# Title Page

**Title:** What do kids with Acquired Brain Injury want? Mapping neuropsychological rehabilitation goals to the International Classification of Functioning, Disability and Health: Children and Youth Version

**Authors:** Robyn Henrietta McCarron[1,2], Suzanna Watson[1,3], Fergus Gracey[1,3,4]

1. Cambridgeshire and Peterborough NHS Foundation Trust (CPFT)
2. Department of Psychiatry, University of Cambridge
3. National Institute of Health Research (NIHR) Collaborations for Leadership in Applied Health Research and Care (CLAHRC) East of England Programme
4. Department of Clinical Psychology, University of East Anglia

**Mailing address:** The Cambridge Centre for Paediatric Neuropsychological Rehabilitation (CCPNR), Brookside Clinic, 18D Trumpington Road, Cambridge. CB2 8AH

**Contact details:** 01223 465212, robyn.dudley@cantab.net

**Word count abstract:** 240 **Word count main text:** 4765

# Abstract

## Objective

To increase understanding of the community neuropsychological rehabilitation goals of young people with Acquired Brain Injury (ABI).

## Method

326 neuropsychological rehabilitation goals were extracted from the clinical records of 98 young people with ABI. The participants were 59% male, 2-19 years old, and 64% had a Traumatic Brain Injury. Goals were coded using the International Classification of Functioning, Disability and Health: Children and Youth Version (ICF-CY). Descriptive statistical analysis was performed to assess the distribution of goals across the ICF-CY. Chi Squared and Cramer's V were used to identify demographic and injury-related associations of goal type.

## Results

The distribution of goals was 52% Activities and Participation (AP), 28% Body Functions (BF), 20% Environmental Factors (EF) and <1% Body Structures (BS). The number of EF goals increased with age at assessment (V=0.14). Non-traumatic causes of ABI were associated with more EF goals (V=0.12). There was no association between gender or time post-injury and the distribution of goals across the ICF-CY.

**Conclusions**

Young people with ABI have a wide range of community neuropsychological rehabilitation goals that require an individualised, context sensitive and interdisciplinary approach. Community neuropsychological rehabilitation services may wish to ensure they are resourced to focus intervention on AP, with increasing consideration for EF as a young person progresses through adolescence. The findings of this research support models of community neuropsychological rehabilitation that support wellness by combining direct rehabilitative interventions with attention to social context and systemic working across agencies.

## MESH Terms

Education

Emotions

Environment

Family

Friendships

Relationships

Participation

Social

## Full Text

# What do kids with Acquired Brain Injury want? Mapping neuropsychological rehabilitation goals to the International Classification of Functioning, Disability and Health: Children and Youth Version

Robyn Henrietta McCarron, Suzanna Watson, Fergus Gracey


## Abstract

### Objective

To increase understanding of the community neuropsychological rehabilitation goals of young people with Acquired Brain Injury (ABI).

### Method

326 neuropsychological rehabilitation goals were extracted from the clinical records of 98 young people with ABI. The participants were 59% male, 2-19 years old, and 64% had a Traumatic Brain Injury. Goals were coded using the International Classification of Functioning, Disability and Health: Children and Youth Version (ICF-CY). Descriptive statistical analysis was performed to assess the distribution of goals across the ICF-CY. Chi Squared and Cramer's V were used to identify demographic and injury-related associations of goal type.

### Results

The distribution of goals was 52% Activities and Participation (AP), 28% Body Functions (BF), 20% Environmental Factors (EF) and <1% Body Structures (BS). The number of EF goals increased with age at assessment (V=0.14). Non-traumatic causes of ABI were associated with more EF goals (V=0.12). There was no association between gender or time post-injury and the distribution of goals across the ICF-CY.

**Conclusions**

Young people with ABI have a wide range of community neuropsychological rehabilitation goals that require an individualised, context sensitive and interdisciplinary approach. Community neuropsychological rehabilitation services may wish to ensure they are resourced to focus intervention on AP, with increasing consideration for EF as a young person progresses through adolescence. The findings of this research support models of community neuropsychological rehabilitation that support wellness by combining direct rehabilitative interventions with attention to social context and systemic working across agencies.

## Introduction

Acquired Brain Injury (ABI) is defined as any injury to the brain after birth due to traumatic or non-traumatic causes, including infection and inflammation, vascular events, cerebral anoxia, toxic and metabolic insults and brain tumours. Traumatic brain injury (TBI) is a leading cause of death and disability in young people (defined as children and adolescents) worldwide (World Health Organization, 2006), affecting 280-1373/100,000 young people a year (McKinlay & Hawley, 2013). Non-traumatic causes of ABI affect a further 82.3/100,000 young people a year (Chan, Pole, Keightley, Mann & Colantonio, 2016).

