem as being external to the person. It includes a strength-based approach focusing on the many strengths, abilities and values that the individual can use to reduce the impact of the problem(s). Narrative therapy was developed from the theory that people make sense of their lives through the story's they create and the meaning they give to these stories – in the way particular events are linked together in a particular way. Sometimes these stories are problem-focused and unhelpful, and through exploring alternative stories individuals can break free of the problem-focus and create new meanings for their lives.

Clinical question – Is Narrative Therapy an effective intervention to use with children who have an acquired brain injury? Additionally, is Narrative Therapy an effective intervention to use with the families of children who have an acquired brain injury?

Implications

Assessment

- Initial psychosocial assessment as standard. This should identify any initial indications of need and want for psychological therapeutic intervention.

Interventions

- One to one therapeutic sessions. Length of sessions should be dependent on child and/or family's need, capacity and practical issues such as time available in between other sessions.
- Work with any combination of parents, child with the injury and siblings may be required.
- Creation of 'books', particularly by young people, can be used to thicken the alternative story.

Outcome measures

- Regular reviews within therapy regarding sessions usefulness
- Clear goals created at the start of sessions
- Assessments of psychological distress as appropriate

Summary of the evidence

There is some emerging practice-based evidence that narrative therapy approaches may be beneficial when working with young people with an acquired brain injury. However, no empirical research has explored the effectiveness of the use of Narrative Therapy with children with an acquired brain injury. All of the evidence that has been reported is case-study based and qualitative.

Use directly with children with an ABI

The use of a Narrative autobiographical approach in clinical practice, in supporting children with an ABI, has been discussed by Perkins (2015). Perkins (2015) describes the creation of the document between the child and therapist as a tool to accommodate their complex needs, allow the child control over the therapy, store the information and allow the child the opportunity to consider their entire lifespan. The Narrative Approach can also include the building of positive stories based on survival, resilience and patience (for example). The document created can also be a useful tool to support the sharing of information about the child's brain injury with others. Perkins (2015) presents several case studies where these approaches were of benefit to young people and their families. Additionally evidence of effectiveness is presented based on 17 young people who were offered this approach. Sixteen out of 17 young people chose to reflect on, piece together and return to information regarding their experiences. Of the 10 children who made photographic or computer documents, 9 showed it to a parent during a session and all 10 took it home. The remaining 6 young people who created a less formal document, and one chose to share the document and take it home.

Use by children who have other difficulties

Beads of Courage is an initiative that encourages children living with a complex health condition to recognise their strength and bravery through adding a bead to a piece of string for every medical procedure. Baruch (2010) reports, through qualitative methods, on this being used with children with cancer. The beads were considered to form a 'narrative medicine' that tell the story of the young person's journey through treatment.

Clinical experience

Positive experiences of using this approach at The Children's Trust for identity rehabilitation and adjustment to ABI.

Every young person is offered the opportunity to explore their identity post ABI. For those experiencing high levels of trauma, significant low mood or with complex cognition (episodic memory, attention etc) this has not be the most appropriate approach.

Child/family experiences

Young people frequently develop a narrative surrounding their injury which informs presentations they give to peers, ways of talking to others about their injury. Young people frequently tell us that they keep their beads of courage/tree of life, story book about their injury and continue to use this beyond their time at The Children's Trust.

Clinical recommendation at The Children's Trust

Build relationship with child, young person and family

Assess child/young person using MDT approach

Consider adapted narrative approach when working directly with children/young people

Involve family and team

Monitor outcomes and collect data to build evidence in future

Cognitive Behavioural Therapy at The Children's Trust
Evidence Summary
February 2019

Rationale

Cognitive Behavioural Therapy (CBT) is widely used therapeutic approach known to be effective with a range of mental health difficulties. CBT is commonly used as a treatment approach with individuals experiencing anxiety and/or low mood, and has been recommended for use with some more complex mental health conditions such as Psychosis. CBT is widely used to support children experiencing these mental health difficulties, as well as adults. CBT is based on the theory that how we think, feel and behave influences each other, and that treatment works by adapting and changing at least one of these.

Clinical question – Is cognitive behavioural therapy an effective intervention with children with an acquired brain injury?

Implications

Assessment

- Initial psychosocial assessment as standard. This should identify any initial indications of need and want for psychological therapeutic intervention.
- MDT assessment of acquired difficulties, particularly cognition
- Vineland Adapted Behaviour Scale (VABS)
- Child Behaviour Checklist (CBCL)

Interventions

- One to one therapeutic sessions. Length of sessions should be dependent on child and/or family's need, capacity and practical issues such as time available in between other sessions.
- Work with any combination of parents, child with the injury and siblings may be required.

Outcome measures

- Regular reviews within therapy regarding session usefulness
- Clear goals created at the start of sessions
- Assessments of psychological distress as appropriate

Summary of the evidence

Most evidence completed regarding the use of CBT with children with an acquired brain injury (ABI) is completed with children several years after they acquired their injury, and was completed in the community. The Children's Trust is a residential rehabilitation setting, and generally young people arrive directly from their acute hospital stay. Therefore the findings should be applied to the context of The Children's Trust with caution.

Use of CBT with children with a brain injury

Pastore, Colombo, Liscio, Galbiati, Adduci, Villa & Strazzer (2011) completed a random controlled trial with children with a brain injury between the ages of 4 and 18. The study had a small sample, with 28 participants receiving CBT and 12 not receiving any treatment. Parent reports on the CBCL and VABS Socialisation domain were used as indicators of psychological or behavioural problems. Those that completed CBT was found to score better on the CBCL scales and demonstrated more adaptive behaviour on the VABS.

Smith (2006) presents a case study of a cognitive-behavioural treatment programme for a 17 year old male from Botswana with conduct disorder. He had expressive language difficulties and a history of multiple brain injuries. An adapted CBT treatment programme was used, including guided imagery, education, skills acquisition and application training. The young man responded positively to the treatment programme and his aggressive behaviours reduced, as well as anxiety and depression scores.

Brain tumour survivors

Poggi et al. (2009) completed a random controlled trial with children between the ages of 4 and 18, who have had a brain tumour. The study had a small sample, with 17 participants receiving CBT and 23 receiving no treatment. Parent reports on the CBCL and VABS were used as indicators of psychological or behavioural problems. After treatment those who had received CBT were more likely to have better scores on the withdrawn, somatic complaints, social problems, attention problems, internalising problems and total problem scales. One the VABS, those that received CBT performed better on the social skills domain. CBT was seen to be an effective treatment for children who had experienced a brain tumour.

Clinical experience

- Cognitive Behaviour Therapy hasn’t been used routinely as a pure therapeutic intervention in this setting.
- Tools and approaches from the CBT model have been useful for this population
- This approach has had to be adapted to support the child’s emotional and cognitive difficulties

Feedback from children/young people and families

Some positive feedback regarding this approach has been received from young people.

Clinical recommendation at The Children’s Trust

- Build relationship with child, young person and family
- Assess child/young person using MDT approach
- Consider adapted cognitive behaviour therapy approach when working directly with children/young people
- Use outcome measures before and after intervention
- Involve family and team
- Monitor outcomes
- Collect data to build evidence in future

Functional:
Gross motor skills

- Orthotics
- Aquatic therapy
- Standing frames
- Strength training
- Ataxia
- Functionally mobile children
- Treadmill training

Ankle foot orthosis for use in gait rehabilitation
Evidence Summary
August 2017

Rationale: Ankle foot orthoses (AFOs) are a form of assistive devices used to stabilise the foot and ankle and counteract foot drop, with the aim of enabling and progressing upright mobility (Tyson et al. 2013). Physiotherapists at The Children's Trust regularly recommend AFOs with the aim of allowing children to develop their functional mobility skills, but they are a costly resource.

Clinical question – Should AFOs be provided for children/young people on residential rehabilitation programmes following an ABI or at The Children's Trust school?

Implications

Assessment and decision making

- All children should have an individual assessment of their muscle tone, range of movement, strength, coordination and control on admission. The impact of impacts of their functional abilities should be assessed.
- The possible benefits and implications of ankle-foot orthoses provision should be considered for all children/young people at The Children's Trust who demonstrate the potential to stand, participate in transfers or mobilise but presenting with physical impairments that limit their functional performance (Morris et al. 2011).
- Children should be assessed jointly by a qualified physiotherapist and orthotist in regards to optimising biomechanics, kinematics and kinetics during weight-bearing activities (Owen, 2014).
- Assessment should include lower limb joint ranges of movement, lower limb muscle lengths, muscle tone, co-ordination, proprioception, sensation and joint biomechanics in standing and stepping (Morris et al. 2011)
- Consideration should be given to the child's cognition and willingness or ability to comply with wearing AFOs as part of their therapy programme / rehabilitation (Morris et al. 2011)
- Decisions regarding the type of AFO and tuning of the AFO should be made following the algorhythm attached (Elaine Owen, 2014)
- Evidence suggests that a fixed AFO tends to normalise ankle function more than hinged in children with diplegic spastic CP (Res et al. 2015), therefore for children with increased tone fixed AFOs may be preferential.
- Studies suggest that both off the shelf carbon fibre AFOs and customised fixed/hinged AFOs improve walking speed and quality, but patients report increased confidence and preference for customised splints (Rao et al. 2014; Slijper et al. 2012)
- AFOs need to be cast within the child's available range ankle range of movement with knee extended, and then wedged appropriately (Eddison et al. 2017)
- Assessment of the child's gait in the AFO needs to be assessed to ensure it is promoting the optimum gait pattern possible. Continued reassessment is required as the child progresses and/or grows.

Summary of the evidence

- No studies have investigated the use of AFO's for increasing functional mobility in children with ABI.

Evidence for children with CP

- Solid and hinged AFOs can increase range of movement, reduce energy expenditure, improve gait kinematics, gait speed and functional outcomes in children with CP but studies of poor quality (Figueiredo et al. 2008)
- Walking quality, speed, symmetry and independence was better in AFO's as compared to barefoot walking or walking in shoes without AFOs (Kesikburun et al. 2017, Carse et al. 2015, Gaili et al. 2016)
- Changes in gait pattern cause a reduction in energy expenditure (Makaram et al. 2016)
- Insufficient reporting of type of AFO and AFO prescription in studies for children with CP to allow recommendations to be made (Eddison et al. 2017)

Evidence for adults with ABI

- AFOs improve step length, walking speed, standing balance, functional mobility (scored using the Functional Ambulation Categories) in adults presenting with hemiplegia following a stroke (Tyson et al. 2013)
- There is insufficient evidence to recommend type of AFO, or which patients will benefit the most (Tyson et al. 2013)
- Patients who received AFOs early after stroke did significantly better on the 10m walk test than those who received them later, although all patients displayed improvements (Nikamp et al. 2017)

Evidence for use with individuals with ataxia

- Use of splints to stabilise the ankle joint can reduce the amount of body segments the child needs to control during standing and stepping. This can help children overcome the challenges of multi-segmental control resulting from cerebellar damage (Kelly and Shanley, 2016).

Evidence from clinical practice

- AFOs can promote functional mobility in children who have unilateral, bilateral or ataxic presentations.
- AFOs need to be pitched appropriately and reviewed regularly as the child progresses
- Consideration of the child's functional mobility needs (walking, stairs, sit to stand, on/off floor) needs to be considered in prescription of the AFO.

Child and family view

- Children and their families often like, and tolerate their AFOs well if they are making a difference to their child's level of functioning
- Fitting AFOs into 'acceptable' footwear is often a priority, especially for teenagers, and a compromise regarding the prescription of the AFO may need to be made.

Clinical recommendation at The Children's Trust

- Consider provision of AFOs for children with lower limb impairments and the potential to progress in their functional mobility skills should be assessed for AFOs.
- Prescription of AFOs should be made by an orthotist in conjunction with the child's physiotherapist, based on individual assessment and need.
- AFOs should be reviewed and tuned appropriately to maximise the efficiency and independence of the child's gait.
- AFOs should be reviewed as the child progresses and/or grows.

Aquatic Therapy at The Children’s Trust
Evidence summary
August 2017

Rationale

Aquatic therapy is routinely provided to all children and young people at The Children’s Trust, unless the children have specific contraindications to its use. There are many perceived benefits of aquatic therapy, including improvements in flexibility, respiratory function, strength and gross motor function (Gorter and Currie, 2011). This review aims to establish the evidence base for the provision of aquatic therapy for children/young people with PMLD or ABI.

> *Clinical question* – Is there evidence to support the provision of aquatic therapy for children/young people with PMLD or ABI?

Implications

Assessment

- *All children with PMLD or ABI should have an individual assessment of their physical needs, and specific indications/contraindications for aquatic therapy. This should include assessment of tone, range of movement, muscle strength and control, and balance and gait as appropriate. Appropriate outcome measures for the child’s level of ability should be used (see outcome measure folder).*
- *Goals for aquatic therapy should be established, and may include physical, communication and/or leisure and enjoyment based goals.*
- *Outcomes should be monitored, at least monthly if the child is new to aquatic therapy, or is changing, or at least termly if the child is stable. Provision adapted as required.*

Summary of the evidence

Children with ABI

There is no evidence for the use of aquatic therapy for children with ABI.

Children with PMLD

There are no studies investigating the use of Aquatic Therapy for children with PMLD

Children with CP

- Studies have focussed on children who ambulatory, but these have low internal validity (Gorter and Currie, 2011).
- 30-60 minutes of aquatic therapy, 2-3 times a week for 10-14 weeks that include swimming, walking, running, jumping and strengthening exercises is suggested to improve muscle strength, energy expenditure, gross motor functions and mobility performance at home and in the community (Gorter and Currie, 2011; Franzen and Tryniszewski, 2013).
- Children enjoyed acquatic therapy, and displayed long term benefits with walking endurance and swimming skills (Declerak et al. 2016)
- The evidence is currently not of sufficient quality or consistency to recommend the effectiveness or the type of dosage of exercise required to improve walking speed or gross motor skills (Roostaei et al. 2016).
- Children with spastic cerebral palsy show a reduction in muscle tone during aquatic therapy interventions (Kim et al. 2017)
- Parents report that aquatic therapy improves their child’s ability to move, and complete activities such as walking and changing body position (Gueita-Rodriguez et al. 2017)
- No studies have looked at children classified as GMFCS V (Gorter and Currie, 2011).

Adults with stroke

- There is conflicting evidence as to whether aquatic therapy produces more benefits that land based therapy for ambulatory adults following stroke (Jung et al. 2014; Zhang et al. 2016; Chan et al. 2017).
- Overall, there is fair evidence to suggest that aquatic therapy can improve dynamic balance and gait performance (Marinho- Buzelli et al. 2014)
- There is insufficient evidence to either confirm, or refute that aquatic therapy improve individuals ability to complete activities of daily living after stroke (Merholz et al. 2011).

