

Brain Injury Rehabilitation Impact and Outcomes Report 2020-2021



Who we are and what we do

The Children's Trust is the UK's leading charity for children with brain injury and neurodisability. We provide a range of rehabilitation, education, care, and community services to children and young people from across the UK with acquired brain injury, neurodisability and complex health needs.

Through our highly skilled teams, we work with children and young people to give them the opportunity to live the best life possible. Located just south of London in Tadworth, Surrey, our national specialist centre is home to the UK's largest rehabilitation service for children with acquired brain injury. Widely recognised as the country's leading centre of excellence, our service is one of the only services outside of an acute hospital setting which can provide the most complex rehabilitation in the UK.



Our services are provided through:

Individually tailored rehabilitation programmes of multidisciplinary therapy for children who have experienced a brain injury.

The Children's Trust School, for children with a range of complex education, health, therapy and care needs. The School also offers an early years programme.

Our Brain Injury
Community Service,
information service
and online Brain
Injury Hub providing
resources and
therapeutic support
to children with
acquired brain injury.

Placements at The Children's Trust

Our paediatric neurorehabilitation service is commissioned directly by NHS England, and our long-standing partnership ensures that children with the most complex needs have access to the specialist rehabilitation they need.

These needs are classified as 'category A' and typically a child meeting this criteria will present with severe physical, cognitive and/or communicative disabilities and challenging behaviours.

These children have highly complex rehabilitation needs and require specialist facilities like those we offer at our national specialist centre, alongside an intensive, coordinated, interdisciplinary intervention from four or more therapy disciplines.

We also support children with 'category B' needs, typically presenting with moderate to severe physical, cognitive and/or communicative disabilities which may include mild-to-moderate behavioural problems.

Goals for children with category B needs may be the same as those with category A needs and a rehabilitation programme would usually involve an intensive, coordinated intervention from two-to-four therapy disciplines.

We work in partnership with various parties to secure funding for category B rehabilitation placements, together with clinical commissioning groups (CCGs) and local authorities, including health and social care teams. We also accept private placements, typically funded by case managers, private medical insurers, medico-legal organisations and international embassies.



Outcomes 2020-21

It is our mission that all children with brain injury and neurodisability live the best life possible. Partners and funders believe in this mission and support us to deliver our services. In return it is vital that we can robustly demonstrate the impact we have on the children we support and the wider world.

This outcomes report is split into three sections reflecting our core services:

- 1. Rehabilitation
- 2. The Children's Trust School
- 3. Brain Injury Community Service.

This outcomes report, covering the period of April 2020-March 2021, is set against a backdrop of a year of considerable disruption as a result of the COVID-19 pandemic. During this time we continued to offer a specialist in-paediatric neurorehabilitation service providing level 1 neurorehabilitation.

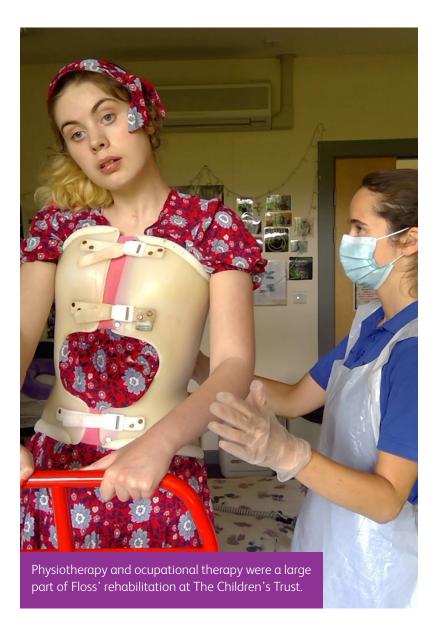


Data from the first lockdown

During the six weeks of the first national lockdown (April/May 2020) The Children's Trust had a flexible approach to rehabilitation placements. Some families chose to return home, some children were admitted sooner to relieve pressure on NHS hospital beds, and some children had shorter placements.

Infection control requirements affected the delivery of our face-to-face rehabilitation services. Restrictions meant that some interventions were delivered remotely, the on-site school was closed, group sessions stopped and families, nurses and carers collaborated more with a restricted group of practitioners.