Childhood ABI results in physical (de Kloet et al., 2015), cognitive (Anderson, Godfrey, Rosenfeld, & Catroppa, 2012a), psychiatric (Max et al., 2012), and social (Ryan et al., 2016) consequences. In 35% to 50% of young people with ABI these deficits persist (Brehaut, Miller, Raina & McGrail, 2003; Lewis, Morris, Morris, Krawiecki & Foster, 2000). Rehabilitation of the

*"cognitive, emotional, psychosocial, and behavioral deficits caused by an insult to the brain (p.141)"*

is termed neuropsychological rehabilitation (Wilson, 2008). With increasing awareness of the long-term psychological sequelae (Anderson *et al*. 2012) and prevalence of criminal justice involvement (McKinlay, Corrigan, Horwood & Fergusson, 2014) for young people with ABI there has been a call for supporting wellness, resilience and participation to maximise the trajectory of young people affected by ABI. The Foresight Report (2008) defines well-being as:

*"a dynamic state, in which the individual is able to develop their potential, work productively and creatively, build strong and positive relationships with others, and contribute to their community. It is enhanced when an individual is able to fulfil their personal and social goals and achieve a sense of purpose in society (p.10)."*

Consequently, promoting wellness through neuropsychological rehabilitation may require a shift in emphasis away from traditional views of rehabilitation as a means to restore function and reduce the impact of disability (British Society of Rehabilitation Medicine, 2015; World Health Organization, 2011) and towards models that focus on participation, environment,

relationships (Gracey, Olsen, Austin, Watson, & Malley, 2015), and the subjective experience of self within such social contexts (Gracey *et al.* 2008).

Neuropsychological rehabilitation for young people with ABI commonly involves goal-setting (Tucker, 2015). Setting goals supports success in rehabilitation by focussing attention, energising, clarifying strategies and knowledge, and encouraging persistence (Locke & Latham, 2002). Goal setting can support wellness by placing young people at the centre of decision making (Department for Education, 2014). Therefore, analysing the goals of young people within a neuropsychological rehabilitation service facilitates consideration of key components of wellness as well as identifying service and support needs.

However, young people with ABI are a heterogeneous group (McCarron, 2017) and may have different neuropsychological rehabilitation goals depending on gender, age, type of ABI and TPI. Although ABI affects the same gross areas in males and females, some gender-specific differences have been identified. For example, males may have more goals around learning and memory (Donders & Hoffman, 2002), and females may have more goals around managing physical and emotional symptoms (Ewing-Cobbs, Cox, Clark, Holubkov & Keenan, 2018). Increasing age may be associated with a greater focus on goals around support and environmental factors, as increasing educational (Gamino, Chapman & Cook, 2009) and psychosocial expectations (Steinberg, 2008) through adolescence may magnify the support needs of young people with ABI compared to their peers. Due to enhanced service provision through the UK Major Trauma Networks (National Institute for Health and Care Excellence, 2016) and the greater prevalence of traumatic causes of ABI, which may result in increased societal awareness, young people with TBI may have less goals around

environmental support than young people with non-traumatic causes of ABI. With increasing TPI there may be a reduction in goals related to physical and cognitive impairments as functional impairments show improvement over time (Anderson, Godfrey, Rosenfeld, & Catroppa, 2012b). However, goals around participation may increase as the discrepancies between the young person's representations of their current and pre-injury self are re-evaluated (Gracey, Evans & Malley, 2009).

The International Classification of Functioning, Disability and Health: Children and Youth Version (ICF-CY) (World Health Organisation, 2007) provides a framework for mapping the neuropsychological rehabilitation goals of young people with ABI and developing a further understanding what 'wellness' means for young people with ABI. The ICF-CY is derived from the The International Classification of Functioning, Disability and Health (World Health Organisation, 2001). It was designed to facilitate consideration of the interrelationship between contextual factors (Environmental Factors (EF)) and components of functioning and disability (Body Structures (BS), Body Functions (BF) and Activities and Participation (AP) components), whilst accommodating the developmental processes occurring during childhood and adolescence.

Previous studies have used the ICF to classify outcomes important to carers and professionals working with people with ABI (Mbale, Taylor, Brabin, Mallewa & Gladstone, 2017; McCulloch et al., 2016). A wide range of outcomes spanning across the ICF domains were identified. The ICF-CY has been used as a foundation to consider the role of contextual factors in the rehabilitation of young people with TBI (Cicca & Threats, 2015), but to our knowledge no other study has used the ICF-CY to analyse goals or outcomes in young people

with ABI. Community and residential paediatric neurorehabilitation services in the UK have begun to analyse the rehabilitation goals of young people with ABI in order to shape the interventions provided (Dunford, Bannigan, & Wales, 2013), but further research is needed in order to develop a systematic and evidence-based approach for this. This study aimed to:

1) Increase understanding of the community neuropsychological rehabilitation goals of young people with ABI, and how these goals map onto the ICF-CY two-level classification.
2) Identify if there is an association between demographic and injury-related factors and the types of community neuropsychological rehabilitation goals young people with ABI have.

The hypotheses were:

1) The community neuropsychological rehabilitation goals of young people with ABI will span across the ICY-CY domains of BS, BF, AP and EF.