Physiological effects of aquatic therapy

- Buoyancy opposes gravity and decreases load on muscles and joints, allowing children to access more movement than is possible on land (Severin et al. 2016; Becker 2009).
- Viscosity of water provides resistance to movement and therefore can help with strength and endurance (Severin et al. 2016; Becker 2009)
- Thermodynamics: water has a great capacity for heat, and is able to transfer this, meaning the heat effects can be used therapeutically (Becker 2009).
- Heat is known to reduce muscle tone, and lower spasticity related pain (Smania et al. 2010).
- Warm water emersion increases demands on the respiratory and cardiovascular systems, as well as the genitourinary system leading to increased urine production, and the nervous system, which can reduce pain, but increase feelings of fatigue (Mooventham and Nivethitha, 2014)

Clinical experience at The Children's Trust

- Aquatic therapy can be a fun and motivational activity for children with ABI and those with PMLD.
- Children can demonstrate greater volitional movements in the pool, due to buoyancy and freedom of movement.
- Aquatic therapy can be useful for children who are beginning to stand and weight bear after prolonged periods of immobility, especially if pain and anxiety are factors.
- Children with ABI are often motivated to regain swimming skills
- Children will often work until they are out of breath, suggesting that they will gain cardiorespiratory benefits.
- Children with a unilateral presentation practicing their swimming skills predominately use their unaffected side, and often gain associated reactions into their affected side. The long term detrimental effects of this are not known.
- Accessing aquatic therapy is resource intensive.

Child and family views

- Children and their families often value aquatic therapy as an enjoyable and beneficial activity. They often report that their child is able to do more, and is happier, in the pool as compared to land based interventions.

Clinical recommendation at The Children's Trust

- All children should have individual assessments of their physical needs, and their need for aquatic therapy
- If clear therapy goals are identified they should be offered aquatic therapy.
- If there are not clear therapy goals, but children enjoy the session, they should be offered sessions with assistants, carers or parents.
- Given the lack of evidence, decisions regarding the duration and type of interventions offered should be made based on clinical reasoning, but strengthening, swimming and gait based exercises should be considered for ambulatory children.
- Outcomes of aquatic therapy should be monitored and interventions adapted as required.

Use of standing frames at The Children's Trust
Evidence Summary
February 2017

Rationale

Supported standing programmes are used in an effort to reduce and prevent complications associated with being non-ambulatory as well as optimise various aspects of function. In spite of widespread clinical use, there is a lack of evidence-based recommendations for their use and dosage.

Clinical question – Does the evidence support the use of standing frames in clinical practice with children who present with profound and multiple learning disabilities?

Implications

Assessment

- All children should be assessed using the Oxford assessment and Chailey levels of ability, and classified using GMFCS level equivalent. The child should also be part of the local hip surveillance programme (CPIPS).
- The goals of use of standing frames should be clearly documented and reasoned. This may include maintaining range of movement (Marcias-Merlo et al. 2015; Paleg et al. 2014), minimise the level of hip displacement (Marcias-Merlo et al. 2016), maintaining bone density (Caulton et al. 2004; Paleg et al. 2014), promoting bowel elimination (Rivi et al. 2014), increasing awareness and improving social interaction (Paleg et al. 2014).
- The type of standing frame should be determined based on the child's mobility status (GMFCS level) and postural needs (as assessed by Chailey levels of ability and Oxford assessment).
- Regular reassessment of the child's posture in the standing frame is required.

Interventions

- A supported standing programme should be offered that targets the child's individual needs and requirements (Taylor et al. 2009).
- Where possible, standing in abduction should be used with the aim of minimising the level of hip displacement they will obtain, and improving hip range of motion (Marcias-Merlo et al. 2016)
- Exact dosage requirements are unknown, but there are studies that indicate longer standing times (up to an hour, 5 times a week) improved bone density (Caulton et al. 2004). 30 -45 minutes 5 times a week are the most common times and durations used in clinical practice (Taylor et al. 2009)
- Standing with whole body vibration may improve outcomes over standing alone (Kilebrant et al. 2015)
- Standing should be incorporated into the child's daily routine (Taylor et al. 2009)
- Standing may be discontinued if the child has a progression in their contractures, meaning they cannot stand in alignment, they have orthostatic hypotension, skin breakdown, lower extremity dependent oedema, pain, poor tolerance or they develop the ability to mobilise independently (Taylor et al. 2009). There is no evidence that dislocation of one or both hips should lead to termination of standing (Paleg et al. 2014). If children have to stand at

greater than 20° tilt off an upright position then it should be questioned the level of benefit they will receive from accessing a standing frame (Taylor et al. 2009).

Summary of the evidence

See evidence table.

Clinical recommendation at The Children's Trust

- Do not routinely offer intervention using a standing frame
- There is a limited evidence base that has investigated the use of standing frames for children with profound and multiple disabilities, meaning that therapists must use their clinical reasoning to guide the use of a standing programme.
- A supported standing programme could be offered to children who are unable to mobilise, with the goals of maintaining range of movement, hip integrity, bone mineral density and social interaction.
- Dosage could be 30-60 minutes, 5 times a week, with the aim of being closer to 60 minutes if the goal is to improve bone mineral density.
- Standing programmes should be regularly reviewed, and discontinued if the child is no longer able to stand comfortably and in a good alignment.

Strength training at The Children's Trust
Evidence summary
January 2017

Rationale

It is known that muscles of children with cerebral palsy (CP) are weak (Pak and Kim 2014) and clinically, this is seen to be the case for children with Acquired Brain Injuries (ABI). Muscle weakness has been shown to be a major factor limiting motor performance in other neurological populations (Pak and Patten 2008). Interventions targeting strengthening the muscles of children with ABI may therefore improve their physical abilities, and thus their ability to participate in their daily lives.

Clinical questions –

Should strengthening interventions be offered as part of the rehabilitation programme for children with ABI at The Children's Trust? Which interventions are most appropriate?

Assessment

All children should have a full individually tailored assessment of their physical abilities. This should include the gross motor function measure (GMFM) plus an additional measure relevant to their level of their physical functioning. This could include the 10m walk test, or movement ABC.

Intervention

A variety of interventions are aimed at strengthening muscles. Although many therapeutic interventions include an element of strengthening, this review considers those that are specifically aimed at increasing muscle strength. These are progressive resisted strength training and electrical stimulation (ES). Functional electrical stimulation (FES) will not be considered as this aims to improve functional movement patterns as opposed to pure strengthening.

Summary of the evidence

Children with ABI

- None Available

Children with CP

- There are discrepancies in findings of systematic reviews with some finding positive effects for strengthening (Pak and Kim 2014; Vershunen et al. 2011) and some finding no significant effects (Scillino et al. 2009)
- The best quality review was the systematic review and meta-analysis by Park and Kim (2014) which only included high quality RCT's.
- Electrical stimulation, progressive resisted strength training and aerobic exercise with strengthening (such as cycling), all displayed significant benefits for performance on the GMFM, individual muscle testing, sit to stand and stair climbing (Pak and Kim 2014).
- Electrical Stimulation had appeared to have the largest treatment effects, although direct comparison is challenging due to the differences in the studies (Pak and Kim 2014).
- Progressive strength training had a greater effect on specific muscle strength and activities that cardiovascular strengthening exercises such as cycling (Pak and Kim 2014)
- Strengthening did not improve walking speed (Pak and Kim 2014).
- Younger children responded had larger treatment effects than adolescents (Pak and Kim 2014).
- Strengthening interventions did not increase spasticity (Pak and Kim 2014).

- Not sufficient evidence for any recommendations for upper limb strengthening interventions (Pak and Kim 2014)

Adults who have had strokes

- Strengthening interventions had a statistically significant effect on gait speed (Pak and Patten 2008) and specific muscle strength, with resistance training having the greatest effect (Pak and Patten 2008)
- Strengthening interventions produced significant improvements on self-perceived measures of limitations and quality of life (Pak and Patten 2008)
- Strengthening interventions did not produce an increase in spasticity (Pak and Patten 2008)
- Adults with severe impairments did not benefit from strengthening interventions (Moreland et al. 2003).
- Specific resisted strength training demonstrated greater benefits with moderate upper limb impairments rather than mild impairments (Harris and Eng 2010), although all levels of impairments had some benefits.
- Significant effects in sub-acute and chronic stages post stroke (although possibility of type 2 error in chronic group as there are only five trials) (Harris and Eng 2010)
- No evidence to suggest strengthening has a direct impact on independence in ADL (Harris and Eng 2010).
- Strength training increases restoration of motor function whereas task training increased compensation, with strength training followed by functional training producing the greatest overall benefits (Corti et al. 2012)

Typically developing children

- Pre- adolescent children display benefits in motor unit recruitment and firing rate and coordination of muscle activity, with less changes in the muscles themselves
- Adolescents respond in a similar way to adults with changes in muscle bulk seen.

Recommendations for strengthening protocols

- Insufficient specific evidence to make firm recommendations (Vershunen et al. 2011), with no studies directly comparing different strengthening protocol (Pak and Patten 2014).
- Studies indicate that 6-8 weeks, 3 times a week, for 30-40 minutes, with sufficient resistance to allow completion of 8 exercises before fatiguing, and completing 3 sets of each exercise (Vershunen et al. 2011; Pak and Patten 2008).
- Use electrical stimulation as an adjunct if children are unable to move against gravity (Pak and Kim 2014).

Summary

Although there is no evidence for use of strengthening interventions with children with ABI, there is sufficient information from past studies to guide the parameters for strengthening interventions, however optimum interventions are not yet known.

Clinical recommendation at The Children's Trust

Assess child/young person's strength and physical activities on admission using standardized measures where possible

Explore child and family preference of rehabilitation interventions

Consider a lower limb/ upper limb progressive strength training programme to improve physical activity in children with moderate or mild impairments. This should include resistance (weights/gravity) so that children can complete 8 repetitions of the movement, and complete 3 sets, 3 times a week for 6 to 8 weeks

Consider electrical stimulation for children who do not have sufficient strength to move against gravity.

Management of ataxia at The Children's Trust
Evidence Summary
August 2017

Rationale

Children who sustain damage to their cerebellum as a result of their ABI will present with ataxia. They will present with difficulties with coordination and grading of movements, motor planning and balance which will impact on all aspects of their mobility. Regaining functional mobility skills will be more difficult for this group of children, due to the cerebellum's role in motor learning. These children therefore require a specific approach to their physiotherapy management in order to maximise their potential for regaining functional mobility.

Clinical question – How should the physical difficulties of children/young people presenting with ataxia following an ABI be managed?

Implications

Assessment

- All children should have a detailed assessment of their physical needs, tailored to their individual level ability. This should include the GMFM, and a functional mobility score (such as the functional mobility scale, or GMFCS).
- The child and families goals and priorities should be established

Treatment

- Use a declarative learning approach- teach the child what to do using handling/environment/ verbal prompting, rather than learning through trial and error (Saywell and Taylor 2008)
- Reduce degrees of freedom to enable development of function (Zachowski, Thach and Bastian, 2002) e.g. use perch sitting/standing frame to develop head control and trunk control, use AFO to control ankle to develop standing balance, use a supportive chair to develop upper limb function (Kelly and Shanley 2016).
- Use high numbers of repetitions, in different situations (Saywell and Taylor 2008)
- Include interventions in the child's own environment: 24 hour approach needed (Sartor-Glittenberg and Brickner 2014)
- Use targeted balance work appropriate to the child's level of ability-e.g. sitting, standing, single leg balance (Keller and Bastian 2014) (Armutlu, Karabudak et al. 2001)
- Offer strengthening interventions focusing on developing mid range control and functional extensor trunk and hip strength (Sartor-Glittenberg and Brickner 2014)
- Teach and develop the components necessary for gait, eg upright standing, stepping, using environmental clues to help if required (Im, Kim et al. 2017)
- Practice mobility skills in a variety of environments (Sartor-Glittenberg and Brickner 2014)
- Offer opportunities to develop motor planning skills eg obstacle courses
- Development of global extensor strength (eg with prone extension) (Vaz, Schettino et al. 2008, Freund and Stetts 2010)
- Offer treadmill training if child is able to step with hand hold (Freund and Stetts 2010)
- Challenge children to move in different ways that include rotation eg stand through half kneeling, reaching involving rotation (Keller and Bastian 2014)
- When appropriate, practice mobility skills in the community as this is likely to be particularly challenging for this group of children (Sartor-Glittenberg and Brickner 2014)
- Use mobility aids that do not increase the coordination demands (i.e. wheeled rollators) to establish functional mobility (Marsden and Harris 2011)

- Consider the use of lycra for individual children (Almeida, Fonseca et al. 2017)
- Use pre-injury learning as much as possible (e.g. if the child liked gymnastics incorporate skills if possible into therapy) (Marsden and Harris 2011)
- Gradual progression of skills can occur over long periods of time (Sartor-Glittenberg and Brickner 2014)- ensure parents/carers are able to offer the child opportunities for progression, and there is community physiotherapy in place.

Summary of the evidence

- **No evidence for the physiotherapy management for children with ataxia following ABI**
- Systematic review of evidence for adults with ataxia found that physiotherapy interventions did improve mobility skills, but unable to conclude the best intervention due to a variety of causes of ataxia (MS, degenerative ataxia's etc), poor descriptions of techniques used, and wide variety of interventions offered (Martin and Bragge, 2009)
- Multi-dimensional programmes including strengthening, balance, gait re-education (with and without devices) in the clinic, home and community improved functional and participation outcomes in 3 adults presenting with ataxia following TBI (Sartor-Glittenberg and Brickner 2014)
- Balance programmes set at the level of challenge appropriate for the individual can improve mobility in adults with degenerative ataxia (Keller and Bastian 2014)
- Task orientated gait training can improve walking abilities of adults with degenerative cerebellar lesions (Im, Kim et al. 2017)
- Treadmill training has been shown to be effective in improving balance and functional mobility in 2 single case experimental design studies with adults with ataxia following ABI (Vaz, Schettino et al. 2008)
- Inconclusive evidence of whether dynamic lycra suits has an effect on functional outcomes in children with CP (Almeida, Fonseca et al. 2017)
- Children presenting with damage to the cerebellum are likely to make slow, and incomplete progress with their motor skills (Deluca, Moretto et al. 2011)

Evidence from clinical practice

Individualised assessment and treatment following the strategies described above can improve the functional mobility skills of children with ABI.

Child/young people and family views

No consistent views have been expressed

Clinical recommendation at The Children's Trust

- Complete an individualized assessment and deliver a tailored programme from the above components
- Ensure programmes offer sufficient repetitions in different environments, at sufficient frequencies to allow the children to learn throughout a 24 hour period
- Consider use of orthotics and equipment to allow children to develop functional mobility
- Consider the need for ongoing rehabilitation on discharge from The Children's Trust.

Physiotherapy for functionally mobile children at The Children's Trust
Evidence Summary
March 2017

Rationale

Children who are functionally mobile following ABI can present with physical impairments which limit their ability to keep with peers in school and in the community, and participate in sporting activities (Gavin et al. 2010). With the recognition that physical activity is important for physical, emotional and psychosocial development of children (Verschuren et al. 2016), it would appear necessary to improve the physical activity of children following ABI.

Clinical question –
Which interventions should be offered to target the physical difficulties of children at TCT who are functionally mobile following their ABI?