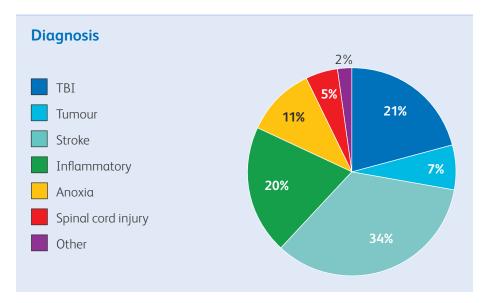
Despite the restrictions, analysis of the data immediately before, during and straight after this lockdown period was encouraging and demonstrated that children and young people continued to meet their goals and make functional gains.



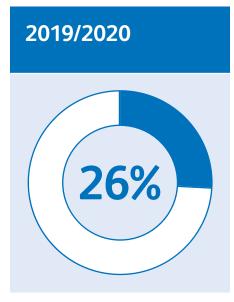


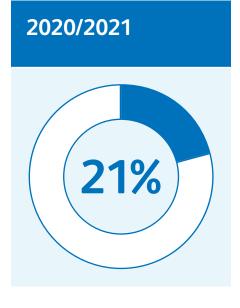
Change in profile of children and young people

This year has seen a change in the presenting profile of children and young people receiving rehabilitation at The Children's Trust.



Colleagues in trauma hospitals report that the number of children sustaining a severe traumatic brain injury (TBI) decreased nationwide during the period in question, as children had pandemic-related restrictions on their activities. The Children's Trust also saw this pattern reflected in the admissions to rehabilitation.





Traumatic Brain Injury accounted for 21% of admission compared to 26% in 2019/20.

Rehabilitation functional outcomes

As one of the only services which can provide the most complex rehabilitation to children and young people with acquired brain injury outside of a hospital setting, our work sees us support children from right across the UK.

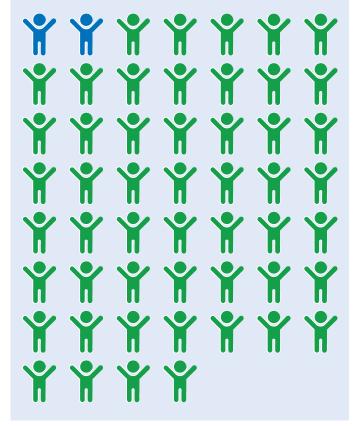
Our rehabilitation service aims to:

- maximise each child's potential
- restore lost skills where possible, develop alternative skills and provide compensatory aids as needed
- facilitate new learning beyond the end of the child's natural recovery period
- develop an understanding of the child's needs
- ensure the child's home environment is modified to support them after their brain injury
- prevent secondary problems such as joint contractures developing.

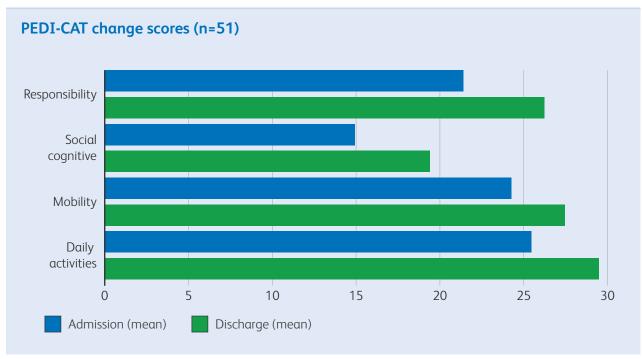
The rehabilitation team also works with the child and their family to help them come to terms with their child's new needs.

Inpatient rehabilitation

A total of 53 children were admitted for a rehabilitation placement during the year. **Two of these children had category B needs** and were funded by their respective clinical commissioning group (CCG), and the remaining **51 children had category A needs**, with their placement supported by NHS England. The outcomes data for these placements has been combined for the purposes of this report.