2) There will be no association between gender and the distribution of goal codes across the ICF-CY domains, but the most common two-level classification goal codes will be different for males and females, with males having goals around cognitive symptoms and females having goals around physical and emotional symptoms.

3) The proportion of EF goal codes will increase with increasing age at assessment.

4) Young people with non-traumatic brain injuries will show a greater proportion of EF goal codes than those with TBI.

5) With increasing TPI the proportion of BF goal codes will decrease, and the proportion of AP goal codes will increase.

## Method

### Ethical approval

This study was approved by the local National Health Service (NHS) Trust's quality improvement department as a service evaluation. All data was obtained and analysed in compliance with data protection legislation and the Trust's regulations.

### Setting

This study was conducted within a specialist community neuropsychological rehabilitation service for young people with ABI based within the UK NHS. The service consists of an interdisciplinary team including specialists from clinical psychology, neuropsychology, educational psychology, speech and language therapy, occupational therapy, paediatric neurology and child and adolescent psychiatry. The service takes a multisystemic and evidence-based approach to assessment and context sensitive rehabilitation, working closely with young people, their families, educational settings, and other services involved (Gracey et al, 2015).

### Participants

Inclusion and exclusion criteria for participants were based on service acceptance criteria, and an ability to participate in the goal setting process. The service accepts young people with any type and severity of ABI up to the age of 19 years. The young people referred to the service have complex psychosocial needs that cannot be met through non-specialist

community mental health, physical health or education support services alone. The participants were retrospectively identified from all new consecutive accepted referrals of young people with ABI who had previously attended the specialist community neuropsychological rehabilitation service between 2010 and 2015. Young people who were seen multiple times within the service were only included once. This yielded 100 young people. Two children (one male child aged 2 with an ABI due to encephalitis, and one female child aged 4 with a severe TBI) were excluded as they were not able to participate in the goal setting process due to their level functioning, giving 98 participants.

### Goal setting

Goal setting was conducted as part of the initial assessment of young people. Two healthcare professionals from the interdisciplinary team met with the young person and their primary caregivers. Young people were asked what they would like to be different in their first appointment to shape the assessment and goal setting process for rehabilitation. This was part of an ongoing dialogue with them and their family during the assessment process, at the end of which identified goals were summarised and agreed with the young person and their family. Goals were articulated using the 'SMART' (specific, measurable, achievable, realistic, and time-limited) approach (Bovend'Eerdt, Botell & Wade, 2009).

### Data extraction

Neuropsychological rehabilitation goals, gender, age at assessment, ABI type and TPI information was extracted from service users' initial assessment clinical records. Participants were grouped into categories to facilitate the translation of the research findings into the

settings in which they participated and into the services they accessed. Participants were divided into the age categories preschool or primary school (<11 years), secondary school (11-<16 years) and post-compulsory education (≥16 years). TPI was classified according to categories commonly used in research (LeBlanc *et al.* 2008, Ponsford *et al.* 2014); less than 2 years, 2-5 years and 5 years and over. ABI type was classified as TBI or non-TBI.

**Measures**

The concise version of the ICF-CY (World Health Organisation, 2007) was used in this study to improve the sensitivity at which similarities in the goals of young people with ABI could be detected.

The ICF-CY has a "nested" structure so that broader categories are increasingly defined to include more detailed subcategories. It is structured into four domains of Body Functions (BF), Body Structures (BS), Activities and Participation (AP) and Environmental Factors (EF). Each domain is structured into chapters (first level). Each chapter consists of further descriptions of components of functioning and disability called branching levels. The concise form of the ICF-CY consists of one branching level (second level) within the chapters, to give a two-level classification of chapter headings and first branching level.

The ICF-CY utilises an alphanumeric coding system. The letters b, s, d and e donate the domains of BF, BS, AP and EF. This is followed by a numeric code denoting the chapter number (one digit) and second level (two digits).

### Coding

The goals were independently coded by two researchers (RHM and SW). There was 90% concordance between coders at the ICF-CY two-level classification code level. Following discussion consensus was reached on all disagreements. Where possible the single best ICF-CY code to define the goal was sought. Goals composed of several distinct aspects were allocated multiple codes. Where an EF related to a component of functioning and disability on which it exerted its' affect, both the EF and additional component codes were applied. This is in accordance with the ICF-CY guidelines.

### Statistical analysis

Data was analysed using Microsoft Excel. The analysis was conducted in terms of goal codes to reflect the multiple goals per participant. The reliability of this approach was assessed using The Chi-Squared Goodness of Fit Test to determine if the distribution of participants and goals codes across the demographic and injury-related groups was significantly different. Descriptive statistical analysis was performed to identify the proportion of goals according to ICF-CY domains and chapters. Proportions were calculated out of the total number of ICF-CY codes assigned. Two-level classification goal codes with a frequency of ten or above were reported at a code level. The Chi-Squared Test of Independence was used to test the null hypothesis that there was no difference in the distribution of goal codes across the AP, EF and BF ICF-CY domains according to gender, age at assessment, ABI type and TPI. BS was excluded from the Chi-Squared analysis due to there only being one goal in this domain. One Chi-Squared analysis was performed for each independent variable initially, with significant

results being explored through further Chi-Squared analysis for each domain of the ICF-CY. Effect size was calculated using Cramer's V. The top three two-level classification goal codes for each subgroup were reported. Results were considered significant if $p<0.05$, and the Holm-Bonferroni correction was applied to correct for multiple comparisons.