Implications

Assessment

- All children who are functionally mobile should be individually assessed by a qualified physiotherapist with consideration of their strength, balance, coordination, walking ability, walking speed and fitness.
- Wherever possible the Movement ABC 2 (Henderson, Sugden and Barnett, 2007) should be used as a standardised measure of physical abilities. This has not be validated in children with ABI, but is widely used as a reliable and valid measure of motor abilities for children with other neurological conditions, with normative data for typically developing children (Schulz et al. 2011). It is acknowledged that children with significant behavioural and/or executive functioning difficulties may not be able to attend to and complete this measure.
- Comfortable walking speed should be measured using the 10m walk test (10mWT) (Rehab Measures, 2014). This has shown excellent reliability and validity in adults with neurological conditions (Tyson and Connell 2009) and acceptable reliability for children with CP (Thompson et al. 2008). Walking speed has been shown to be directly related to functional mobility and quality of life in adults with stroke (Scmid et al. 2007).
- Cardiovascular fitness should be assessed using the 6 minute walk test. This has been shown to be an accurate measure of cardiovascular capacity for children with CP (Jung et al. 2015).

Interventions

- Individually tailored, targeted interventions for cardiovascular fitness, balance, coordination and strength (Veerbeck et al. 2010; NICE 2013)
- See The Children's Trust strength training EBG for specific guidelines
- Functional exercises using major muscle groups (eg sit to stand, walking, running, cycling, step ups, dancing and swimming) (Basques et al. 2016; Maltans et al. 2015, Verschuren et al. 2016)
- Virtual reality eg Wii for balance, coordination and cardiovascular training (Basques et al. 2016)
- Targetted gait speed during gait practice overground or on treadmill (Moreau et al. 2016)
- Return to community based physical/sporting activities wherever possible (NICE 2013, Maltans et al. 2015), with education as to its importance (Maltans et al. 2015)

- 20-30 minutes of moderate intensity exercise 2-3 times a week (Maltals et al. 2015). Level and intensity of exercise may need to be developed over time (Verschuren et al. 2016)

Evidence base
Children with ABI

- Systematic review by Basques et al. (2016) found some **limited** evidence for functional training programmes, and **low quality evidence** for use of virtual reality (eg Wii) for balance and activity training.

Adults post stroke

- Systematic review by Veerbeck et al. (2010) and NICE guidelines (2013) show strong evidence for adults post stroke that targeted interventions can improve balance, strength, walking speed, cardiovascular fitness and quality of life (Veerbeck et al. 2010; NICE 2013)

Children with CP

- Systematic reviews by Maltals et al. (2015) and Verschuren et al. (2016) show aerobic exercise training using functional activities such as walking or running, with or without a combination of strength training significantly improve cardiovascular fitness.
- Support needed to access and continue with physical activities in the community
- Systematic review by Moreau et al. (2016) states that interventions that specifically train improving walking speed are required to improve walking speed.

Impression from clinical practice

- Gaining engagement in sufficient activity to offer benefits can be challenging, especially if the child has severe behavioural or executive functioning difficulties.
- Use of games/favourite sports/bikes or trikes/gym programmes with tick sheets, and a wide variety of activities in different locations (gym, outside, softplay, pool) have increased engagement.

Clinical recommendation at The Children's Trust

- Assess children who are functionally mobile following a severe ABI, for high level physical impairments and cardiovascular fitness using standardised measures where possible.
- Consider the use of the Wii for balance and coordination
- Consider targeted interventions addressing impairments including gross motor activities (e.g. walking, running, jumping, swimming)
- Consider overground walking or treadmill training to improve walking speed
- Consider working towards a moderate intensity of exercise for 20-30 minutes 3 times a week
- Measure and record outcomes to further knowledge in this area.

Treadmill training at The Children's Trust

Evidence Summary
March 2017

Rationale

Use of the standard treadmill, both with and without partial body weight support is a common intervention used by physiotherapists to improve the walking skills of patients with neurological conditions. It is a common clinical intervention offered as part of the physiotherapy management for children with ABI who are receiving rehabilitation at The Children's Trust.

Clinical question –
When, how and why should the treadmill be used in clinical practice at The Children's Trust?

Implications

Assessment

- All children should be individually assessed for suitability for treadmill training by a qualified physiotherapist. This should include medical status, tone and range of movement, pain, strength, balance and functional mobility, as well as understanding of any cognitive, communication or behavioural difficulties.
- The goals of use of treadmill should be clearly articulated and may include improving walking quality, walking speed, walking distance and cardiovascular fitness.
- All children who are being considered for the treadmill should be assessed using the Gross Motor Function Measure, as a standardised measure of physical abilities (Russell et al. 1989).
- All children should also be assessed using the Gross motor classification system, and functional mobility assessment and the Gillette functional assessment questionnaire as classifications of their functional mobility status.
- All children who are able to walk more than 10m should be assessed using the 10m walk test at comfortable walking speed (Rehab Measures, 2014). This has shown excellent reliability and validity in adults with neurological conditions (Tyson and Connell 2009) and acceptable reliability for children with CP (Thompson et al. 2008). Walking speed has been shown to be directly related to functional mobility and quality of life in adults with stroke (Scmid et al. 2007).
- If quality of walking is being targeted and the child is able to walk 10m then the Edinburgh visual gait scale should be completed. This has been shown to be the easiest to use, and most reliable of all visual gait scales (Rathinam et al. 2014).
- If cardiovascular fitness is being targeted, and the child is able, the 6 minute walk test should be used. This has been shown to be an accurate measure of cardiovascular capacity for children with CP (Jung et al. 2015).

Interventions

- Use treadmill to increase walking speed, endurance and functional mobility, and improve gait parameters but not to develop independence in gait (Merholz et al. 2014; Zwicker and Mayson, 2010)
- Build up to at least 30 minutes, at least three times a week, for a minimum of two weeks (Merholz et al. 2014; Zwicker and Mayson, 2010)
- Assess for partial body weight support on a needs basis (Merholz et al. 2014; Zwicker and Mayson, 2010)
- Challenge the children to walk as fast as possible, within safety limits (Lau et al. 2011)
- Monitor outcomes regularly.

Summary of the evidence

Children with ABI

- Partial body weight support treadmill training improved walking independence and ability (single case study) (Seif-Naraghi and Hernan, 1999)

Children with cerebral palsy

- Zwicker and Mayson (2010) reviewed all evidence: treadmill training and partial body weight support treadmill training improved temporal-spatial characteristics of gait and GMFM scores. Inconsistencies between individual studies mean parameters of optimum treatment are not known.
- Treadmill training improved walking endurance, speed, PEDI, and GMFM more than over-ground training (GMFCS levels I-III) (Grecco et al. 2013), and other physiotherapy interventions including strength and resistance training (Moreau et al. 2016)
- There is insufficient evidence to conclude whether treadmill training in young children (up to 6 years) can accelerate their development of mobility skills (Valentin-Gudiol et al. 2011)

Adults with stroke

- Treadmill training can improve walking speed and endurance more than other physiotherapy interventions (Merholz et al. 2014; a Cochrane Review)
- Treadmill training does not improve independence in walking. Patients who have no independent mobility (with or without an aid) are unlikely to benefit from treadmill training (Merholz et al. 2014).
- Walking speed and endurance improved with treadmill training in acute and chronic patients (Merholz et al. 2014).
- Treadmill training at least 3 times a week for at least two weeks is required to get increased in speed and endurance. Longer durations of training produce better results (Merholz et al. 2014).
- No evidence to suggest whether there is differences with the use of partial body weight support, or treadmill training alone.
- Higher intensity training (80% of Heart Rate Reserve) for 30 minutes (building up to this intensity and duration) produced greater gains in aerobic capacity than lower intensity training (50% of Heart Rate Reserve) for 50 minutes (building up to this intensity), twice a week for 6 months. However there were no significant differences in walking endurance and speed, or number of steps in 48 hour period (Ivey et al. 2016).
- Walking at maximum walking speed for 30 minutes increases walking speed, stride length and balance significantly more than walking at fastest over-ground walking speed (Lau et al. 2011)

Evidence from clinical practice

- The treadmill can be used with children of a variety of ages and physical presentations, but achieving sufficient durations and intensity can be challenging due to fatigue, motivation and cognitive function deficits.

Clinical recommendation at The Children's Trust

- Lack of supportive available evidence children with no independent gait following ABI (with or without aid). Assess, document clinical reasoning, monitor closely and measure outcome.
- Consider treadmill training as part of their physiotherapy programme for children with some independent gait, if goals are to improve gait parameters, walking speed or endurance
- Build up to use for 30 minutes, at least 3 times a week, for at least two weeks, at the child's maximum walking speed.
- Assess the need for partial body weight support on an individual basis.
- Document outcomes to further develop knowledge in this area.

Functional: Upper limb rehabilitation

- Upper limb bimanual therapy
- Constraint-induced Movement Therapy
- Upper limb NMES as a therapy adjunct
- Handwriting intervention
- Upper limb dynamic splinting

Upper limb bimanual therapy at The Children's Trust

Evidence based summary-November 2017

Rationale

Bimanual upper limb training encourages the use of the affected hand within bimanual tasks (Charles and Gordon, 2006). There is a well-established evidence base for the use of intensive bimanual therapy for children with cerebral palsy (Tervahauta, Girolami et al. 2017), yet in adults who have had strokes the evidence suggests it is inferior to unilateral upper limb training (Hatem, Saussez et al. 2016).

Clinical question –

Should bimanual upper limb training be offered to children with acquired brain injuries (ABI) during residential rehabilitation?

Assessment

- All children should have an upper limb assessment based on the CPUPS assessment
- Either the Melbourne Assessment of Unilateral Upper Limb Activity or the Assisted Hand Assessment should be used as part of the assessment
- Children should also be classified according to their MACS level as a functional classification.
- Child and families goals and priorities relating the upper limb also need to be established

Intervention

- Activities should be functional and goal directed
- Activities need to be adapted to be achievable for the child
- Activities should be motivational for the child
- It is likely that high doses are needed to ensure children gain maximum benefit

Summary of the evidence

Children with ABI

- Children who were at least two years after ABI were included in a study by (Deppe, Thuemmler et al. 2013), alongside children with CP, to investigate modified constraint induced therapy (mCIMT) as compared to bimanual training. They found that both interventions produced similar changes in spontaneous upper limb use, but that mCIMT improved unilateral upper limb function more.

Children with CP

- Bimanual training is better than no treatment or very basic treatment, at improving hand and arm function (Novak, Mcintyre et al. 2013, Sakzewski, Ziviani et al. 2013).
- The evidence is insufficient to determine whether bimanual or mCIMT is more effective at improving unimanual or bimanual hand and arm function, participation in daily activities and achievement of individualised goals (Sakzewski, Ziviani et al. 2013, Tervahauta, Girolami et al. 2017)

- Bimanual training causes less frustration than mCIMT in children (Cohen-Holzer, Katz-Leurer et al. 2017)
- Bimanual training has typically be offered in intensive packages (6 hours a day for 10 days). A lower dose (30 hours) has resulted in clinically meaningful results, but these are not as great as those offered at a higher does (Sakzewski, Provan et al. 2015)

Adults who have had strokes

- Within the adult stroke literature bimanual training has involved non- functional upper limb movements, where the affected limb is either moved simultaneously to, or opposite to the unaffected limb. Evidence suggests that this does not improve upper limb impairments or disabilities (Hatem, Saussez et al. 2016)
- There is evidence that task specific training can improve upper limb function in adults post stroke (Foley et al. 2016).
- Higher doses of task specific upper limb training do not necessarily lead to better outcomes (Lang, Strube et al. 2016, Winstein, Wolf et al. 2016). This has looked at the number of repetitions of movements offered within an hour of therapy time 4 days a week, over 8 weeks and an extra 30 hours of therapy over 10 weeks (Winstein, Wolf et al. 2016)

Guidance derived from clinical experience at TCT

Bimanual training can be incorporated into the child's rehabilitation programme, but achieving sufficient dosage can be challenging giving the demands on the child. Incorparating bimanual training into their day to day lives can help increase dosage provided outside of therapy sessions.

Child and family experiences

Children and families experience of bimanual training tends to vary depending on their level of upper limb impairment, cognitive abilities and their motivation for improving their arm. For those that have some functional activity, and the ability and attention to participate in bimanual arm activities it has been successful and productive.

Clinical recommendation at The Children's Trust

Assess child/young person's upper limb function on admission using standardized measures where possible

Explore child and family preference of rehabilitation interventions

Consider use of bimanual, functional, goal directed training as part of the child's rehabilitation programme

Explore methods of increasing dosage of intervention through use in daily activities, and motivating activities to do on house. Ensure the child, family and nursing staff understand the child's level of ability and how to adapt tasks to be challenging yet successful.

Monitor outcomes and collect data to further develop knowledge in this field.

Constraint induced movement therapy at The Children's Trust

Evidence based summary-November 2017

Rationale

Constraint Induced movement therapy (CIMT) aims to increase upper limb function in children who have unilateral upper limb impairments. It involves restraining the unaffected upper limb to force the use of the affected limb during intensive task practice {Cimolin, 2012}. It is commonly used in rehabilitation for adults who have had strokes, and children with cerebral palsy. CIMT consists of casts worn on the affected limb, with 6 hours of therapy a day. Modified CIMT (mCIMT) involves protocols where the method of constraint and/or dose of intervention are changed.

Clinical question –

Should modified constraint induced movement therapy be offered to children with reduced upper limb functioning following acquired brain injuries (ABI) during residential rehabilitation?

Assessment

- All children should have an upper limb assessment based on the CPUPS (Scandinavian version of Cerebral Palsy Integrated Pathway) assessment
- Either the Melbourne Assessment of Unilateral Upper Limb Activity (MA2) or the Assisted Hand Assessment (AHA) should be used as part of the assessment depending on their age
- Children should also be classified according to their Manual Ability Classification System (MACS) level as a functional classification.
- Child and families goals and priorities relating the upper limb also need to be established
- Children need to have sufficient movement in their upper limb, and cognitive abilities, to engage in half an hour of unilateral upper limb activity.

Intervention

- Restrain the unaffected upper limb using a mitt.
- Engage the child in upper limb activities that are motivating, challenging, but achievable. These can include use of technology (iPAD, Timocco, Nintendo Wii), arts and crafts and/or games and tasks such as Connect 4, building blocks, Jenga,
- Aim for as a high a dose as possible (number of hours wearing the mitt), through completing sessions with qualified therapy staff, therapy assistants and nursing and care staff.
- Ensure that the child engages in bimanual training activities either alongside, or after, the mCIMT.

Summary of the evidence

Children with ABI

- Statistically significant changes in upper limb impairment, function and participation were shown in a group of 20 children who underwent a 2 week programme of mCIMT with 4 hours of therapy a day. All children had functional movement at shoulder and elbow, and sufficient cognitive and behavioural ability to engage in programme. On an individual basis 65% of children improved in AHA, and 80% in at least one Canadian Occupational Performance Measure (COPM) goal {Komar, 2016}

- Statistically significant changes in upper limb impairment, function and on goals were seen in children with ABI who underwent a 23 day programme of CIMT of either 6 hours a day or 3 hours a day of therapy (dependent on age and ability to participate). Children had all been discharged home, although it is unclear how far post injury they were {Reidy, 2012}
- Children with brain tumours and resultant hemiplegia also showed improvements in function with a 3 week mCIMT programme {Sparrow, 2017}
- Other case studies and pilot studies that have investigated mCIMT protocols involving between 2 and 4 hours of therapy a day have also shown benefits (Dickerson and Brown, 2007; Karmen et al. 2003; Gordon et al. 2007).