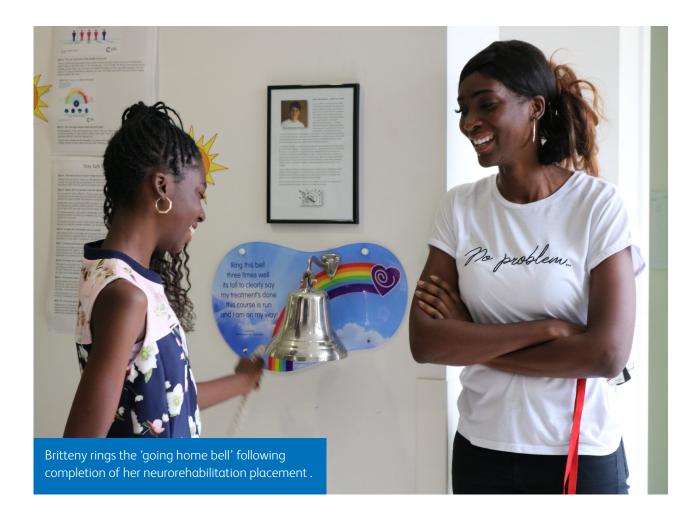
PEDI-CAT scores

Children and young people are easier to care for when they make physical, cognitive, social and occupational gains following an ABI. A score is given as a measure of these gains which is referred to as a PEDI-CAT score.

When the group data for the year is taken, there is a positive change in ability across all the areas of functional ability and participation. PEDI-CAT items include putting on a t-shirt; holding and eating a

sandwich or burger; walking from room-to-room in home; fastening a wheelchair seatbelt; interacting briefly with a peer during play; checking traffic in both directions and knowing where it is safe to cross; choosing and arranging own social interactions.

Some children have difficulty gaining independence in these areas due to the complexity of their injury. Their progress is better reflected in the goal achievement measure, and the family's ability to manage their child's condition.



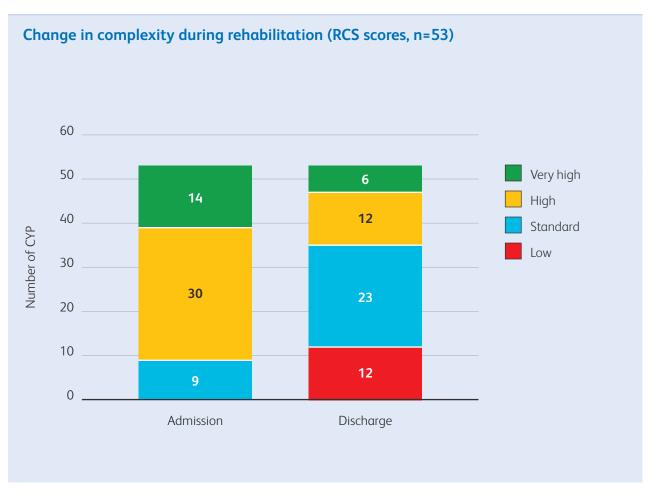
RCS scores

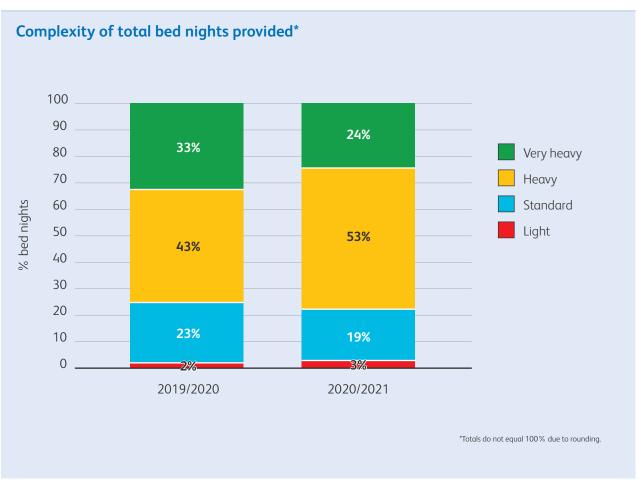
Using the Rehabilitation Complexity Scale (RCS) scores, we are able to see that on leaving The Children's Trust rehabilitation service, there are fewer children and young people in the 'very high' and 'high' categories. These young people are easier to care for and require less specialist service provision.

The chart at the top of the opposite page details the improvement in the children's RCS scores. Complexity data is taken from the Rehabilitation Complexity Scale Extended (RCS-E), and provides a simple overall measure of care, nursing, therapy, medical and equipment needs, and is designed to offer crude banding of complexity. This is used largely within adult neurorehabilitation populations and may not be wholly appropriate at identifying complexity in a paediatric population. Nevertheless, this still gives a like-for-like consistent comparison over previous years complexity data.

RCS scores are also used to determine the complexity needs in terms of bed nights. Specialist rehabilitation providers would expect to have a higher proportion of those with heavy and very heavy needs within their service.