## Results

### Sample

Of the 98 participants 58 were male (59%) and 40 were female (41%). The mean age at assessment was 12.92 years (SD=3.87 years, range=2-19 years). The mean TPI was 3.65 years (SD=4.23 years, range=0-18 years). The type of ABI was 64% (n=63) TBI, 16% (n=16) infection, 7% (n=7) tumour, 7% (n=7) vascular and 5% (n=5) other ABI. Of the participants with TBI the injury severity was classified as mild in 24% (n=15), moderate in 17% (n=11), severe in 32% (n=20) and unknown in 27% (n=17).

Three-hundred and twenty-six neuropsychological rehabilitation goals were identified (a median of 3 goals per participant with a range of 1-9). These goals were given 447 ICF-CY two-level classification codes. There was no significant difference in the distribution of participants and goal codes (Table 1.) across the demographic and injury-related groups (gender: $\chi2(1)=0.00025$, $p=0.99$, age at assessment: $\chi2(2)=2.59$, $p=0.27$, ABI type: $\chi2(1)=2.12.$, $p=0.14$. TPI: $\chi2(2)=0.46$, $p=0.79$).

[INSERT TABLE 1 HERE]

## Distribution of goal codes across ICF-CY domains and chapters.

Goal codes spanned across the ICF-CY domains. AP goal codes were the most common type (n=232, 52% of total goal codes). Twenty-eight percent (n=124) of total goal codes were BF codes, 20% (n=90) were EF codes and less than 1% (n=1) of total goal codes were BS codes. Ninety-four percent (n=92) of participants had AP goal codes, 64% (n=63) had BF goal codes, 49% (n=48) had EF goal codes, and 1% (n=1) had a BS goal code.

Eighty-seven different two-level classification goal codes identified, spanning 17 different chapters (Table 2.). The three most common chapters came from three different domains (BF, AP and EF) and were mental functions (n=116, 26% of total goal codes), major life areas (n=72, 16% of total goal codes) and support and relationships (n=45, 10% of total goal codes).

[INSERT TABLE 2 HERE]

### Common two-level classification goal codes

Twelve two-level classification goal codes were endorsed ten or more times (Table 3.). School education (d820, an AP code) was the most common two-level classification goal code (n=60, 13% of total goal codes). This was followed by emotional functions (b152, a BF goal code; n=43, 10% of total goal codes), support and relationships, other specified (e398, an EF goal code; n=28, 6% of total goal codes) and family relationships (d760, an AP goal code; n=22, 5% of total goal codes). The two-level classification code e398 (support and relationships, other specified) was commonly used for goals referring to a specific type of

support that could not be coded for using the more specific support and relationship codes relating directly to family, friends or people in positions of authority for example.

[INSERT TABLE 3 HERE]

### Gender

Gender did not appear associated with the proportion of goal codes across the different ICF-CY domains ($\chi2(2)=4.12$, V=0.096, p=0.13). The top three two-level classification goal codes for both males and females were the same and were d820 (school education), b152 (emotional functions) and e398 (support and relationships, other specified) (Table 4.)

[INSERT TABLE 4 HERE]

### Age at assessment

Figure 1. shows the distribution of goal codes across ICF-CY domains according to age at assessment. There was an overall association between age at assessment and the proportion of goal codes across the different ICF-CY domains ($\chi2(4)=10.83$, V=0.11, p=0.029). There was an association with the proportion of EF goal codes ($\chi2(2)=9.14$, V=0.14, p=0.010), with the proportion of EF goal codes increasing with age. However, the effect size was small and when this was corrected for multiple comparisons it did not reach the level for significance (corrected level of significance=$p<0.005$). There was also an association between the proportion of AP goal codes ($\chi2(2)=6.93$, V=0.12, p=0.031), with the proportion of AP goals decreasing with age. The effect size was small, and the significance was not maintained when corrected for multiple comparisons (corrected level of significance=$p<0.005$). There was no

association between age group and BF goal codes ($\chi2(2)=0.25$, V=0.024, p=0.88). The top two two-level classification goal codes (Table 4.) in all age groups were d820 (school education) and b152 (emotional functions). E398 (support and relationships, other specified) was the third most common goal code in secondary school and post-compulsory education participants, and d920 (recreation and leisure) was third most common in preschool and primary school participants.