Children with CP

- A systematic review showed mCIMT improves upper limb function in children with hemiplegia who have CP {Chen, 2014}.
- Benefits include increased use of affected limb in bimanual activities (Sakzewski et al., 2013), and improvement in children's goals and measures of occupational performance (Charles et al. 2006; Eliasson et al. 2013; Reidy et al. 2010)
- Children with severe upper limb impairments, and less than the recommended 20^o of active wrist extension (Brady and Garcia, 2009) can show benefits (Eliasson et al. 2013)
- Systematic reviews indicate that mCIMT improves upper limb impairment and function more than no treatment, but is no more effective than treatment without constraint {Chiu, 2016}{Tervahauta, 2017}

Guidance derived from clinical experience at TCT

Clinician's note that mCIMT can be well tolerated, especially if the child is able to understand the reasoning behind its use. Activities need to be carefully chosen and monitored by the treating therapist to ensure they are set at the right level for the child. Younger children, and/or those with cognitive difficulties require close supervision and may require physical prompts to ensure they use their affected upper limb.

Child and family experiences

Children and families have found the intervention beneficial, and have enjoyed the structured activities that were set for them. They have reported that it is tiring, especially when done at lunchtimes or in the evenings.

Clinical recommendation at The Children's Trust

Assess child/young person's upper limb function on admission using standardized measures where possible

Explore child and family preference of rehabilitation interventions

Consider use of mCIMT for children who have some a unilateral impairment, but have functional use of their affected upper limb, and the ability to engage in half an hour of activities.

Explore methods of increasing dosage of intervention through providing mCIMT within therapy sessions, and programmes set for it to be done outside of sessions.

Monitor outcomes and collect data to further develop knowledge in this field.

Upper limb NMES as a therapeutic adjunct at The Children's Trust

Evidence based summary

July 2016

Rationale

Neuromuscular electrical stimulation (NMES) is an established treatment technique in neurological rehabilitation. Functional electrical stimulation (FES) is a form of NMES that stimulates muscles in functional patterns. It can be used to increase strength and range of movement, and aid motor relearning. There is strong evidence supporting its use in adults who have sustained strokes, and an emerging evidence base for its use in children with Cerebral Palsy. Early pilot studies indicate that it is of benefit to children with ABI.

Clinical question –

Should NMES be offered as part of the upper limb rehabilitation programme at The Children's Trust?

Assessment

- All children should have an upper limb assessment based on the CPUPS assessment
- Either the Melbourne Assessment of Unilateral Upper Limb Activity or the Assisted Hand Assessment should be used as part of the assessment
- Children should also be classified according to their MACS level as a functional classification.
- Child and families goals and priorities relating the upper limb also need to be established

Intervention

- Programmes for NMES should be individually set based up on the child's needs, goals and target for intervention.
- There are no clear recommendations regarding the best parameters to be used (deKroon et al. 2006), therefore parameters need to be selected based on manufacturers recommendations and an understanding of the principles of NMES.
- A study has suggested that there is no difference between cyclic or patient triggered stimulation (de Kroon and Ijzerman 2008). Hypothetically, the cognitive engagement of patient triggering will assist with motor learning (Hubbard et al, 2013), however, this effort may also increase tone and impact upon function (Knutson and Chae 2015). Therefore, this should be assessed on a case by case basis.
- Engagement in task training during the stimulation can help improve activity and function (Howlett et al. 2015).
- Half an hour a day, 5 days a week, or more has been shown to make changes (Hsu et al. 2010).

Summary of the evidence

Children with ABI

- *Pilot study using FES in children at least a year post stroke showed that it improved upper limb activity and function (Kapadia et al, 2012)*
- *Single case experimental design in a child in the subacute stages post stroke demonstrated that FES improved upper limb activity (Kelly, 2016)*

Children with CP

- *Randomised controlled trial (RCT) showed that NMES plus constraint induced movement therapy was significantly better at improving upper limb functional outcomes than CIMT alone (Xu et al, 2015)*
- *Literature reviews consisting of case controlled trials and single case studies concluded that FES is of benefit to improve upper limb function in children with CP (Bosques et al, 2016; Wright et al, 2012)*

Theoretical evidence

- *Triggering of the NMES by the patient will improve outcomes over cyclic triggering, due to the need for cognitive engagement, which is important in motor learning (Hubbard et al, 2013).*
- *Using task training alongside the stimulation will produce the greatest benefits, due to the need for repetitive task practice to induce neuroplasticity (Teasell and Hussain, 2013)*
- *Children who have no volitional upper limb movement are unlikely to change with the intervention (Foley et al, 2013).*

Guidance derived from clinical experience at TCT

Use of NMES has been beneficial for children with upper limb deficits following an ABI. Children who present between a MACS level of III and V, but with some intentional upper limb activity, have shown positive improvements with daily NMES over a 4 week period. Children who have no volitional upper limb control have not benefitted from the intervention.

Child and family experiences

Some children have been unable to tolerate the intervention due to the sensation of the stimulation. Other children and their families have been very motivated by the intervention.

Summary

There is little research evidence supporting the use of NMES in the paediatric ABI evidence. However, clinical experience, theoretical evidence and research evidence from patient groups with similar physical presentations do support its use.

Clinical recommendation at The Children's Trust

Assess child/young person's upper limb function on admission using standardized measures where possible

Explore child and family preference of rehabilitation interventions

Consider 30 minutes of individually tailored NMES, in combination with repetitive task training daily for four weeks for children who present between a MACS III and V.

Document outcomes and collect data to help build the evidence in this field

Monitor outcomes closely if the intervention is offered to children with no volitional upper limb movement.

Handwriting at The Children's Trust

Evidence Summary

October 2013

Rationale:

- Independent functioning at school requires an effective method of producing written output
- 30% to 60% of a child's school day is comprised of fine motor activities, with handwriting tasks accounting for most of this
- Children with handwriting difficulties require more time to complete tasks
- Composition of writing is affected by handwriting difficulties
- Handwriting remediation is one of the most common reasons for referral of school-age children to occupational therapy

What are the most effective interventions to improve handwriting?

Refer to CanChild Handwriting Assessment Protocol 2nd ed

Assessment:

1. **Gaining preliminary information:**
   a) reason for referral
   b) Identify handwriting expectations for the child
   - consider National Curriculum targets
2. **Classroom observations:**
   a) workstation – desk and chair, environment
   b) postural control – head/trunk alignment, position of feet, forearms
   c) behavioural observations – attention, activity level, motivation, fatigue
   d) Workbook review: typical written work at school
3. **Testing:**
   a) assessment tasks – pencil grip, pencil pressure, paper positioning, cursive writing
4. **Analysis:**
   a) handwriting speed
   b) legibility
   c) content
5. **Identify treatment plan**

- building motivation for handwriting into the treatment plan is paramount
- encouragement of a move towards integrated motivation is important i.e. a point at which the child values what the activity can do for him/her

Interventions:

1. **Consultation with teachers**
   a) effective when OT is integrated into school rather than an outside agency
   b) working in conjunction with educators to examine the effectiveness of more handwriting practice for all students as a preventative measure to handwriting problems
2. **Individual intervention**

        a) handwriting practice – interventions to allow for a minimum of two sessions per week for a minimum of 20 sessions in order for results to be evident
        b) These sessions could include homework or group sessions
        c) handwriting practice sessions with younger children may incorporate sensory components
        d) handwriting sessions for older children may incorporate cognitive components
        e) although a thorough assessment of components should be done, practice of handwriting may be more critical than specific identification of underlying issues
        f) Environmental adaptation
    - Correct set-up of workstation and posture
      90-90-90 posture most ideal for seated work
      Feet firmly on floor
      Shoulders and wrists stabilised
    - Position within classroom
3. **Group work for handwriting**
    a) 'handwriting club' interventions can help with motivation
    b) group work supports the child's sense of relatedness through development of good relationships with teacher and other students
    c) effectiveness of group relies on using practice strategies while supporting development of relationships through the shared activity and allowing the child choice as to written topics and writing personas

Performance measures

1. Baseline and post intervention evaluation is important to monitor improvement
2. Possible outcome measures
    a) Detailed Assessment of Speed of Handwriting (DASH) (Barnett, Henderson, Scheib & Schulz 2007)
    b) School Function Assessment
    c) Goal Attainment Scaling – light (Turner-Stokes, 2009)
    d) Canadian Occupational Performance Measure (Law et al, 2005)

Summary of the evidence

1. *A Systematic Review of Interventions to Improve Handwriting* (Hoy et al, 2011) looks at 11 different randomised and non-randomised control trials to review treatment interventions that look to improve handwriting speed and legibility. Handwriting interventions that include handwriting practice at a minimum twice per week for a total of at least 20 sessions are effective for proving handwriting outcomes. Handwriting interventions that do not improve handwriting practice have been shown to be ineffective.
2. *CanChild Handwriting Assessment Protocol – 2nd Edition* (Pollock et al, 2009) is a clinical decision making tool designed to give clinicians some direction in the identification of area of difficulties and whether to and where to intervene. The protocol is designed to look at the occupation of handwriting and outlines components for assessment and considerations impacting on the occupation of handwriting.

Clinical recommendation at The Children's Trust

- In the absence of literature specifically relating to children and youth with ABI it is recommended that we are guided by the evidence described above.

Upper limb dynamic splinting at The Children's Trust

October 2016

Rationale

Dynamic splinting is a treatment method that can be used with adults and children with a variety of conditions to support or enable participation in grasp and release activities. Without hand function, the rest of the upper limb has reduced function. One of the main functions of the upper limb/hand is reach and grasp. A dynamic extension splint is an orthosis that positions the hand optimally for function and allows active flexion to grasp objects and then uses springs to return the fingers to extension to release. The hypothesis is that opportunities for repetitions in functional, task-oriented grasp and release activities improves motor learning, reduces learned non-use and improve hand function (motor learning and occupational engagement theory).

Clinical question – Is dynamic splinting an effective intervention to help improve upper limb function in children following an acquired brain injury?

Implications

Assessment of baseline tone, range of movement and strength

- Measurement of passive range of movement using goniometer or biometrics (use guidelines).
- Oddstock tracing, photographic record.
- Observation of position at rest and on exertion, and reported range of movement during sleep.
- Assessment of tone and spasticity (Oxford Manual Muscle Testing Scale or Modified Ashworth Scale) in consultation with lead physiotherapist.

Assessment of baseline function

- Assessment of carer burden in personal care (reported or observed)
- Assessment of upper limb function (taken from AMPS, FIM+FAM, PEDI, MACS and clinical observations)

Evaluate/Consider:

- Compliance and buy-in
- Education on motor learning and neuroplasticity
- Support, encouragement and motivation from family/carers
- Cost – time, resources, intensity and child's time/fatigue
- Effect of effort on tone and positioning
- Secondary complications following ABI and UL impairment (soft tissue shortening, learned non-use, weakness)
- Other possible interventions
- Possible impact of splinting on participation in other activities

Interventions

- Saebo products – SaeboFlex
- Custom-made dynamic splints

- The strength of the springs can be adjusted to accommodate the individual's strengths and needs, providing assistance or requiring active extension.

Strategies

- Clear goals and agreed expectations
- Log of home exercises
- Communication with MDT - Education of child, family and carers on rationale and application
- Programme to include aims of splint, application instructions, regime and activities

Performance measures

- Repeat assessment of tone, range of movement and strength using base line tools
- Repeat assessment of function using baseline tools
- Measure changes in spring tension

Review Considerations

- Evaluate compliance, review possible alternative interventions and the impact of splinting on participation.
- Evaluate feedback from child, family and carers on impact/effect of splinting

Summary of the evidence

No evidence was found for dynamic splinting in children with acquired brain injury (ABI). One study showed increased grip and dexterity amongst children with CP when using dynamic splints. The evidence summarized below is based on **adults** with stroke.

A number of studies were sourced that evaluated the use of dynamic splinting with adults with acquired neurological conditions. Much of the evidence is limited by small sample sizes and case reports. Some of the evidence has potential bias as it is supported or conducted by Saebo, the company who manufacture readymade dynamic hand splints. The research findings are difficult to synthesize due to the variety of intervention protocols. The training protocols ranged from a minimum of 45/60 minutes (Woo et al 2012, Barry poster, Sampson poster) up to a maximum of 6 hours per day (Farell et al 2007). The intervention lasted days (Farell et al 2007, Butler et al 2006), weeks (Barry poster, Woo et al 2012) and months (Sampson poster).

Wearing the dynamic splint was not evaluated as an intervention in itself. While the adults were wearing the splint they were involved in a number of activities including repeated task-orientated activities, grasp and release activities, real world activities, neuromuscular stimulation of weak wrist and finger extensors and exercises to improve strength, motor control and range of movement, particularly proximally (Farell et al 2007, Butler et al 2006). Some researchers reported general improvement in upper limb function (Samson poster, Barry poster) while others report specifically about impairment, muscle tone, wrist and finger movement, muscle catch angle and manual dexterity (Farell et al 2007, Butler et al 2006, Woo et al 2012, Jeon et al 2012, Deering poster). The results were inconclusive with some authors reporting no change (Farell et al 2007) and others reporting significant change (Woo et al 2012). Butler et al (2007) showed change over a 3 month period and included a measure of Quality of Life.

In addition to the direct evaluation of the dynamic splint some authors discussed the benefit of dynamic splinting in conjunction with other upper limb interventions. Constraint Induced Movement Therapy (CIMT) and some other bilateral task-orientated training is not accessible to all clients whose upper limb function is extremely limited. Using a dynamic splint may enable people with more significant upper limb impairments to participate in repeated, task oriented activities and thus improve arm function in a modified CIMT programme (Morfis, Bondon and Brown, poster, Jeon et al 2012).

Dynamic splinting involves costly resources and time from the clinician as well as significant time, motivation and buy-in from the client to carry out exercises independently. Clients need to be trained in using the dynamic splint and benefit from education on the supporting theories as well as support from those around them.

COT guidelines on splinting adults issued in 2015 stress the need for clinical benefits of splinting to be determined through evidence gathered in OT practice. The guidelines do not recommend routine splinting, but acknowledge that it may be beneficial in selected cases.

Clinical recommendation at The Children's Trust

Do not routinely offer dynamic splinting.
Consider use in conjunction with the modified constraint induced movement therapy or bimanual training.
Follow the TCT Protocol for splinting and casting (Sept 2015) and the Practice Guidelines for OTs and Physios (COT and ACPIN 2015).
Document baseline assessment, clinical reasoning and ongoing evaluation.
Analyse this group data to further the evidence base in this clinical field.

Functional: assessment and management

- Music therapy assessment
- Upper limb static splinting
- Stretching interventions
- High level language

Music Therapy Assessment of Disorders of Consciousness at The Children's Trust

Evidence Summary

[09/10/2017]

Rationale

Children and youth with disorders of consciousness (DOC) are defined as those under 18 years of age who show wakefulness, but with absent or reduced awareness. Although some guidance for working with adults with PDOC is available (Royal College of Physicians, 2013), there are no differentiated, specific clinical guidelines for working with children and youth with PDOC. Furthermore, there are no specific, validated tools for assessing awareness in this population.