The chart at the bottom of the opposite page shows that in the previous year there was a slight increase in the complexity of total bed nights with regards to those categorised as 'very heavy' or 'heavy'.





Rehabilitation goals (GAS Goals)

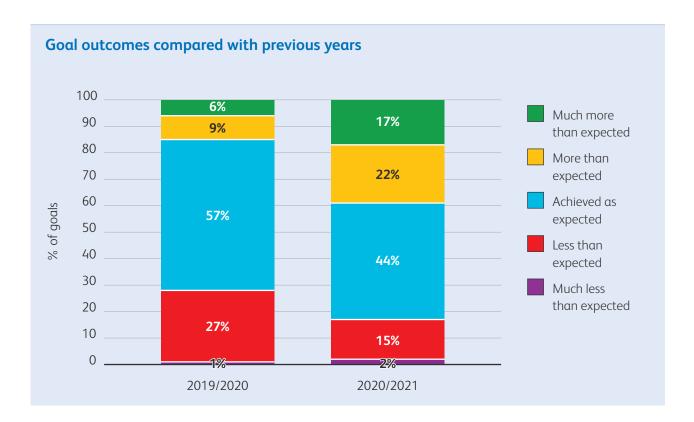
At the start of their rehabilitation placement each child and their family are asked to set five goals that they want to achieve during their time with us. These are integrated into both individual and group therapy sessions and throughout the day.

43 children were discharged during 2020/21 with their GAS (goal attainment scale) goals documented by the therapy team in their discharge reports. They set an average of 5.7 goals each, totalling 246 goals set overall.

This year 83.1% of the goals set were achieved as expected, more or much more than expected.

It is encouraging to see that from the 246 individualised goals, jointly set by children, families and the teams supporting the children, so many are met as expected and above. This demonstrates that our rehabilitation service is helping children meet therapy goals and achieve their personal targets, giving them a better quality of life after a brain injury.

The chart below shows the results of these goals this year, compared with last year.

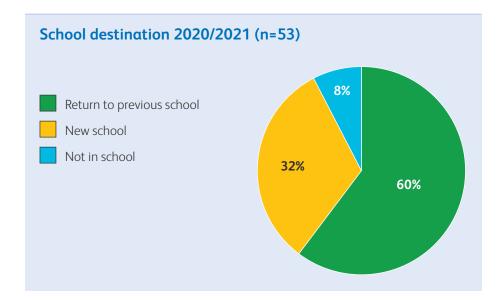


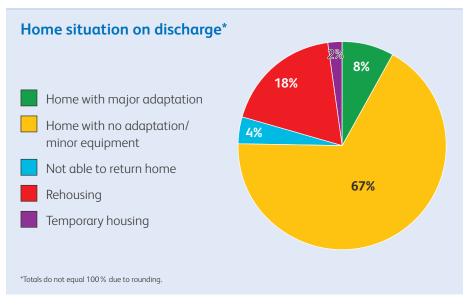
Discharge destination

The children and young people who access the 'Level 1' specialist rehabilitation service at The Children's Trust have a more severe presentation and often require adaptations to their environment at home and at school to participate in everyday life.

In the school year 2020/2021, 53 children left the Surrey Teaching Service that supports children with their education during their stay with us. 32 went back to their previous school (60%). The multidisciplinary team supported 17 children and young people into a new school. Four children are yet to return to school.

In terms of a child's home situation after discharge i.e. whether any adaptive accommodation or rehousing was needed for example, most children returned home from their stay at The Children's Trust not needing any adaptation or minor equipment.



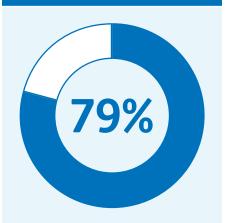


Family-centred care

Families complete an assessment at the end of their child's rehabilitation placement to report their experience of the care that they received.



This year 28 families completed the Measure of Process of Care survey (MPOC).



At the end of the rehabilitation placement, 79% of families reported that The Children's Trust helped them feel more competent as a parent and supported them to meet their child's needs (to a very great or greater extent).

The survey aims to understand more from the families about what The Children's Trust can do to ensure staff support them in every way possible. This evaluation ensures that staff do everything they can to meet the families' needs and always take on board feedback.