[INSERT FIGURE 1 HERE]

**ABI type**

The distribution of goal codes across the ICF-CY domains according to ABI type is shown in Figure 2. There was an overall association between ABI type and the proportion of goal codes across the different ICF-CY domains ($\chi2(2)=6.77$, V=0.12, p=0.034). ABI type was associated with the proportion of EF goal codes ($\chi2(1)=6.85$, V=0.12, p=0.0089), with a greater proportion of EF goal codes in the non-TBI group. This was not significant when corrected for multiple comparisons (corrected level of significance=$p<0.005$), and the effect size was small. There was no association between ABI type and the proportion of BF ($\chi2(1)=0.47$, V=0.033, p=0.49) goal codes. There was no association between ABI type and the proportion of AP ($\chi2(1)=1.99$, V=0.067 p=0.16) goal codes. The top two two-level classification goal codes in participants with both TBIs and non-TBIs were d820 (school education) and b152 (emotional functions). The third most common two-level classification goal codes were d760 (family relationships) in participants with TBI and e398 (support and relationships, other specified) in the non-TBI group.

[INSERT FIGURE 2 HERE]

### Time post-injury

There was no association between TPI and the proportion of goal codes across the different ICF-CY domains ($\chi 2(4)=5.47$, V=0.078, p=0.24). The top two two-level classification goal codes in all groups were d820 (school education) and b152 (emotional functions) (Table 4.). The third most common two-level classification goal code was e398 (support and relationships, other specified) in participants under 5 years post-injury. In participants 5 years and over post-injury d760 (family relationships) and d750 (informal social relationships) were joint third most common.

## Discussion

This study sought to increase understanding of the neuropsychological rehabilitation goals that young people identify in the post-acute community phase following an ABI, extending previous literature on post-ABI outcomes that has been more focused on impairments such as neuropsychological functioning and psychiatric diagnosis. The results provide a picture of what young people with ABI believe is important for wellness. The broad range of community neuropsychological rehabilitation goals identified, is in keeping with previous studies (Mbale *et al*. 2017; McCulloch et al., 2016), and reflects the diversity of the common consequences of childhood brain injury (Anderson & Catroppa, 2006) which may need to be met by community services. Our first hypothesis was that the community neuropsychological rehabilitation goals of young people with ABI will span across the ICY-CY domains of BS, BF, AP and EF. This hypothesis is partially supported, as whilst there was a large proportion of goals in the BF, AP and EF domains, only one goal was a BS goal code. This is likely

explained by the setting as children with physical (body structure) rehabilitation goals may have been seen within a different service.

The associations found in this study were of a small effect size and were not significant when corrected for multiple comparisons. There was no association between gender and the types of goals young people with ABI had, and no difference in the most common two-level classification goal codes males and females had. Consequently, our second hypothesis that there will be no association between gender and the distribution of goal codes across the ICF-CY domains, but the most common two-level classification goal codes will be different for males and females is only partially supported. There was an association between age and goal types with an increasing emphasis on Environmental Factors as children moved into, and progressed through, adolescence. This supports our third hypothesis that the proportion of EF goal codes will increase with increasing age at assessment. Our fourth hypothesis that young people with non-traumatic brain injuries will show a greater proportion of EF goal codes than those with TBI is supported. There was an association between ABI type and the proportion of EF goal codes, with young people with non-traumatic ABIs having a greater proportion of EF goal codes than those with TBIs. Our fifth hypothesis predicted that with increasing TPI the proportion of BF goal codes will decrease, and the proportion of AP goal codes will increase. This hypothesis was not supported as there was no association found between TPI and the proportion of goal codes across the different ICF-CY domains. This suggests that goals around Activities and Participation are highly important to young people at all points in the post-ABI journey.

Over half of the goal codes were Activity and Participation goal codes, with 94% of participants having at least one AP goal code. These most commonly related to school education, family relationships, recreation and leisure, carrying out the daily routine and informal social relationships. These aspects of participation are crucial to well-being in enabling young people to achieve a sense of purpose in society and fulfil their personal and social goals (Foresight, 2008), and emphasize the importance of a holistic approach to neuropsychological rehabilitation.

Without adequate support from family, friends and the wider community a young person's ability to participate in meaningful life situations can be impaired after an ABI (Thompson et al., 2016). Participation needs to be considered alongside contextual and environmental factors (Ciccia & Threats 2015; Greenham et al., 2015), including family functioning (Yeates, Taylor, Walz, Stancin & Wade, 2010) and the relationships with others that are key components of wellness. Consequently, for neuropsychological rehabilitation services to affect change for young people with ABI it would seem crucial to engage their school, family, friends and the wider community.

Emphasising the importance of considering participation alongside environmental factors, the top two-level classification goal code irrespective of age, gender, injury type and TPI was to participate in school education (d820). There are cognitive, social, behavioural and psychological aspects to education (Ylvisaker et al., 2001) that contribute to the importance of this goal. However, understanding of ABI amongst educators may be limited (Linden, Braiden & Miller, 2013). This is reflected in the common two-level classification environmental goal codes around individual attitudes of people in positions of authority (e430

- which for most young people was a reference to the attitudes of teachers), and education and training services, systems and policies (e585). This supports the important role of the attitudes and understanding of those around young people with ABI in shaping supportiveness of relationships on the one hand, and scaffolding for learning on the other (Gracey *et al.* 2015). Consequently, community neuropsychological rehabilitation services should ensure they are resourced to work closely alongside school to optimise a child or young person's participation and support their longer-term education and training.