Children and youth with DOC need care that can meet their highly complex needs. This care includes careful stimulation to elicit purposeful responses in assessment and evaluation, and managing an individual's environment optimally to meet their sensory needs. Accuracy in determining awareness is paramount due to several factors. First, ethical issues surround the provision of appropriate care (Ashwal, 2013) regarding the design and use of the type of sensory stimulation and the intensity of the intervention. Second, admission to rehabilitation programmes is affected by accurate diagnosis (Eilander et al., 2005), as this would ensure that those who could benefit are not excluded from admission to these programmes. Third, end-of-life decisions are critically dependent upon correct diagnosis (Ashwal and Cranford, 2002), when clinicians, families, and the legal system consider continuation or withdrawal of intervention in the light of the patients' pain and suffering and their prognosis for recovery.

Clinical question – Is music therapy assessment of awareness essential for the interdisciplinary assessment of children and young people admitted with suspected disorders of consciousness?

Assessment

Assessment of awareness with people with disorders of consciousness has often relied on multidisciplinary consensus. This is vulnerable to misdiagnosis due to observers missing signs of awareness (Schnakers *et al.*, 2009). Therefore, it is recommended that at least one standardised tool is used to inform diagnosis.

The Music Therapy Assessment Tool for Awareness in Disorders of Consciousness (MATADOC) is an assessment tool which combines a structured protocol for presenting stimuli with systematic recording of detailed observations. It is carried out over four sessions within an eight to ten-day period. It is designed to contribute to the interdisciplinary diagnosis of a disorder of consciousness while also providing recommendations for goal-setting, and treatment and care planning. It can only carried out by a qualified music therapist with specific training and uses musical stimuli as part of the protocol.

The MATADOC is an assessment tool that has been standardised and validated for use with adults with DOC. Diagnostic outcomes had 100% agreement with a validated external reference standard – Sensory Modalities Assessment and Rehabilitation Techniques (SMART) (Gill-Thwaites and Munday, 2004). The results indicate that the MATADOC principal subscale provides a new behavioural measure that can contribute to interdisciplinary assessment of awareness with DOC patients (Magee et al., 2014).

The assessment may be conducted with others present and facilitating, if appropriate. For example, a physiotherapist might be required to support a child/young person's head to support his/her movement where orthotics would restrict movement.

Summary of the evidence

Implications:

Music can be used to create an enriched environment to increase arousal and maximise patients' potential to respond and to engage in interpersonal interaction. Live presentation of music and song provides opportunities and encouragement for interaction and social participation.

Children with DOC have been known to respond more effectively to parental voice above other voices. Familiarity is fundamental to working with this population: songs may reduce agitation and enhance orientation in adults suffering from post-traumatic amnesia; Familiar music triggers greater emotion-related brain activity than music that is 'liked' and 'not familiar. Musical stimuli that are familiar and salient can optimise arousal to promote responses and elicit awareness.

The Essential Categories principal subscale of the MATADOC is reliable, unidimensional and has diagnostic utility. The MATADOC has moderate-good inter- and intra-rater reliability. The MATADOC has higher sensitivity within auditory and visual domains than the SMART. The MATADOC has been used in one study with the children and young people. The MATADOC provides a sensitive measure of responsiveness to sensory stimuli. It may contribute to differential diagnosis, but this is not conclusive from this small study alone.

Guidance derived from clinical practice at TCT

Currently, clinicians at TCT are using adapted versions of the SMART and Wessex Head Injury Matrix (WHIM) (Shiel *et al.,*2000). However, these versions have not been tested for validity. The MATADOC is currently being used in the version that has been validated for use with adults. However, this version has not been tested for validity with the paediatric population. A paediatric version of the MATADOC is currently in development and will be tested for validity and reliability in a multisite, international study.

Clinicians at TCT have been trained in the use of the MATADOC and have found that music can be used to explore and stimulate individuals' awareness and their responses to various stimuli. The whole interdisciplinary team have reported that the MATADOC report provides useful information for treatment and care planning at TCT and for recommendations in discharge planning.

Patient and family opinion

Some families have found it difficult to attend sessions. Some have attended, but have become disengaged and have avoided participation. It is clear from these observations that it can be a challenging and emotional demanding experience for these families. However, some families have played active roles in the therapy sessions, providing comfort and stimulation through touch, using their voice to give instruction and occasionally singing meaningful songs to the child/young person.

Clinical recommendation at The Children's Trust

Assess child/young person's arousal and awareness as a priority as soon as possible after admission using the MATADOC. This will support the interdisciplinary team in planning rehabilitation and care.

Explore child and family experiences and preferences regarding music and use of music in their lives prior to the first assessment session.

Consider involving family in the assessment and/or treatment, if they feel able to participate. However, it might be inappropriate for family members to participate due to the emotional load and loss they are experiencing at the time.

Document evidence of responses to specific stimuli and changes in musical parameters. *Monitor* changes in the child/young person's medication and sleep-wake cycle, as these can have significant impact on the effects of sensory stimulation.

Upper limb static splinting at The Children's Trust

Evidence Summary

August 2015

Rationale

Static splinting is a treatment approach used with adults and children to maintain range of movement following an acquired brain injury. It involves use of a ready- made or custom-made splint to position a joint or joints in a preferred position than the position at rest. The hypothesis is that provision of a prolonged, low-load stretch will help to maintain the length of muscle fibres in the muscles affected by the splint.

Clinical question – Is static splinting an effective intervention to help maintain upper limb range of movement in children following an acquired brain injury?

Implications

Assessment of baseline tone and range of movement

- Measurement of passive range of movement using goniometer or Biometrics (use guidelines).
- Oddstock tracing, photographic record.
- Observation of position at rest and on exertion, and reported range of movement during sleep.
- Assessment of tone and spasticity (Oxford Manual Muscle Testing Scale or Modified Ashworth Scale) in consultation with lead physiotherapist.

Assessment of baseline function

- Assessment of carer burden in personal care (reported or observed)
- Assessment of upper limb function (taken from AMPS, FIM+FAM, PEDI, MACS and clinical observations)

Evaluate/Consider:

- Potential compliance in prescription of intervention
- Other interventions
- Possible impact of splinting on participation on all activities

Interventions

- Ready-made elbow extension splint, or wrist and hand extension splint
- Custom-made elbow extension splint or wrist and hand extension splint
- Custom-made elbow, wrist and hand extension splint.

Strategies

- Programme to include aims of splint and application instructions
- Clear wearing regime
- Education of child, family and carers on rationale and application
- Attention to be given to aesthetic components for compliance and satisfaction
- Regular review of fit, compliance and progress, and adjustment

Performance measures

- Repeat assessment of tone and range of movement using base line tools
- Repeat assessment of function using baseline tools
- Measure range on splint with goniometer.

Review considerations

- Evaluate compliance, review possible alternative interventions and the impact of splinting on participation.
- Evaluate feedback from child, family and carers on impact/effect of splinting

Summary of the evidence

While there is clear evidence of the effectiveness of *casting* to maintain passive range of movement in the presence of increased tone (Prizzi et al, 2005, Moseley et al, 2008)*. Clinical experience at The Children's Trust demonstrates that casting can reduce access to other effective/valued activities including personal care, hydrotherapy, play and education. Therefore greater use of splinting has been adopted.

However, although static splinting is widely used following acquired brain injury, there is considerable variability in the design of splints provided, materials used and the recommended wearing protocol (Kilbride et al, 2013). In addition, there is considerable variability in the outcome measures utilised in research (See Appendix 1).

Upper extremity spasticity can result in extreme functional limitations, pain and skin integrity which can impact on a person's participation in activities of daily living (Denham 2008, WFOT, 2012). Restriction in range of movement can lead to changes in soft tissue structures such as shortening and increased stiffness (Lannin et al, 2003, Ada et al, 2006).

There is a general assumption that splinting is beneficial (Kilbride et al, 2013), and anecdotal evidence from highly specialist occupational therapists at The Children's Trust of both positive and negative episodes of intervention. There is some evidence in support of splinting to maintain upper limb range of movement in acquired brain injury (Prizzi et al, 2005, Adrienne et al, 2011, Copley et al, 2013) but little evidence to support the impact of splinting to maintaining range on function (Burtner et al, 2008). Several studies found that upper limb splinting was clinically unimportant (Lannin et al, 2003 and 2007, Basaran et al, 2012).

Numerous studies suggest that the lack of evidence in support of splinting reflects the heterogenous population, inadequate design, poor compliance and the use of inappropriate outcome measures (Lannin et al, 2003, Prizzi et al, 2005, Burtner et al, 2008). In addition, there is clear evidence that splint comfort, design and appearance impact significantly on compliance with wearing protocols (Kuipers et al, 2009, Jackman et al, 2014).

COT Guidelines on splinting adults issued in 2015 stress the need for clinical benefits of splinting to be determined through evidence gathered in OT practice. The Guidelines do not recommend routine splinting, but acknowledge that it may be beneficial in selected cases.

Clinical recommendation at The Children's Trust

There is not consensus evidence that static splinting is an effective intervention to help maintain upper limb range of movement in children following an acquired brain injury. It should not be used routinely. It is essential that clinicians follow the TCT Protocol for splinting and casting (Sept 2015) and should follow the Practice Guidelines for OTs and Physios (COT and ACPIN 2015).

Splinting should never be undertaken without the appropriate baseline assessment and clinical reasoning. In addition, there must be ongoing evaluation for every client for all splints. It is essential that occupational therapists at The Children's Trust collect data (according to the TCT protocol) to further the evidence base in this clinical field.

*see additional TCT evidence based guidelines for stretching

Stretching interventions at The Children's Trust
Evidence Summary
Oct 2015

RATIONALE
This stretching guideline has been developed to inform clinical practice at The Children's Trust.

Stretches have traditionally been applied as an intervention for individuals presenting with neurological impairment. Historically, stretches have been used in the belief that they may affect spasticity and can address and correct tightness in the tissues and assist in maintaining or improving joint range. It is often hoped that by maintaining joint range or reducing spasticity activity limitation may be addressed, which might impact on participation.

Katalinic (2010) describes stretch as " the mechanical elongation of soft tissues for varying periods of time"

The main types of stretch are active and passive stretching. An active stretch is one where the person holds a position without assistance. Passive stretching is where an external force applies the stretch.

Passive stretch should not be confused with passive movement which is *movement* of a joint through range. The movement is applied by an external force.

Clinical question –
Does the evidence support the use of passive stretching in clinical practice with children who present with neurological impairment?

IMPLICATIONS
Assessment:
-Goal attainment eg GAS
-Body system structure and function measures eg Range of movement, spasticity measures such as the Modified Ashworth Scale
-Activity or function- active and passive function measures:
Active function (performance of a functional task by active movement of the individual's affected limb) eg gait measures, mobility indices.
Passive function (when a task is carried out by the individual using their unaffected / less affected limb or by someone else) eg verbal or visual analogue ratings of 'ease of care' or timed care tasks.

Baseline and post intervention evaluation is important in order to monitor change

Interventions
Interventions are varied:
- Manual passive stretch to upper limbs, lower limbs or spine
- Orthotic and splint use eg ankle foot orthoses, upper limb orthotics
- Casting eg serial casting, use of soft casts
- Positioning and use of positioning equipment eg standing frames

Strategies
Passive stretch may be applied as a short term or long term stretch. Length of stretch is usually dependent upon how the passive stretch is applied.

Considerations:

- Passive manual short term stretching does not appear to be an effective intervention in tone or contracture management
- Passive manual short term stretching does not appear to be an effective intervention for increasing range of movement
- Stretch interventions applied in the short term (less than 7 months) do not appear to confer clinically important changes in joint mobility, pain, and spasticity in people with neurological conditions.
- There needs to be more research on whether passive stretch may prevent loss of movement range or may slow down loss of movement range. This research should be well designed.
- The effects of stretch on quality of life, activity limitation and participation restriction have not been well investigated. From the limited research it appears there is no clear beneficial effect, this requires further investigation.
- Positioning, incorporating stretch, as part of a long term postural management programme across a long period of time, might be useful in the treatment and prevention of contracture and joint management. However, there needs to be further research, that is well designed, to investigate this.
- Research on the effectiveness of postural management programmes may help to identify subgroups of children who might benefit from programmes.
- Programmes should not adversely impact, but enhance environment, activity and participation
- Use of lower limb orthotics may be indicated
- AFOs to maintain / improve range of motion may be more effective in children with a more significant decrease in dorsiflexion at baseline
- Orthoses should be supplied by an appropriately qualified professional
- Use of lower and upper limb casts may be indicated
- Use of upper limb splints may be beneficial in selected cases only
- Splints, casts and orthotics are likely to be most effective if used as part of a long term management programme
- Stretching may be linked to negative painful experiences
- More research needs to be conducted to examine the response of different muscles and tendons to stretch and to clarify the impact of longer term immobilisation, stretch and strengthening on muscle tendon units and neural and non-neural mechanisms in neurologically impaired populations
- Passive movement appears to have an impact on brain activity, but active movement has a greater impact
- This best practice recommendation considers articles that are not specific to one type of neurological presentation. In addition it also includes evidence from studies that were not child specific.

Clinical recommendation at The Children's Trust:

- Interventions should focus on modalities that provide positioning as part of a long term postural management programme
- Use of orthotics may be appropriate
- Upper limb splints may be indicated in selected cases only
- If serial casting is applied it should be used with short change intervals. It may be appropriate to use serial casting to gain range if used with a longer term postural management programme
- Any intervention should be applied with the individual in mind and the impact of the intervention on the individual should be monitored
- Active goal / task orientated movement should be encouraged. However, in individuals with very limited movement passive movement of the limbs may be appropriate, but in a functionally relevant way as part of the daily routine, whilst encouraging active movement.
- Where able encourage activity participation, dynamic weight bearing and fitness in children with neurological impairment.

Higher-level language difficulties after acquired brain injury (ABI)
Evidence Summary
January 2019

Higher-level language can be described as the language skills required to successfully communicate and participate in increasingly diverse social, vocational and educational contexts (Ciccia et al 2009, Moran & Gillon 2005, Caplan et al 2016). Higher-level language is not consistently defined or understood. Lewis & Murdoch (2011) include understanding ambiguity and interpreting inferential language as higher-level language skills. In addition, understanding and interpreting figurative language (eg, metaphors, similes, idioms, proverbs) and other non-literal language, such as sarcasm, could also be considered as higher-level language skills. These skills begin to emerge in early school years and continue to develop through to late teenage years. Higher-level language difficulties are prevalent and persistent after ABI in children and young people (CYP) and adults (Bernstein 1999, Hinchliffe et al 1998, Ewing-Cobbs & Barnes 2014, Barwood & Murdoch 2013, Crowe et al 2016, Wong, Murdoch and Whelan, 2010). These skills continue to develop at a later developmental age and emerge only when the cognitive, linguistic, emotional or social demands are sufficiently challenging (MacDonald 2016), meaning these subtle difficulties may be under-identified and easily missed (Moran et al 2012, Ciccia et al 2009).

Clinical question – What is the recent evidence relating to assessment and intervention of higher-level language difficulties following ABI in CYP?