Case study Floss's story

In May 2019, Floss was celebrating her birthday when she was a passenger in a high-speed car accident. She suffered devastating injuries which put her in a coma for a month and left her with limited awareness of the world around her for nearly a year.

Prior to the accident, Floss was a fit and healthy A-level student and keen rugby player working towards a career as a lawyer. The accident left her with a severe brain injury, unable to walk, communicate or feed herself.

Nine months after her brain injury, Floss arrived at The Children's Trust with complex neurological needs. She presented with a Prolonged Disorder of Consciousness which meant that she had a reduced awareness of herself and her environment. Floss was fully dependent on others for all aspects of her care and used a hoist for all transfers. Her only way of moving around was in a wheelchair, and she did not have any voluntary movement of her arms, legs, head or body.

"Within the first week of focused rehabilitation, my daughter showed responses not seen before and, three months later, she was clinically declared conscious and on the road to recovery," explained dad Robin.

During her time at The Children's Trust, Floss received a combination of intensive physiotherapy, speech and language therapy, occupational therapy, aquatic therapy, play therapy and music therapy to try and relearn the skills she had lost.

She also began a range of treatment interventions, including splinting for her arms and legs to maintain joint range of movement and Botulinum Toxin injections to reduce muscle over activity. This, combined with the regular therapy sessions enabled Floss to make remarkable progress – meeting one of her goals to regain a level of independence.

When Floss left The Children's Trust, she was able to participate in washing and dressing and was using a transfer aid rather than being hoisted. This involved her reaching and holding on to a bar and being able to pull to stand.

"The Children's Trust helped Floss to start to communicate, start to look after herself, make her first steps in trying to eat and even put her back on her feet with a few tentative and supported steps," said Robin. "Most importantly, The Children's Trust gave my daughter her smile back."



2. The Children's Trust School



Specialist education, therapy and care

The Children's Trust School is a non-maintained special school supporting children and young people aged 2-19 with a wide range of needs including complex education, health, therapy and care requirements. Offering day and residential placements, in 2020-21 the School supported 27 residents, 12 day placements and five nursery children.

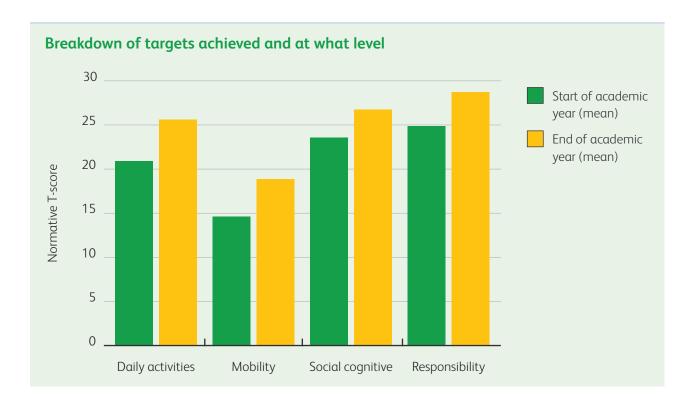
The Children's Trust School uses the ImPACTS Curriculum to set annual goals for each child and young person. ImPACTS is an assessment tool and curriculum that has been developed to ensure the pupil is at the centre of the assessment and planning process. It is used widely by schools that support children with profound and multiple learning difficulties and

our goal setting and scoring is externally moderated with partner schools.

The chart below uses a normative T-score which is used to measure tagets set for the children on admission and targets reached on discharge. As you can see below progress was made in all areas of their targets.

Some goal examples set for the pupils include:

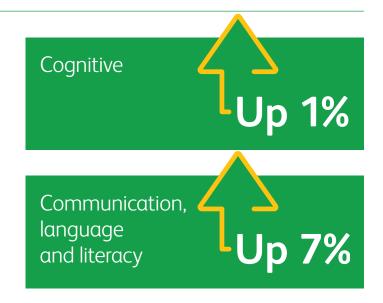
- respond to a known adult voice
- track sound-making objects
- show clear responses to a small range of stimuli
- attempt to repeat a movement again for desired effect, such as banging a drum
- vocalise in response to a favourite activity.