The difference in goal types across age bands supports a conceptualisation of rehabilitation that maintains a strong developmental focus (Anderson & Catroppa, 2006; Byard et al., 2011). As young people with ABI progress through adolescence the psychosocial (Steinberg, 2008) and educational (Gamino et al., 2009) scaffolds that exist routinely for younger children begin to fall away as society demands increasing independence. However, for adolescents with ABI the neuropsychological consequences of their ABI increase the challenge of this, and there is an increasing need for environmental support, in terms of supportive relationships, the attitudes of others, and services, systems and policies. The developmental change in rehabilitation goals was also seen at an individual code level, with secondary school and post-compulsory education young people having a greater preference for support and relationships (e398), whilst primary school children placed more importance on recreation and leisure (d920).

The greater proportion of EF goal codes seen in young people with non-traumatic TBI's may reflect a lower level of societal awareness of the impact of relatively rare causes of paediatric ABI, such as strokes, infections and brain tumours (NHS England, 2013), on young people

than of the impact of TBIs. This interpretation is supported by the increased importance of the two-level classification code e398 (support and relationships, other specified), in the non-TBI group. However, the small effect size and lack of significance between ABI types and the types of goals, suggests that services can be designed to meet the needs of young people with any ABI rather than being restricted to specific types of ABI or arbitrarily based on diagnostic criteria, as indicated in UK specialist healthcare commissioning guidance (NHS England, 2013).

This study is further evidence that young people with ABI require appropriate psychological and psychiatric support. Emotional functioning was the second most common goal across gender, age at assessment and TPI groups. The development of psychiatric disorders in young people after ABI is common (Max et al., 2012), and the level of emotional problems between young people with ABI and children referred to mental health service have been found to be similar (Gracey et al., 2014). Consequently, this study supports models of rehabilitation that include a strong psychological perspective (Gracey et al., 2015) to support wellness.

### Strengths and Limitations

This study used a relatively large and heterogeneous clinical sample, with a large number of goal codes for analysis, and 90% initial concordance between coders. However, the findings may not be generalizable as it was conducted within a single service and the participants had highly complex psychosocial needs. Further research is needed to assess the validity of these finding across different clinical populations of young people with ABI and in different services. The role of the healthcare professionals in the goal setting process may have biased

the results, but the 87 different two-level classification goals codes is supportive of young people being encouraged to identify goals that reflected their individual needs. The effect sizes seen in this study were small and did not meet the level of significance when the Holm-Bonferroni correction was applied, so require cautious interpretation. Whilst the use of the ICF-CY enabled a large number of goals to be analysed the richness of individual goals was lost, and this may have been a reason why no differences were detected in the goals of males and females. Further qualitative research exploring the individual rehabilitation goals of young people with ABI could build on the findings of this study. Associations about wellness can only be inferred from this study as no specific measures of well-being or wellness were administered.

## Conclusion

Young people with ABI approach community neuropsychological rehabilitation with a wide range of goals that require an individualised and interdisciplinary approach and should be viewed with a context-sensitive and developmental perspective. Overwhelmingly, young people with ABI want to participate alongside their uninjured peers in school, family and community life. Supporting this, both directly and through consideration of environmental factors, is vital for the wellness of the young people. Consequently, the findings of this research support models of neuropsychological rehabilitation that combine direct rehabilitative interventions with attention to social context, psychological understanding and systemic working across agencies. Community neuropsychological rehabilitation services should ensure that they work in an individualised, context-sensitive and interdisciplinary manner to optimise the environmental supports around a young person with ABI to maximise their participation. Ensuring that young people and their families have access to

psychological support to understand and address their emotional difficulties is also vital in this. Ongoing research into participation-focussed interventions and outcome measures, and measures of environmental or contextual factors, is now required to ensure that the goals of young people with ABI can be addressed in an evidence-based manner.

**Acknowledgements**

We thank the young people and their families who have made this work possible, and the clinical team who have supported them through their neuropsychological rehabilitation journeys. FG and SW were supported by the National Institute of Health Research (NIHR) Collaborations for Leadership in Applied Health Research and Care (CLAHRC) East of England Programme. RHM was supported by an Academic and Clinical Fellowship in Psychiatry jointly funded by the University of Cambridge and Cambridgeshire and Peterborough NHS Foundation Trust. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR, the University of Cambridge or the Department of Health and Social Care.

**Conflicts of interest and funding**

SW holds a clinical management role overseeing the service within which the data was collected. The authors declare that there are no other conflicts of interest. There are no sources of financial support to declare for this paper.

## References

Anderson, V., & Catroppa, C. (2006). Advances in postacute rehabilitation after childhood-acquired brain injury: a focus on cognitive, behavioral, and social domains. *American Journal of Physical Medicine & Rehabilitation*, 85(9), 767-778.