Assessment

- Test of Language Competence Expanded (TLC-E)
- ERRNI (Expression, Reception and Recall of Narrative Instrument)
- S-FAVRES (Student Functional Assessment of Verbal Reasoning and Executive Strategies)
- TASIT (The Assessment of Social Inference Test)
- TALC 2 (Test of Abstract Language Comprehension)
- CELF-4 and 5 (Clinical Evaluation of Language Fundamentals)
- La Trobe Communication Questionnaire
- MCLA (Measure of Cognitive and Linguistic Abilities)
- Mount Wilga High Level Language Test
- Brain Injury Community Service informal language screen

Performance measures

- Repeat formal assessment
- Informal assessment and observation
- CYP, parent and teacher report

Summary of the research evidence (see Appendix for details)
There are inconsistencies in the literature relating to how higher-level language is affected after ABI. All studies reviewed are relating to traumatic brain injury (TBI) only as no studies were found relating to high-level language (as defined above) after non-traumatic ABI.

Assessment
ABI is a heterogeneous population and as such a variety of studies have found inconsistent outcomes from assessment. Studies have highlighted difficulties interpreting results and concluded that there is a lack of sensitivity in elements of assessment. The studies recommend that the assessments administered should match the individual CYP's academic, social or vocational demands. This includes assessment of written language. (Turkstra 2005, Turkstra et al 1995, Ciccia, Meulenbroek & Turkstra, 2009, MacDonald 2017). Standardised test scores may overestimate a child's ability to use language flexibly in everyday school home and social life (Turkstra et al 2005 & 2015).

Intervention
Chapman et al's (2001) longitudinal study highlighted the need for intervention at various stages of development and time after injury. Review of the literature highlights that there are limited studies examining the effectiveness of intervention targeting high-level language after ABI. However, the following interventions have been found to be effective:

- Gist reasoning training (Chapman 2006, Chapman et al 2016)
- Metaphor training (Brownell 2013)
- Inference training (Tompkins 2012)
- Metacognitive strategy instruction (Copley et al 2015)
- Reading comprehension (Watter et al 2016)
- Targeted writing intervention (Dinnes and Hux 2017).

Evidence based on clinical experience at TCT
Higher-level language difficulties have been identified using formal and informal assessment during inter-professional assessments and provision of Brain Injury Community Service neurorehabilitation packages. The impact on everyday function has been reported by CYP, parents, school and other professionals.

Child/young people and family view
Parent - *"C has not meet the criteria for SLT although it is widely recognised she has needs in higher-level language."*

Clinical recommendation at The Children's Trust

- Assess for higher-level language abilities, including written skills.
- Provide appropriate intervention for higher-level language difficulties.
- Support local speech and language therapy services to consider higher-level language needs after ABI.
- Advocate for assessment and intervention of higher-level language at various stages in development and time after injury.

Technology and environmental

- Virtual reality
- Multi-sensory rooms
- Single switch access

Virtual reality at The Children's Trust
Evidence Summary
June 2017

Rationale
Virtual reality (VR) has been defined as "use of interactive simulation created by computers to present users to engage in environments that appear and feel similar to real world objects and events" (Weiss 2006). VR can either involve commercially available games consoles, such as the Wii, or specially created devices such as the Timocco or Biometrics. The intended benefit of VR within rehabilitation as it can allow active task training within fun and motivating activities.

Clinical question – How and when should virtual reality be used within rehabilitation programmes at The Children's Trust?

Assessment

A multidisciplinary assessment of the child's impairments, functioning and goals should be completed to identify the rationale for using virtual reality. A domain specific baseline and outcome measure chosen. Child's preference would be assessed.

Intervention

Variety of platforms including Nintendo Wii, Wii Fit, X-Box Kinect, Green Room, Timocco, Biometrics. Range of intervention protocols.

Summary of the evidence

There has been little research investigating the use of the virtual reality in the rehabilitation of children with ABI. Research from literature studying both adults with stroke and children with cerebral palsy is also considered.

<u>Upper limb</u>

- Early research indicates that use of virtual reality can improve functional upper limb outcomes for children with CP (Chen et al. 2014: Ravi et al. 2016)
- A Cochrane review of the adult stroke literature indicated that inclusion of virtual reality as an adjunct to, or in place of conventional therapy may improve upper limb function and use in ADL (Laver et al. 2015).
- Factors indicating a more favourable outcome include patients with mild to moderate deficits, and who had access to more than 15 hours a week of treatment (Laver et al. 2015).
- Use of all virtual reality methods appear to be of benefit, but **no evidence** as to which type is the most effective for patients with different levels of functioning (Proenca et al. 2017; Laver et al. 2015)
- Study comparing virtual reality to recreational games (10 sessions of 60 mins for 2 weeks) indicated there is no difference in outcomes, and hypothesised

that any added intensity of upper limb practice will be beneficial (Saposnik, 2016).

Gross motor skills

- Systematic review by Baque et al (2016) showed prelimary evidence that the Wii and X-Box Kinect improve the gross motor skills of ambulant children following ABI (limited in quality and quantity at present).
- Systematic review. **Moderate evidence** suggesting virtual reality improves balance in children with CP. Intervention ranged from 20-120 mins per session; 2-10 sessions per week (Ravi et al. 2016)
- Systematic review of balance training with virtual reality by Wii Fit produced better benefits than standard balance training alone for adults with stroke. Dosage ranged from 2-6 days per week; from 2-6 weeks; from 20 mins to 1 hour (Corbetta et al. 2015). Authors suggested that greater effect would be seen if extra treatment time was added.

Gait

- Use of virtual reality treadmill training system improved gait speed over standard treatment alone in adults with stroke (Corbetta et a. 2015)

Cognition

- Use of virtual reality increases motivation and compliance with rehab programmes (Howard 2017)
- Insufficient studies investigating cognitive outcomes completed in stroke rehabilitation to recommend its use (Laver et al. 2015).
- May be beneficial to improve attention and memory for adults with acquired brain injuries (Shin and Kim, 2015)

Guidance derived from clinical experience at The Children's Trust

Clinicians have used Wii, Wii Fit, Timocco and Biometrics. Some difficulty grading the task to the ability and age of the child.

Child and family views

Children and families report having fun with this intervention

Clinical recommendation at The Children's Trust

- Consider use of virtual reality in addition to standard rehabilitation to improve upper limb and gross motor outcomes, and memory and attention.
- Select the type of virtual reality, and programme based on an assessment of the child's needs, and their likes and preferences.
- Monitor outcomes and adjust programmes accordingly.
- Collect data to add to the evidence base

Multi- sensory room use at The Children’s Trust
Evidence Summary
June 2017

Rationale

Multi sensory environments (MSE) are spaces designed to provide sensory stimulation to users through a range of visual, auditory, tactile and olfactory equipment (Carter and Stephenson 2012). MSE are currently used for therapy, education and leisure for children with a variety of diagnoses in both The Children’s Trust school and Children’ services. There are currently no consistent guidelines for the use of MSE, or understanding of their benefits.

Clinical question – What is the evidence for the use of the multisensory room for therapy, education or leisure and relaxation activities?

Summary of the evidence

- A meta analysis of current research looking at the use of multi-sensory environments for children with PMLD demonstrates that there is insufficient evidence to make clinical recommendations (Lotan and Gold, 2009).
- Strongest evidence for the use of MSE is as a relaxation and leisure environment, as opposed to educational or therapeutic environment to develop skills. However, there is still insufficient evidence to recommend their use for this purpose (Lotan and Gold, 2009).
- Small studies have shown that they can have short term effects on heart rate, muscle tone and levels of agitation (Hotz et al. 2006).
- A survey found teachers use MSE to aid learning and visual development, commonly using it as a uni-sensory environment- control and autonomy, use of senses, development of motor skills, exploration and development of cognitive skills, soothing and calming of agitation, and building of trust, relationships and communication (Stephenson 2002).

Parental views

- Parents have declined placement at The Children’s Trust school in the past due to lack of adequate MSE, indicating their perceived importance
- Parents commonly feedback that they feel that their child enjoys the multisensory environment.

Current experiences

- Therapists are currently using the MSE for unisensory purpose eg vision in a dark room, cause and effect with sensory equipment, a quiet non- stimulating environment
- MSE are used by education and care staff.

Clinical recommendation at The Children’s Trust

- Do not routinely use MSE as therapeutic/educational intervention
- Consider the goals of individual children and clinically reason whether use of MSE could benefit sensory functions.
- State the expected outcomes and monitor regularly to ensure these are being achieved.
- Consider use of MSE for relaxation/ leisure if the child shows signs of relaxation or enjoyment whilst being in the room.
- Consider if the perceived benefits of the multisensory room can be transferred into everyday life.

Single Switch Access for Teaching Cause and Effect
Evidence Summary - September 2018

Rationale

Single switch access assistive technology (AT) is seen as a useful tool for children and young people (CYP) with profound and multiple learning disabilities (PMLD) or severe acquired brain injury (ABI) to help learn cause and effect. Professionals select switch access based technology to compensate for an individual's complex motor disorder which prohibits them from using their hands for everyday activities. AT can reduce the level of assistance provided by an adult / caregiver enabling the CYP to have greater autonomy (Tam et al 2007). Profound and multiple learning disabilities is where there is more than one disability, with one being an intellectual impairment (Nakken & Vlaskamp, 2007, Lacey and Oyvry 2013). The degree of disability experienced is severe and they often experience sensory impairment (Evenhuis, Theunissen, Denkers, Verschure, & Kemme, 2001). Assistive Technology and devices (AT) have the primary purpose is to maintain or improve an individual's functioning and independence to facilitate participation and to enhance overall well-being. (World Health Organisation, 2018)

Clinical question – *Should single switch access continue to be used in therapy to teach cause and effect to enhance participation for CYP with severe acquired brain injury and profound and multiple learning disabilities at TCT?*

Assessment

- The assessment should be completed in collaboration with relevant stakeholders
- All children should have a baseline assessment of single switch access for cause and effect taking into account their health condition, body structures and functions, the activity, participation, personal and environmental factors, based on the International Classification of Functioning, Disability and Health, World Health Organisation (2001).
- Assessors require knowledge of the assistive technology and its various properties.
- As part of a thorough assessment of the individuals abilities and health condition the following should take place:
    - An optimum position for access should be identified to minimise the interference of pain / discomfort and maximise the CYP ability for volitional motor control when using a switch.
    - Where assessing hand switch access, all children should have an upper limb assessment based on the CPUPS (Scandinavian version of Cerebral Palsy Integrated Pathway) assessment.
    - When assessing eye tracking as a method of access, a functional vision assessment should be completed, including assessment by ophthalmology and / or optometry specialists
    - Referral to other professionals / agencies as required to identify strengths and abilities of other functions such as hearing, cognition, language understanding
    - Assessments should include well documented trials of equipment in context

Interventions

- Assessment and intervention is likely to be a dynamic process
- Consider alternatives to teaching cause and effect such intensive interaction, objects of reference
- Repetitive trials of assistive technology should be integrated in the relevant context, in daily routines
- Document a detailed plan on how to carry out switch access activity and how to record the session, as more than one person will be involved in supporting the use of switch. This will enable consistency and improve validity of observations made.
- Indications of reliable switch access may be: physiological responses, stilling to the stimulus, repeat press once the stimulus has stopped, change in behavior / facial expression / vocalizations
- Individualize the stimulus / reward e.g. use videos of familiar people

Performance measures

- Goal attainment scaling and education targets - CYPF goals and priorities relating to communication, play / leisure, education, mobility, environmental controls, ICT / computer access need to be established.
- Family focussed performance measures – include survey / informal discussion with main carer or parent
- The Assessment of Learning Powered Mobility Use to be used for charting progress in powered mobility (Nilsson L, Durkin J 2014)
- Formal clinical observation data to be collected and reviewed, e.g. no. of accidental switch presses

Summary of the evidence

Evidence in this area is weak both in health and educational fields (Haines, David John 2015). Research is comprised of mainly evidence rated at level III-V (Oxford Centre of Evidence Based Medicine); detailing case studies, practice analysis and expert opinion. There is some higher level evidence around the general use of assistive technologies in childhood disability, but this rarely takes into account CYP with PMLD or ABI for whom learning cause and effect for active participation / choice-making may be a long-term goal.

Clinical experience

- Locally developed tools such as the TCT 'Assistive Technology Summary Form' have helped document a baseline assessment of the CYP's abilities and formulate goals and enable collaborative discussion from all stakeholders (health, education and family)
- Potential bias has been observed eg when we over interpret responses and ignore switch presses made in error, attributing it to other factors as the CYP being 'funny' rather than the CYP not yet acquiring the skill.
- Barriers exist to sufficient opportunity to practice switch access for cause and effect in context. Some factors are unavoidable such as the CYP being unwell.
- At times there has been a temptation to increase the (motor, sensory, cognitive) demands of the task before the CYP is ready to compensate for concerns that the CYP is bored / frustrated. Boredom can be eliminated by using more individualised stimuli
- AT is viewed as a tool - AT is not the goal for the CYP, but a tool to consider in achieving the goal.

Feedback from children and their families

Informal feedback suggests that using technology is important as it is what all CYP do. Parents and families have reported positive benefits of switch access for powered mobility, gaming and participation in baking. It can be frustrating for CYPF as, although technology is rapidly advancing at an accelerating rate, it is still difficult to understand why the technology alone has not 'unlocked' the CYP's skills and compensated fully for motor, intellectual and sensory disabilities to enable the CYP to actively participate in everyday activities.

Clinical recommendation at The Children's Trust

- A whole team assessment of the individual, activity, assistive technology and environment should be collaborative and well documented.
- Consider optimal positioning for functional motor control.
- Consider the clinical reasoning of assistive technology instead of or alongside other methods such as intensive interaction / objects of reference to teach cause and effect.
- Consider individualising stimulus and informal opportunities to get feedback from CYPF
- Set goals, state the expected outcomes and use data to monitor.
- Include observations of the CYP alongside feedback from the various stakeholders.
- Educate the team around the CYP to enable a consistent switch access plan so that single switch access practice of cause and effect is integrated in relevant context.
- Educate those supporting trials on the use of the equipment and what data to collect for when determining if switch press was volitional / reliable and if the CYP has an understanding that they caused the effect / stimulus
- Consider a means to encourage open, informal feedback from family

2019 Evidence summaries

Appendices

Appendix 1 Reference list for formulation

Appendix 2 Reference list for goal setting

Appendix 2 Reference list for Coaching for family-delivered therapy

Appendix 3 Reference list for Neuroendocrine screening

Appendix 4 Reference list for headaches following mild TBI

Appendix 5 References list for Concussion

Appendix 6 Cognitive rehabilitation literature review

Appendix 7 Reference list for CO-OP

Appendix 8 Reference list for Ataxia

Appendix 9 Reference list for Upper limb rehabilitation

Appendix 10 Reference list for Constraint induced Movement Therapy

Appendix 11 Reference list for upper limb bimanual

Appendix 12 Reference data summary, high level language after ABI

Appendix 13 Reference list for High level language

Appendix 1

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Appendix 7 Cognitive rehabilitation literature review

What are the common 'effective ingredients' to successful cognitive skills training groups tested with CYP that have severe-moderate acquired brain injury?