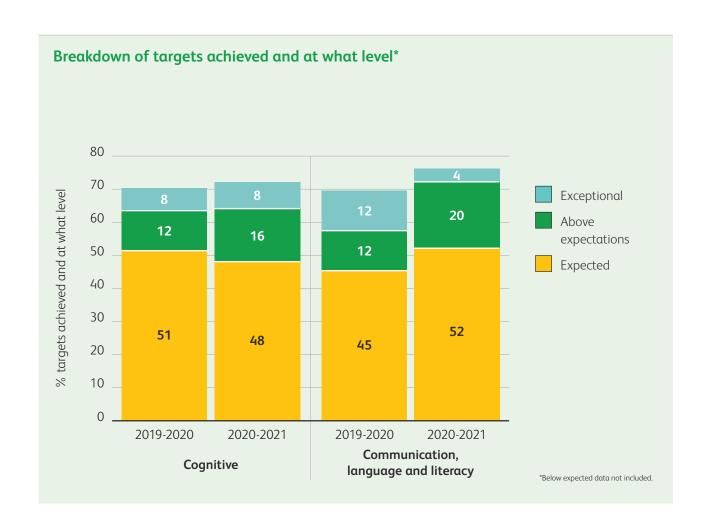


We also look at the comparison between targets achieved compared to the previous year.

The graph below shows that in 2020/21 the young people in the School have achieved a greater number of targets as 'expected' and above than the previous year.

More targets were achieved at 'above expectations' and 'exceptional' than in the previous year, so not only have these targets been achieved but the young people have gone above what was expected of them for these goals.



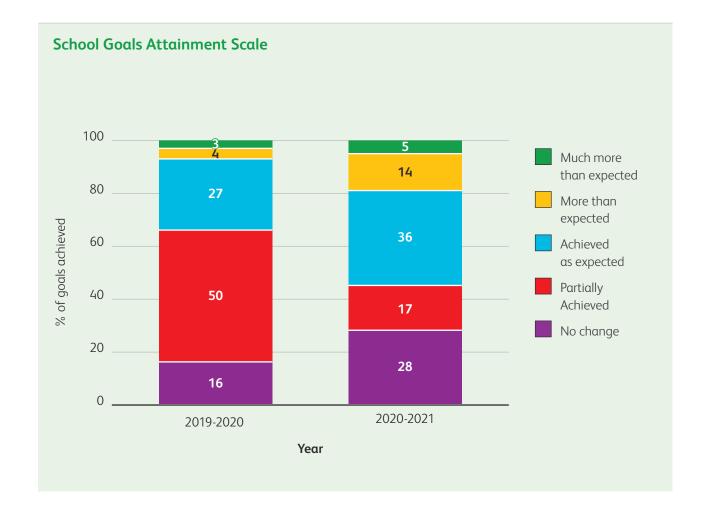


In addition to using the ImPACTS Curriculum to set goals, The Children's Trust School also uses the Goal Attainment Scale (GAS) goals. This is a more developmental goal-scaling approach for use across disciplines with any students where individual goals are set as part of the therapy process.

Throughout the academic year the students and their families are asked to set goals that they want to achieve. These goals are integrated into sessions in the students' individual house and class sessions. Some goals are set within very specific and measurable timeframes, whereas others may represent aspirations of the child and family, such as supporting quality of life or reducing pain.

The graph below shows the achievement of goals, at what level, and in comparison to last year. Last year 66% of goals were not achieved fully and we were concerned that goals were perhaps too challenging for the young people and set over too long a period. This year we have been setting and measuring goals much more frequently so that we can capture incremental changes and progress that happens throughout the year.

We're pleased with the outcomes this year as they demonstrate that the goals were both challenging and realistic, with an increase of goals achieved as expected or above.



Case study Kenny's story

Sensory activities helped Kenny adjust to a new kind of learning during the COVID-19 pandemic.

Kenny has epilepsy, autism and complex education, health, therapy and care needs. He has been a pupil at The Children's Trust School since 2019.

During the past year Kenny's school day routine and class groups changed due to social distancing rules. While he initially found the changes unsettling, he quickly adapted.

During lockdown Kenny continued to have planned opportunities to continue skill acquisition and development against his intended learning targets.

Kenny participated in many creative sessions both virtually and face to face wherever possible both indoor and outdoor to provide a variety in approach.

There was a real effort by staff to ensure that routines were maintained to support the children's understanding of what was happening and to make them feel secure during a time where change was huge for them.

