

Changing Lives



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The difference we make

Today, charities are expected not only to do good work but also to contribute to economic, social environmental well being and to demonstrate the social value of their work.



Economic value

In demonstrating the social value of Chailey Heritage Foundation, we could have focused on our economic impact, the difference we make to the local economy. We have around 450 employees and more than 60 volunteers and this number continues to grow year on year in response to meet the increasing demand for our services and the increasing complexity of the support needs of the young people we serve. Most live in Sussex not far from Chailey itself and so the Charity is contributing approximately £8.5 million to the local economy.

Where ever we can, Chailey Heritage Foundation uses Sussex companies for regular supplies or services. Our latest £3.1m Dream Centre project was designed by Brighton based architects and built by a Sussex construction company, with gifts in kind from local building suppliers and technical support to specify, procure and install the cutting-edge audio visual systems.

Our economic impact isn't confined to Sussex. With our local NHS partners, Chailey Clinical Services, we now have four pupils on long-term ventilation (LTV) with others seeking places; some live at home and come to school daily, while others live at Chailey Heritage. We have developed the skills needed to allow these children to leave hospital or other settings where the cost of a paediatric bed for a LTV child was just under £2,000 per day – £719k per year (calculated in 2016). If young people from Chailey Heritage need to go to hospital, they can be discharged earlier because of the nursing care and medical backup they can have here.

Social value

The softer elements of Social Value such as our contribution to disability awareness are harder to calculate. Through our website and digital media, we are raising awareness of just what children and young people

can achieve and why they are worth the high investment needed in their education, care and health needs.

We engage with influential local people, including MPs, to raise awareness of the needs of disabled young people and get behind national campaigns led by Disabled Children's Partnership.

Impact on children, young people and families

However, as a charity, our focus is on the children and young people and their families. They are the heart of all that we do and so we wanted to focus on the difference that Chailey Heritage Foundation makes to the children, young people and their families who use our services. We have asked them what have been the additional benefits of coming to Chailey Heritage? What has changed for them?

We have included families because all the children and young people using our services have people who love them – parents, siblings, grandparents, wider family and friends. What happens to the young person has a profound impact on their daily lives.

We engaged a well respected leader in the field of social value to focus on this aspect of the economic impact our work – its impact on the daily lives of young people and families. You can read a summary on our "Social Return on Investment" study by Kingston Smith Fundraising and Management in a separate leaflet.

In the end, proxy measures and ratios of the social value of every £ donated or spent don't come close to explaining the real value of using one of our services makes to the daily lives of young people and their families – so we asked families to explain in their own words. Read how being at Chailey Heritage has affected Raihana, Christopher, Sam, Ellie and their families or watch them in our film and meet Archie to see how Chailey Heritage Foundation CHANGES LIVES.

Meet Raihana



"Raihana is really, really happy at Chailey Heritage she is having a great social life with her friends. Family communication is still very strong – we FaceTime every evening so Raihana can catch up with her twin brother and sister and we visit her at weekends."

Kenny, Raihana's Mum



"Raihana's Consultants at the specialist London hospital she attends for regular check-ups are so impressed with her development, her responses and her interaction with people since joining Chailey Heritage. This is testament to the real difference a fully integrated nursing, care and education package can make to the life of a child with complex needs."

Andrew, Head of Residential Operations

Born 13 weeks prematurely and weighing less than 1kg, Raihana faced several life-threatening complications which would have massive consequences for her life ahead. Her early entry into the world and the ensuing complications haven't held her back from becoming a happy and social little girl; her bright grin and cheeky personality show off her zest for life.

Raihana has complex medical needs and depends 24 hours a day on her ventilator to help her breathe.

Raihana now lives full-time at Chailey Heritage Foundation, which was a very difficult decision for Raihana's mum as she would dearly love her to live at home with her twin brother and her sister, but caring for Raihana 24 hours a day was having a significant impact on the whole family.

Living at Chailey Heritage Foundation means that Raihana is now able to go to school every day just like any other child. This is made possible with the two-to-one support she receives at all times from highly-trained staff from the bungalow where she lives, school and, very importantly, the NHS nurses from our clinical partners on site.

Raihana's complex health needs certainly don't stop her leading a full life. She enjoys swimming, horse riding, trampolining, cooking and music, all on site at Chailey Heritage Foundation. She also loves going to the cinema and her highlight of the year was going

on holiday with all her friends from the bungalows. Mobility and communication are key to Raihana's independence and these are priorities for young people at Chailey Heritage Foundation. Raihana is learning to communicate and drive her powered wheelchair using assistive technology. She is now able to express what she likes and dislikes and chooses which clothes to wear each morning; staff no longer have to answer for her.



Pioneering Special Education for more than a hundred years



The programmes of study the pupils of Chailey Heritage School follow are very different to their mainstream peers because each and every one of our learners is very different. They have varying levels of needs matched with different abilities, but they all share something very special, and that is bags and bags of potential. Our role as educators is to pursue this through every means possible and discover how to unlock each pupil's potential.