P= CYP with severe-moderate acquired brain injury

I= Cognitive skill rehabilitation/ training/ remediation for individuals and groups

C= Compared to treatment as usual (TAU)

O= Increased skill performance in formal testing and everyday activities

Summary of common 'effective' ingredients:

- Combination of process-specific approach and metacognitive strategies
- Involvement of coach (e.g. teacher/parent)
- Everyday intervention/routine
- Homework
- Repetition weeks
- Clinical input to formulate more individualised approach
- Addressing motivation

Programmes being used:

- **AMAT-C** (Amsterdam Memory and Attention Training for Children)
- **AIM** (Attention Intervention and Management Program)
- **FORAMEN Rehab Program**
- **Attenzione e Concentrazione (6-8)**
- **Rehacom (8-18)**
- **DSIT (Diary and self-instructional training)**

Key Information from Relevant Studies

Reference	**Target population *(sample size, characteristics and setting)***	**Intervention (*details, cost)***	**Mode of evaluation**	**Outcome/ Effectiveness**	**Key elements of success**	**Any other comments**
Galbiati, S., Recla, M., Pastore, V., Liscio, M., Bardoni, A., Castelli, E., & Strazzer, S. (2009). Attention remediation following traumatic brain injury in childhood and adolescence. *Neuropsychology*, *23*(1), 40.	65 TBI patients (6-18 years) with attention deficits. Had sustained severe brain injuries (GCS <8) Discharged from subacute rehabilitation (approx. 6-10 months post-injury) with marked attention deficits. Exclusion criteria: past brain injury, pre-existing psychiatric condition, ADH, cognitive or behavioural disorders, IQ<50. 40: attention-specific training for 6-months 25: Control group (no training) – not randomised. At baseline: *All mild intellectual disability* and	Specific remediation training for attention. Combination of process-specific approach and metacognitive strategies. 4x per week (45 min, individual) 1-1 with therapist, computerised tasks for 30 minutes; table-top tasks for 15 minutes. **'Table top tasks':** Interpretation of pictures and vignettes, giving answers to open and closed questions, providing opinions and suggestion for the management of attention. Material varied by chronological age. *Targeted:* selective, focused, sustained and divided attention, inhibition and shifting. Strategies demonstrated by therapist first. **Computerised tasks** <u>Rehacom (8-18):</u> *Vigilance and sustaining attention.* Subject required to select the elements not matching the given template. Stimuli appear continuously on screen from right to left on a conveyer belt. Difficulty can be changed.	Assessed at baseline and 1-year follow up. WISC-R, Continuous Performance Test II, Vineland Adaptive Behaviour Scales (determine ecological validity)	Intervention group showed greater improvement than controls on CPT II and VABS. Attention training group: less distracted, concentrated for longer, more reflective, less impulsive, more accurate. CPT II fell in normal range at follow up. No group differences in IQ scale – both groups showed improvements.	Combination of process-specific approach and metacognitive strategies?	Study strength: assessing ecological validity of training. Improvements in attention positively influences adaptive behaviour in the context of everyday life. Parents not involved in intervention. Time unconscious affected outcomes.

	‘pathological’ scores on the CPT II.	*Selective attention and inhibition of irrelevant stimuli:* Compare template with a number of pictures onscreen. *Sustained attention and shifting ability* – Subject responds readily to the target stimuli using different modalities. RTs and accuracy recorded. Attenzione e Concentrazione (6-8): Targets selective, sustained and divided attention, attention span, resistance to distraction, shifting. Task example: selection of auditory or visual stimuli (e.g. Press X when hear the word SUN and press Y when see the BLUE STAR). Stroop phenomenon in distraction resistance training. Different levels of difficulty.				
van’t Hooft, I., Andersson, K., Bergman, B., Sejersen, T., Von Wendt, L., & Bartfai, A. (2005). Beneficial effect from a cognitive training programme on children with acquired brain injuries demonstrated in a controlled study. *Brain Injury*, *19*(7), 511-518. Article access not allowed.	38 children (9-16) with ABI. IQ> 70 and performance of 1 SD or more below average for age on 20% of attention and memory tests included. Random assignment to treatment and control groups. Control group: freely chosen interactive	Broad-based cognitive training programme. **AMAT-C (see appendix 1):** Specific attention and memory techniques. Additionally, therapeutic approaches to behaviour modification focused on learning strategies in daily life and the accomplishment of school tasks. 2 versions (9-12; 13+) 30 minutes, 6x per week; 17 weeks. Gradual increase in difficulty.	Assessed pre training, post-training and 6-months after training. Assessment of sustained attention (Visual and Auditory Reaction Time Tests) Assessment of selective attention (Stroop Colour and Word Test; Binary Choice Test, The Coding Test, Trail Making Test)	Treatment > improvement v. controls on complex tasks of attention and memory; sustained improvement 6-months follow up No significant differences on simple RT tests.	Involvement of coach Everyday intervention/routine	

van't Hooft, I., Andersson, K., Bergman, B., Sejersen, T., von Wendt, L., & Bartfai, A. (2007). Sustained favorable effects of cognitive training in children with acquired brain injuries. *NeuroRehabilitation*, *22*(2), 109-116.	activity 30 minutes daily.	Perform task with a coach (teacher or parent) at school or at home. Diary kept. Child and coach visited hospital once a week for feedback and reinforcement.	Assessment of memory (15 Word Test; Digit Span; Rey-Osterrieth Complex Figure Recall; Rivermead Behavioural Memory Test)			
Sjö, N. M., Spellerberg, S., Weidner, S., & Kihlgren, M. (2010). Training of attention and memory deficits in children with acquired brain injury. *Acta paediatrica*, *99*(2), 230-236.	7 children with memory and/or attention deficits after ABI (traumatic BI, tumour, stoke). Time since injury: at least 1 year. 8-16 years. Exclusion criteria: premorbid psychiatric disorder or learning difficulties. Delivered at school (4 mainstream; 3 special schools)	**AMAT-C** 18-20 weeks (19-20 repetition weeks). 45 minutes per day every weekday. Daily record report sheet completed. 1:1 with coach (who has weekly supervision from expert). Supervision provided at the school and lasted 30–45 min. The supervisor takes over the training session and acts as trainer for the child while the trainer observes. Targets: sustained (weeks 1-4), focussed (weeks 5-8) and divided attention (weeks 9-12), strategies for verbal, visual, episodic and semantic memory (weeks 13-18), and mental tracking.	4 evaluation questions to parents, trainers and children. (1) What is your opinion about the training programme? (2) Did you ⁄ your child ⁄the pupil want to start doing the programme every day? (3) Is it easier for you ⁄ your child ⁄the pupil to concentrate ⁄remember and ⁄ or work with new subjects post-training? (4) Have you noticed other things becoming easier to do post-training?	Positive responses to evaluation questions. Improved scores on outcome measures, including 1/11 attention subtests, 1/4 tempo subtests, visuoconstructive abilities, 4/7 learning and memory subtests, 1/5 executive subtests. Mixed results on BRIEF.	Two repetition weeks highly valued (helpful for children to notice their improvement) Study did not examine the most effective componenets of the AMAT-C	Delivering in a school-setting may augment possibilities of transferring trained skills to the child's everyday learning context and increase motivation.

		Increasing difficulty. Each week: builds on skills trained OR practised during previous weeks.	WISC, Neuropsychological Assessment of the school-aged child, Test of Everyday Attention for Children (All pre- and post- training. BRIEF completed by parents and trainers.		programme.	
Catroppa, C., Stone, K., Hearps, S. J., Soo, C., Anderson, V., & Rosema, S. (2015). Evaluation of an attention and memory intervention post-childhood acquired brain injury: Preliminary efficacy, immediate and 6 months post-intervention. *Brain injury*, *29*(11), 1317-1324.	10 children with ABI (8-13 years) Maximum 1-year post ABI IQ > 70 Attention and/or memory difficulty	**AMAT-C**	WASI, TEACH, Children's Memory Scale, Objective Memory Questionnaire (Parent form), Behavioural Assessment System for Children (parent rating), Adaptive Behaviour Assessment Scale, BRIEF	Group (ANOVA) change on memory. Individual change (Reliable Change Index) in a number of different areas including memory, attention and parental reports of behaviour and adaptability. Some change emerged 6-months post intervention.		NB no control group.
Sohlberg, M. M., Harn, B., MacPherson, H., & Wade, S. L. (2014). A pilot study evaluating attention and strategy training following pediatric traumatic brain injury. *Clinical*	11 children (13-16 years) (a) history of hospitalization for complicated mild to severe TBI after age 5, (b) current age between	**AIM (see appendix 2)**: 10 week computerised treatment program. Targets attention and WM. - Goal setting - Metacognitive strategies - Computer based exercises (attention-drills). Hierarchically organised and categorised by the attention domain targeted.	BRIEF, TEA-Ch, D-KEFS, AIM Program gathered data, GAS	Great variability in posttest outcomes ranging from no change, negative change and positive change. Examination of these data led to three hypotheses: (1) the well-	A review of the session and outcome data identified three arenas	Incentives for completing home practices: brain points tied to monetary rewards.

Practice in Pediatric Psychology, *2*(3), 263.	10 and 18, (c) time since injury 12 months, and (d) evidence of current attention problems as defined by a frequency score of 2 or 3 on at least four of nine items from the Vanderbilt ADHD Diagnostic Parent Rating Scale, Attention Subscale	Initial meeting with the child: the computer program leads the clinician through an intake procedure that assists in identifying the nature and severity of the child's attention difficulties and then facilitates the selection of attention training tasks and metacognitive strategies tailored to the needs of the child. Based on the clinician's ratings, an initial, computer generated program of drills and strategies is proposed. The role of clinician is to select the specific, presenting cognitive areas that are impaired, as well as to modify the tasks and strategies in response to improvements over time After the initial intake session, each subsequent session consists of the following components: (a) a review of home-based practice and use of metacognitive strategies, (b) in-session completion of the 5–6 assigned attention training tasks while the clinician is observing, and (c) review of homework for the upcoming week. During the intervention, participants were expected to complete 2–4 practice sessions per week (consisting of about 6 tasks, each 3 mins), and treatment was extended by 1 week for each week that the child failed to complete at least two home practices.		documented variable performance in this population makes static neuropsychological testing an unreliable measure of progress over short periods of time (i.e., 10–12 weeks), (2) the neuropsychological tests do not tap the processes suggested in their validity studies, or (3) the AIM treatment is of insufficient duration and/or intensity or is not efficacious to result in improved neuropsychological outcomes. Improvement on BRIEF and GAS	that required clinical judgment: (a) clinical treatment decisions, (b) promoting and maintaining participant engagement, and (c) clinical interpretation of outcomes.	
Kaldoja, M. L., Saard, M., Lange, K., Raud, T., Teeveer, O. K., & Kolk, A. (2015).	8 children (9-12 years) All had attention impairment.	**FORAMEN Rehab Program** for training specific components of attention in children 10 sessions over 6 weeks.	Follow up after the last training and 1.63 years later.	Improvement in sustained and complex attention. Sustained		100% compliance with program

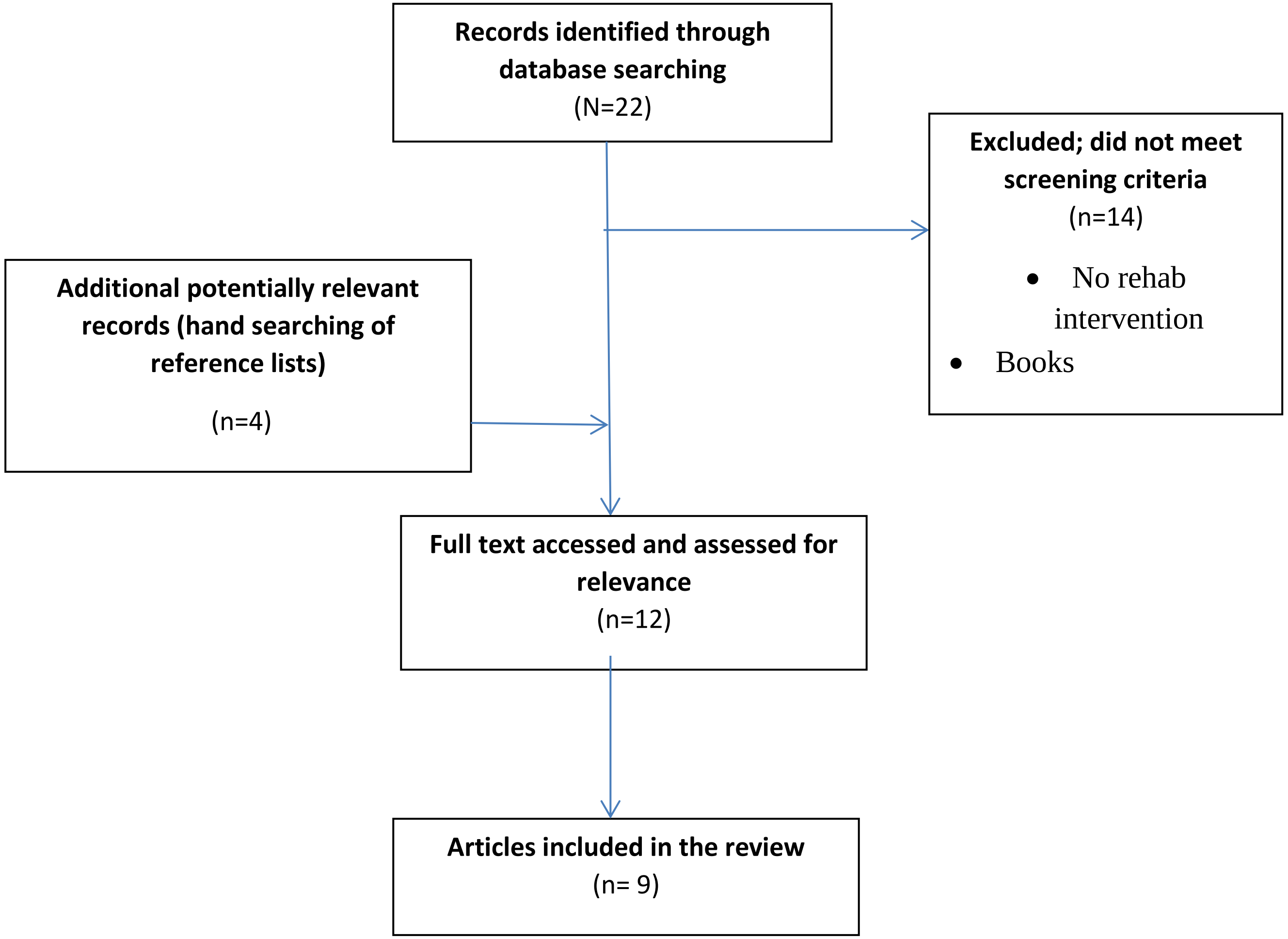
Neuropsychological benefits of computer-assisted cognitive rehabilitation (using FORAMENRehab program) in children with mild traumatic brain injury or partial epilepsy: A pilot study. *Journal of pediatric rehabilitation medicine, 8*(4), 271-283. Unable to access full text	3= partial epilepsy 5= mild TBI 18 controls	Trained four components of attention (sustaining, focusing, dividing, tracking) You may copy, distribute, install and use the software free of charge for evaluation purposes. A licence is required for rehabilitation usage. 1st licence: 1230.00 €		over long-term follow up.		
Ho, J., Epps, A., Parry, L., Poole, M., & Lah, S. (2011). Rehabilitation of everyday memory deficits in paediatric brain injury: Self-instruction and diary training. *Neuropsychological Rehabilitation, 21* (2), 183-207.	15 children (11-17 years) Attending Brain injury rehab programme in Sydney, Australia, for children. ABI 12 months prior to recruitment. Injuries caused by RTA, falls, strikes, drowning, falls and infection. On children with memory difficulties (within or below the low average range on the memory questionnaire were included)	Participants were provided with an 84-page treatment manual developed by the main investigator (Ho, 2006). Divided into 6 sections, one for each week of the programme. **DSIT (Diary and self-instructional training):** combination of internal and external strategies aimed to improve attention, enhance self regulation skills and teach simple skills associated with diary use. 6 x 1.5 hour sessions, run individually or in a small groups: Self-instructional training (WSTC) W: What are you going to do? S: Select a strategy T: Try out the strategy C: Check out how the strategy is working	WISC or WASI (cognition) Rey Auditory Verbal Learning Test (anterograde memory) TEAch (attention) Child behaviour checklist (behaviour) Assessed at 3 time points; 4 weeks pre-invention, 2 weeks post-intervention and 13-weeks post (follow up)	On completion of the programme there was significant increase in abilities to perform daily routines that demanded recall of information and events. Children used diaries more frequent. Secondary gains were found in attention and mood.		Those with poorer attention more likely to be referred to the study and also have poorer memory Only published study at the time to use memory and attention training in children, used the Amsterdam Memory and Attention