Anderson, V., Godfrey, C., Rosenfeld, J. V., & Catroppa, C. (2012a). 10 years outcome from childhood traumatic brain injury. *International Journal of Developmental Neuroscience,* 30(3), 217-224.

Anderson, V., Godfrey, C., Rosenfeld, J. V., & Catroppa, C. (2012b). Predictors of cognitive function and recovery 10 years after traumatic brain injury in young children. Pediatrics, 129(2), 254-61

Bovend'Eerdt, T. J., Botell, R. E., & Wade, D. T. (2009). Writing SMART rehabilitation goals and achieving goal attainment scaling: a practical guide. *Clinical Rehabilitation*, 23(4), 352-361.

Brehaut, J. C., Miller, A., Raina, P., & McGrail, K. M. (2003). Childhood behavior disorders and injuries among children and youth: a population-based study. *Pediatrics,* 111(2), 262-269.

British Society of Rehabilitation Medicine. (2015). *Specialised Neurorehabilitation Service Standards*. London: British Society of Rehabilitation Medicine.

Chan, V., Pole, J. D., Keightley, M., Mann, R. E., Colantonio, A. (2016). Children and youth with non-traumatic brain injury: a population based perspective. *BMC Neurology*, 16(1), 110.

Ciccia, A. H., & Threats, T. (2015). Role of contextual factors in the rehabilitation of adolescent survivors of traumatic brain injury: emerging concepts identified through modified

narrative review. *International Journal of Language & Communication Disorders,* 50(4), 436-451.

de Kloet, A. J., Gijzen, R., Braga, L. W., Meesters, J. J., Schoones, J. W., & Vliet Vlieland, T. P. (2015). Determinants of participation of youth with acquired brain injury: A systematic review. *Brain Injury,* 29(10), 1135-1145.

Department for Education (2014). *SEND Code of Practice*. London: Department for Education.

Donders, J., & Hoffman, N. M. (2002). Gender differences in learning and memory after pediatric traumatic brain injury. *Neuropsychology*, 16(4), 491.

Dunford, C., Bannigan, K., Wales, L. (2013). Measuring activity and participation outcomes for children and youth with acquired brain injury: an occupational therapy perspective. *British Journal of Occupational Therapy,* 76(2), 67-76.

Ewing-Cobbs, L., Cox, C. S. Jr., Clark, A. E., Holubkov, R., Keenan, H.T. (2018). Persistent Postconcussion Symptoms after Injury. *Paediatrics,* EPub ahead of print, doi: 10.1542/peds.2018-0939

Foresight Mental Capital and Wellbeing Project (2008). *Final Project report.* London: The Government Office for Science.

Gamino, J. F., Chapman, S. B., & Cook, L. G. (2009). Strategic learning in youth with traumatic brain injury: Evidence for stall in higher-order cognition. *Topics in Language Disorders,* 29(3), 224-235.

Gracey, F., Evans, J. J., & Malley, D. (2009). Capturing process and outcome in complex rehabilitation interventions: A “Y-shaped” model. *Neuropsychological Rehabilitation*, 19(6), 867-890.

Gracey, F., Olsen, G., Austin, L., Watson, S., & Malley, D. (2015). Integrating Psychological Therapy into Interdisciplinary Child Neuropsychological Rehabilitation. In J. Reed, K. Byard & H. Fine (Eds.), *Neuropsychological Rehabilitation of Childhood Brain Injury* (pp. 191-214). London: Palgrave Macmillan.

Gracey, F., Palmer, S., Rous, B., Psaila, K., Shaw, K., O'Dell, J., ... & Mohamed, S. (2008). "Feeling part of things": Personal construction of self after brain injury. *Neuropsychological Rehabilitation*, 18(5-6), 627-650.

Gracey, F., Watson, S., McHugh, M., Swan, A., Humphrey, A., & Adlam, A. (2014). Age at injury, emotional problems and executive functioning in understanding disrupted social relationships following childhood acquired brain injury. *Social Care and Neurodisability*, 5(3), 160-170.

Greenham, M., Hearps, S., Gomes, A., Rinehart, N., Gonzalez, L., Gordon, A., ... & Anderson, V. (2015). Environmental Contributions to Social and Mental Health Outcomes Following Pediatric Stroke. *Developmental Neuropsychology,* 40(6), 348-362.

LeBlanc, J., Feyz, M., Meyer, K., Duplantie, J., Thomas, H., Abouassaly, M., ... & Robinson, C. (2008). Long-term outcome after severe traumatic brain injury: the McGill interdisciplinary prospective study. T*he Journal of Head Trauma Rehabilitation*, 23(5), 294-303.

Lewis, J. K., Morris, M. K., Morris, R. D., Krawiecki, N., & Foster, M. A. (2000). Social problem solving in children with acquired brain injuries. *The Journal of Head Trauma Rehabilitation*, 15(3), 930-942.