Kenny's mum, Jenny said: "The Children's Trust School has really brought out Kenny's confidence. Previously he was quite shy and would become uneasy meeting new people. Now, he is more confident and will show excitement with a big smile."

She added: "As The Children's Trust has continued to operate during the pandemic, I have been really blessed with the opportunity to continue working, knowing that Kenny is well taken care of and can continue to access full educational activities.

I am very grateful to the staff."







Support in the community

Our Brain Injury Community Service provides goal orientated neurorehabilitation in the child's environment, either in school, or home, or a combination of both. A long-term register is also in place to monitor the needs of the child or young person at key stages of development and offer support if new needs arise.

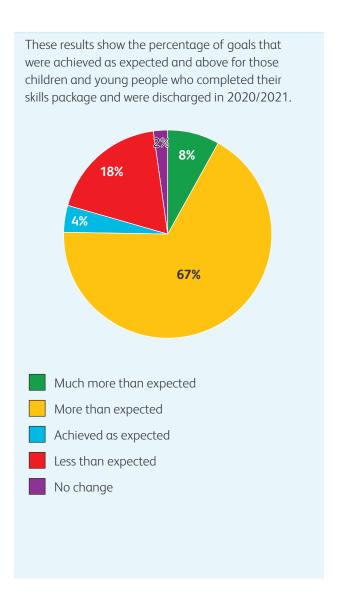
The Brain Injury Community Service supports children and young people who:

- have a confirmed or suspected diagnosis of an acquired brain injury, either recently or some years ago
- are medically stable
- are 18 years and under at the time of referral
- are registered with a UK GP.

During the period in question, 1,711 children and young people were supported by our Brain Injury Community Service. This included access to clinical screening, advice about acquired brain injury and rehabilitation, onward referrals or liaison with the child's professional network. BICS worked with 16 young people on a funded skills package. Of these 16 children, six young people completed their skills package and were discharged from the service in 2020/21.

At the outset of this support each young person works with the brain injury specialist to set some goals to measure the outcomes from the support provided.

Of the 26 goals set with young people at the beginning of their support, 85% were achieved as expected or above. The brain injury community team work closely with the support network around the young person, such as their teachers, carers, parents, and other professionals. These people will have a big influence over the success of these goals and the aim is to work within these networks to achieve the best possible outcomes for the young person.



Case study Henry's story

Henry was four when an infection led to encephalitis – an inflammation of the brain.

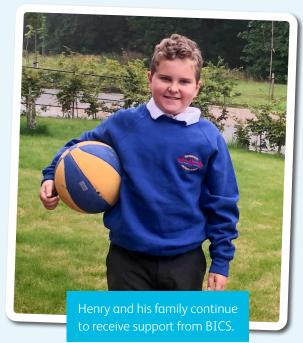
"We were told Henry would recover completely and were given no further information," explained mum, Andrea. "It was a big mistake for him to return to school. He became aggressive and could not cope with noise, smells, and sensation."

"He experienced awful headaches and the feeling of 'ants crawling' in his head. He refused to participate in PE as jumping hurt his head and he ended up being restrained a few times."

Over the next five years the family were advised that Henry's behaviour would improve. After reaching out to The Children's Trust's Brain Injury Community Service (BICS), Andrea said they finally started to understand Henry's difficulties.

"It was such a relief to speak with someone who could tell us why our son struggled so much," she said. "The BICS team described our son's behaviours exactly. I cried with relief when I got off the phone!"

Henry and his family have continued to receive support from BICS who have been able to help them manage the effects of his brain injury through strategies and information.



Our mission is to help children with brain injury and neurodisability live the best life possible. Partners and funders believe in this and support us to deliver our services. This outcomes report demonstrates the positive impact we have on the lives of the young people we support in order to reach this mission.

By taking into account personal targets and clinically-led goals, we have measured the progress that the children we support have made. The progress this year that the children have made demonstrates the huge impact all three of our services have upon in ensuring children reach their goals, giving these children and their families a better quality of life after a brain injury.

Investment in rehabilitation saves money

Each year, 1.4
million people
attend emergency
departments in
England and Wales
with a recent head injury.
Between 33% and 50%
of these are children
aged under 15 years.

Source: NICE 2019.

Around 40,000 children experience a brain injury every year, either through illness or accident.

That's one every 30 minutes.