		Diary training *Acquisition*-taught about the sections/purpose of the diary *Application*-role plays/case studies to practice using the diary *Adaptation*-encouraging use of dairy in everyday practice				Training, however this was not available in English so could not be used.
Phullips, N.L., Mandalis, A., Benson, S., Parry, L., Epps, A., Morrow, A., & Lah, S. (2016). Computerized working memory training for children with moderate to severe traumatic brain injury: A double-blind, randomised placebo-controlled trial. *Journal of Neurotrauma, 33*, 1-8.	Recruitment over a 18 month period through Brain injury rehab service in Sydney for children. 13 in adaptive training condition vs. 14 in control condition Inclusion criteria: moderate-severe TBI, age 8-15, fluent in English, access to internet. Exlcuded: pre-existing developmental behavioural or neurological disorder, TBI sustained by non-accidental means, general IQ below average range.	Cogmed WM training (Pearson Education), designed for school age children age 7+ 30-40 mins of training 5 x per week over 5 weeks. ie. 25 training days in total In each sessions children were required to completed 8 of 12 possible exercises, which were pre-determined to match the child's WM span so they worked to their personal limits. The training had inbuilt rewards (games) and feedback. Training was supervised by parents, in addition to weekly phone supervision from psychologist/researcher. Email reminders sent when training was inactive for 2 days.	WISC (IQ) Automated WM Assessment (AWMA) TEAch (attention) WIAT (academic achievement)	Randomised to either Adaptive training (Cogmed) vs non-adaptive training (control) 10 completed adaptive training vs 13 control condition, others were analysed using intention to treat analysis. Cogmed training had significantly greater gains on WM. No gains were found on tests of attention. Also had greater gains on academic skills, particularly reading.	Specific targeting of WM strategies Length of time training and training adherence.	

Literature Searches Performed:

Search Performed
1. Attention Training Programmes: reviewed from Limond et al.’s (2014) paper.
2. Child* or Paediatric or Pediatric AND Attention OR cog* AND Rehab* or training or remediation AND Acquired brain injury or traumatic brain injury or brain injury or head injury In: Psycinfo, Medline, CINAHL, Psycarticles
3. Additional check of reference lists of papers

Literature search summary:



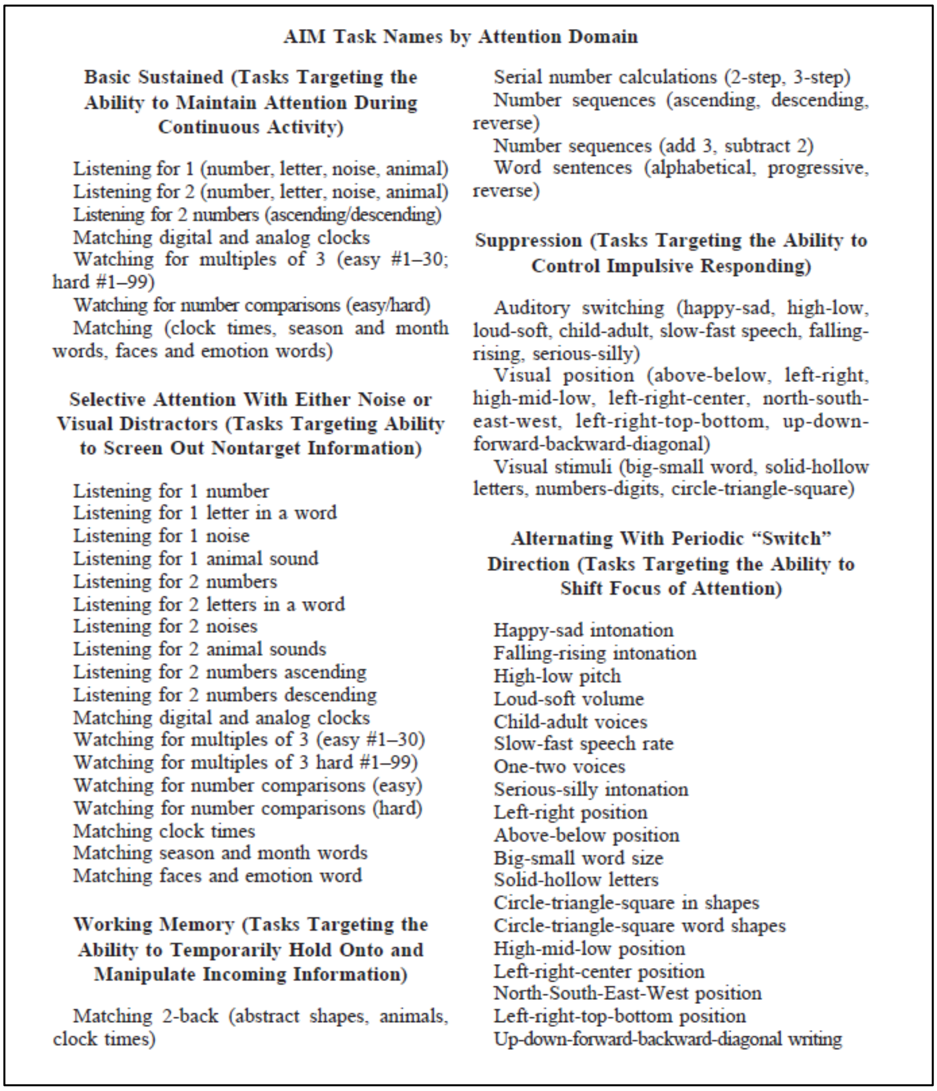
Appendix 1: Example of Phases and Tasks in the AMAT-C

Phase 1—Sustained attention. Training methods focus on learning to concentrate on one task for a period of time. Example: Listening to the clock: The clock's ticking is counted. The distance from the clock is increased and the task repeated until the child is not able to complete the task. The first and the final distance from the clock are measured.

Phase 2—Selective attention. Focused (e.g. ignore distraction) and divided attention (e.g. focusing attention quickly and flexibly). Example: ABCDE Method: The Child is taught the ABCDE Method for approaching a task. A, Appreciating; B, Being Critical; C, Concentrating, D, Deep Thinking, E, Evaluating.

Phase 3—Mental tracking and memory. Techniques to assist memory, including repetition, coding/sorting and visual imagery. Example: Memory—Repeating and Sorting: The child is involved in tasks that require repetition of information and sorting of information in order to enhance memory skills.

Appendix 2: AIM Programme Tasks and Metacognitive Strategy



AIM Task Names by Attention Domain

Basic Sustained (Tasks Targeting the Ability to Maintain Attention During Continuous Activity)

Listening for 1 (number, letter, noise, animal)
Listening for 2 (number, letter, noise, animal)
Listening for 2 numbers (ascending/descending)
Matching digital and analog clocks
Watching for multiples of 3 (easy #1–30; hard #1–99)
Watching for number comparisons (easy/hard)
Matching (clock times, season and month words, faces and emotion words)

Selective Attention With Either Noise or Visual Distractors (Tasks Targeting Ability to Screen Out Nontarget Information)

Listening for 1 number
Listening for 1 letter in a word
Listening for 1 noise
Listening for 1 animal sound
Listening for 2 numbers
Listening for 2 letters in a word
Listening for 2 noises
Listening for 2 animal sounds
Listening for 2 numbers ascending
Listening for 2 numbers descending
Matching digital and analog clocks
Watching for multiples of 3 (easy #1–30)
Watching for multiples of 3 hard #1–99)
Watching for number comparisons (easy)
Watching for number comparisons (hard)
Matching clock times
Matching season and month words
Matching faces and emotion word

Working Memory (Tasks Targeting the Ability to Temporarily Hold Onto and Manipulate Incoming Information)

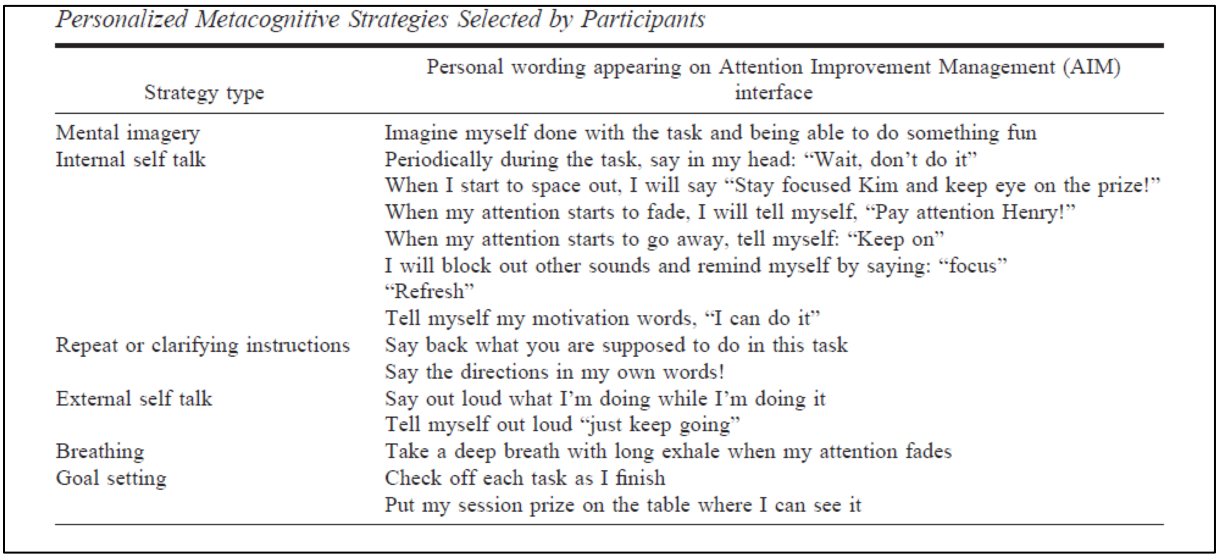
Matching 2-back (abstract shapes, animals, clock times)
Serial number calculations (2-step, 3-step)
Number sequences (ascending, descending, reverse)
Number sequences (add 3, subtract 2)
Word sentences (alphabetical, progressive, reverse)

Suppression (Tasks Targeting the Ability to Control Impulsive Responding)

Auditory switching (happy-sad, high-low, loud-soft, child-adult, slow-fast speech, falling-rising, serious-silly)
Visual position (above-below, left-right, high-mid-low, left-right-center, north-south-east-west, left-right-top-bottom, up-down-forward-backward-diagonal)
Visual stimuli (big-small word, solid-hollow letters, numbers-digits, circle-triangle-square)

Alternating With Periodic "Switch" Direction (Tasks Targeting the Ability to Shift Focus of Attention)

Happy-sad intonation
Falling-rising intonation
High-low pitch
Loud-soft volume
Child-adult voices
Slow-fast speech rate
One-two voices
Serious-silly intonation
Left-right position
Above-below position
Big-small word size
Solid-hollow letters
Circle-triangle-square in shapes
Circle-triangle-square word shapes
High-mid-low position
Left-right-center position
North-South-East-West position
Left-right-top-bottom position
Up-down-forward-backward-diagonal writing



Personalized Metacognitive Strategies Selected by Participants

Strategy type	Personal wording appearing on Attention Improvement Management (AIM) interface
Mental imagery	Imagine myself done with the task and being able to do something fun
Internal self talk	Periodically during the task, say in my head: "Wait, don't do it"
	When I start to space out, I will say "Stay focused Kim and keep eye on the prize!"
	When my attention starts to fade, I will tell myself, "Pay attention Henry!"
	When my attention starts to go away, tell myself: "Keep on"
	I will block out other sounds and remind myself by saying: "focus"
	"Refresh"
	Tell myself my motivation words, "I can do it"
Repeat or clarifying instructions	Say back what you are supposed to do in this task
	Say the directions in my own words!
External self talk	Say out loud what I'm doing while I'm doing it
	Tell myself out loud "just keep going"
Breathing	Take a deep breath with long exhale when my attention fades
Goal setting	Check off each task as I finish
	Put my session prize on the table where I can see it

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Appendix 10

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Appendix 11

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Appendix 12

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Appendix 13

Reference data summary for high level language after ABI

- Turkstra et al (1995) found no group differences in sarcasm scores using the Pragmatic assessment protocol between TBI and the control group but concluded that there is a lack of sensitivity in elements of assessment.
- Channon et al (2005) found that adults with TBI had increased difficulty interpreting sarcasm and often gave incorrect non-literal interpretations rather than a literal error.
- Channon and Watts (2003) found that adults showed reduced sensitivity to pragmatic meanings and difficulty adequately processing more indirect meanings, in a range of cognitive assessments.
- Dennis et al (2001) found that children with severe TBI had overall poorer mastery of a task requiring them to interpret scenarios involving literal truth, ironic criticism and deceptive praise.
- Moran and Gillon (2005) found an adolescent TBI group scored below the control group when presented with inferences that required increased storage demands. They concluded that the comprehension of inference may be reduced due to increased working memory demands.
- Chapman et al's (2001) longitudinal study (3-36 months post injury) found that the severe TBI group performed significantly worse in a global semantic interpretation task than the mild TBI group but showed a greater rate of change with time, e.g. in interpretation of inference.
- Towne & Entwhistle (1993) found no significant difference between a TBI and control group using the Test of Language Competence (TLC) with adolescents.
- Jordan et al (1996) used the TLC-E and found that the ABI group were significantly impaired when compared to controls.
- Moran and Gillon (2004) found inconsistencies with half their TBI group performing below average on understanding figurative language.
- Moran et al (2006) found adolescents with TBI scored significantly below their typically developing peers in their overall understanding of low-familiarity proverbs and that working memory performance was correlated to comprehension of figurative language.
- Yang et al (2010) used functional MRI and diffusion tensor imaging and found that during metaphor judgement tasks there were differences between the brain areas and networks activated between the TBI and control groups.

Appendix 14

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