Linden, M. A., Braiden, H. J., & Miller, S. (2013). Educational professionals' understanding of childhood traumatic brain injury. *Brain Injury*, 27(1), 92-102.

Locke, E. A., & Latham, G. P. (2002). Building a practically useful theory of goal setting and task motivation: A 35-year odyssey. *American psychologist*, 57(9), 705.

Max, J. E., Wilde, E. A., Bigler, E. D., MacLeod, M., Vasquez, A. C., Schmidt, A. T., ... & Levin, H. S. (2012). Psychiatric disorders after pediatric traumatic brain injury: a prospective, longitudinal, controlled study. *The Journal of Neuropsychiatry and Clinical Neurosciences,* 24(4), 427-436.

Mbale, E. W., Taylor, T., Brabin, B., Mallewa, M., & Gladstone, M. (2017). Exploring neurodevelopmental outcome measures used in children with cerebral malaria: the perspectives of caregivers and health workers in Malawi. *BMC Pediatrics,* 17(1), 9.

McCarron, R. (2017). A survey of methods used for determining novel psychiatric research diagnoses in children and adolescents after Acquired Brain Injury, and their limitations. *Clinical Neuropsychiatry,* 14(3), 195-208.

McCulloch, K. L., De Joya, A. L., Hays, K., Donnelly, E., Johnson, T. K., Nirider, C. D., ... & Ward, I. (2016). Outcome measures for persons with moderate to severe traumatic brain injury: recommendations from the American Physical Therapy Association Academy of Neurologic Physical Therapy TBI EDGE Task Force. *Journal of Neurologic Physical Therapy,* 40(4), 269-280.

McKinlay, A., Corrigan, J., Horwood, L. J., & Fergusson, D. M. (2014). Substance abuse and criminal activities following traumatic brain injury in childhood, adolescence, and early adulthood. *The Journal of Head Trauma Rehabilitation*, 29(6), 498-506.

McKinlay, A., & Hawley, C. (2013). Incidence rates for traumatic brain injury in children. *International Neurotrauma Letter*, available at: http://www.internationalbrain.org/incidence-rates-for-traumatic-brain-injury-in-children/ (accessed 20 July 2018).

National Institute for Health and Care Excellence. (2016). Major trauma: service delivery (NG40). London: National Institute for Health and Care Clinical Excellence.

NHS England. (2013). *2013/2014 NHS Standard Contract for Paediatric Neurosciences: Neurorehabilitation.* London: NHS England.

Ponsford, J. L., Downing, M. G., Olver, J., Ponsford, M., Acher, R., Carty, M., & Spitz, G. (2014). Longitudinal follow-up of patients with traumatic brain injury: outcome at two, five, and ten years post-injury. *Journal of Neurotrauma*, 31(1), 64-77.

Royal College of Physicians of London. (2003). *Rehabilitation following acquired brain injury: national clinical guidelines.* London: Royal College of Physicians.

Ryan, N. P., van Bijnen, L., Catroppa, C., Beauchamp, M. H., Crossley, L., Hearps, S., & Anderson, V. (2016). Longitudinal outcome and recovery of social problems after pediatric traumatic brain injury (TBI): Contribution of brain insult and family environment. *International Journal of Developmental Neuroscience,* 49, 23-30.

Steinberg, L., 2008, Adolescence, 6th edn. Boston, MA: McGraw- Hill College.

Thompson, M., Elliott, C., Willis, C., Ward, R., Falkmer, M., Falkmer, T., ... & Girdler, S. (2016). Can, Want and Try: Parents' Viewpoints Regarding the Participation of Their Child with an Acquired Brain Injury. *PLoS One*, 11(7), e0157951.

Tucker, P. (2015). Goal Setting and Goal Attainment Scaling in Child Neuropsychological Rehabilitation. In J. Reed, K. Byard & H. Fine (Eds.), *Neuropsychological Rehabilitation of Childhood Brain Injury* (pp. 151-170). London: Palgrave Macmillan.

Wilson, B. A. (2008). Neuropsychological rehabilitation. *Annual Review of Clinical Psychology*, 4, 141-162.

World Health Organization. (2001). International classification of functioning, disability and health: ICF. Geneva: World Health Organization.

World Health Organization. (2006). *Neurological disorders: public health challenges.* Geneva: World Health Organization.

World Health Organization. (2007). *International Classification of Functioning, Disability, and Health: Children & Youth Version: ICF-CY.* Geneva: World Health Organization.

World Health Organization. (2011). *World report on disability.* Geneva: World Health Organization.

Yeates, K. O., Taylor, H. G., Walz, N. C., Stancin, T., & Wade, S. L. (2010). The family environment as a moderator of psychosocial outcomes following traumatic brain injury in young children. *Neuropsychology,* 24(3), 345.

Ylvisaker, M., Todis, B., Glang, A., Urbanczyk, B., Franklin, C., DePompei, R., ... & Tyler, J. S. (2001). Educating students with TBI: Themes and recommendations. *The Journal of head trauma rehabilitation,* 16(1), 76-93.