Source: NHS England.

30,000 children and young people are admitted to a hospital ward with an ABI a year.



Source: NHS England data 2016-17.

Patients with a traumatic brain injury who receive rehabilitation once they have left an acute hospital setting, cost the NHS and social care £27,800 less a year than those who don't.

Source: Manifesto for Community Rehabilitation: let's live well longer, UKABIF 2019.

For every £1 spent on orthotic services £4 is saved.



This represents a saving of £400 million to the NHS.

Source: NHSE Commissioning Guidance for Rehabilitation 2016.

Annually about
200,000 children
and young people
attend A&E with a
head injury



Source: NHS England data 2016-17.

Neurorehabilitation is one of most cost-effective interventions available to the NHS. Substantial and robust evidence supports the clinical and cost effectiveness of neurorehabilitation. Although individuals with complex needs may require a longer hospital stay, the front-loaded cost of providing early specialist neurorehabilitation for these individuals is rapidly offset by longer-term savings in the cost of community care, making this a highly cost-efficient intervention. These savings are substantial and have been estimated at £500 per week for each ABI **survivor** requiring specialist neurorehabilitation, or over £5 billion of annual savings for the 300,000 individuals who need this service each year.

Source: Time for Change, APPG Report 2018/9.

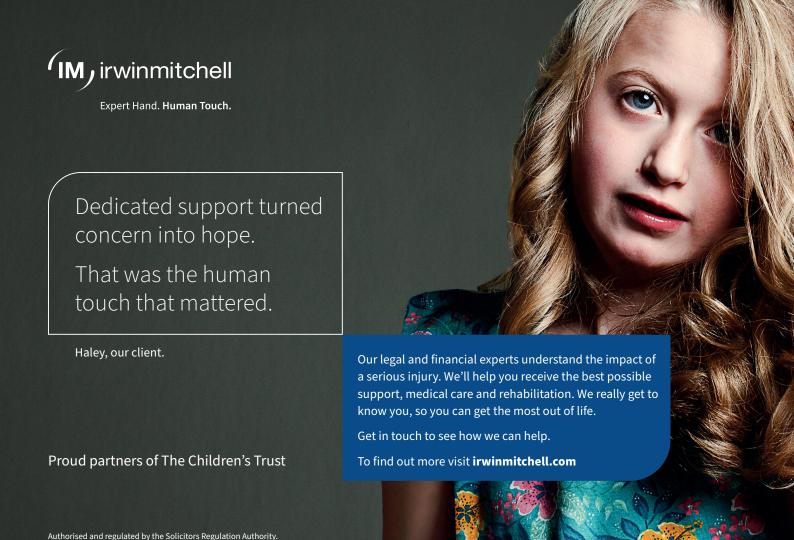
1.3 million people live with the effects of brain injury at a cost to the UK economy of **£15 billion per annum**, a figure that is equivalent to **10% of the annual** NHS budget.

Source: Centre for Mental Health.

A young person with a brain haemorrhage normally moves on from an acute hospital setting to an older person's care home for life. If, instead, they moved to a specialist centre for rehabilitation, within five years they'd be living independently. Over the course of a lifetime, this saves £2 million from social care and NHS budgets.

Source: Manifesto for Community Rehabilitation, Nov 2019/The case for proactive neurological care. London: Sue Ryder; 2018.

Please note that these examples are for illustrative purposes only. Each child/young person will have different rehabilitation needs and therefore different outcomes. Some of the illustrations shown are based on adult measures where paediatric measures are not available.



Want to know more about our work?

We have ambitious plans for the future and want to ensure that every child and young person affected by brain injury and neurodisability has access to the rehabilitation and support they need.

For further information on our work, please get in touch.

01737 365 000 enquiries@thechildrenstrust.org.uk

For enquiries about a placement or support for a child or young person, please contact us via:

01737 365 080 placements@thechildrenstrust.org.uk

The Children's Trust

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Charity registration number: 288018 Company registration number: 1757875











Accredited and Certificated by











The Children's Trust is accredited by CHKS with ISO 9001 certification (for organisational and clinical management systems), inspected and rated 'Outstanding' by CareQuality Commission and rated a 'Good Provider' by Ofsted Care (for residential houses). The Children's Trust School is rated a 'Good Provider' by Ofsted Education. TCT 1260 01/22.