Each pupil has their own curriculum to follow, carefully crafted by those closest to them, including their family, to create a series of 'My Next Steps'. These 'My Next Steps' are little achievements on the way to bigger milestones, each themed around one of the profiles which make up the pioneering CHILD (Chailey Heritage Individual Learner Driven) Curriculum.



It's a joy to hear from parents and families who tell us of the great pride they feel in seeing their child making progress, being able to communicate a choice, or learning to drive a powered wheelchair, coping with new environments, interacting with their classmates and much more.

"Chailey Heritage are absolute experts at spotting those tiny changes that make all the difference – a blink of an eye, a movement in the fingers or a quiet sound."

"We are very happy with Katie's education and care teams. They tailor their plans and activities to Katie's needs and develop processes to help her achieve and reach her goals. Katie's TA is amazing! Thank you everyone!"

"The curriculum is completely developed for each individual child. He or she may be in a class of seven, but each will have their own unique curriculum, their own timetable, and each and every member of staff will be looking out for the tiny bits of progress that we know we're working towards, and even for little bits of progress we didn't know we were looking for; we'll capture those and move on."

Simon Yates, Headteacher

Our mission

"Every young person at Chailey Heritage School will be given every opportunity to make progress towards fulfilment. We will never, ever give up looking for ways to support our young people to make their own choices in life, and to achieve their own desired destinations."



The CHILD curriculum consists of totally personalised learner profiles detailing aspirations, strengths, needs, skills, long-term outcomes and next steps.

The learner profiles are:

Engagement Support, Communication, Physical, Access Technology, Social and Emotional Well-being and Powered Mobility, and for some learners Functional Skills and Subject Specific Learner profiles are applicable.

The CHILD ethos also underpins both Aquatics and Rebound Therapy curriculums for pupils at our School.

Fundraising

How your support helps

The extensive range of specialist equipment and facilities available to the pupils here is second-to-none, and simply would not be possible without the very generous and loyal support of individuals, companies, trusts and foundations and other organisations.

Opportunities to use technology like eye gaze, where pupils control a computer with their eyes, can provide the key to unlocking these very special young people's minds, allowing them to communicate.

Meet Christopher



"Christopher's carers respect the unique knowledge that I have built up over the years, while also offering their own invaluable expertise. It's a collaborative approach that I have not experienced elsewhere."

Paul, Christopher's Dad

As a bright young man with a mischievous sense of humour and a determination to succeed, Christopher cannot help but charm everyone he meets. And it's fair to say that Christopher enjoys meeting new people, especially when they happen to be royalty, sporting heroes or politicians!

Christopher is a full-time resident here at Chailey Heritage Foundation, living in Orchard bungalow with four other young adults. His days are filled with activity, whether working out at the gym, enjoying a trip to laser quest or writing computer code in our IT suite.

Yet when Christopher was born with cerebral palsy as a result of medical negligence, his parents were told that he would not live through the night. As the nights, days and weeks passed, the outlook seemed more hopeful. But even when Christopher's parents finally took him home they were warned: "He will always be a vegetable."

Those predictions were so wrong. While Christopher's physical needs are undoubtedly complex, he has excellent cognitive ability and thrives on intellectual stimulation and social interaction. He is able to communicate using a variety of techniques, including turning his head and eyes left or right to indicate "yes" or "no".

Originally from Kent, where he attended special schools and passed his GCSEs, Christopher first came to Chailey Heritage Foundation in his early twenties as a visitor to our Life Skills Centre. Shortly afterwards, he moved into Orchard bungalow, where he has been able to enjoy increased independence and autonomy in decision-making.

Christopher's Dad Paul says: "I was confident from Christopher's very first day in Orchard bungalow that he was being cared for expertly, that he was being listened to, and that all his needs would be met, all of the time. This was a wonderful feeling – I slept that night!"



There are many aspects of living at Orchard that Christopher enjoys, including weight training, boxing, and playing Crash Bandicoot on the computer. But it's often the little things that mean the most, such as deciding on his own bedtime (preferably as late as possible!).

Despite Christopher's disabilities, he is determined to set challenges for himself. For example, he recently told staff he would like to swim underwater, and so they investigated the purchase of a suitable snorkelling mask that would enable him to fulfill this wish. In fact, this is just the latest in a string of achievements during Christopher's lifetime – he has also beaten F1 champion Lewis Hamilton at bocchia, met the Queen and Prince Philip, and led a deputation to the Houses of Parliament to campaign for disability rights.

"Christopher is very determined and at Chailey Heritage there's a sense that anything is possible," says Paul. "I trust the staff absolutely. I recently lost my father and my mother within a short space of time, and everyone was incredibly supportive not just of Christopher but of the family as a whole. This feeling of family and closeness always shines through – however difficult the situation, there will be a sense of humour and a light heart. Chailey Heritage is a vibrant place, and I am so happy that Christopher has been able to experience all the fantastic opportunities on offer."

Celebrating our staff and volunteers

The impact Chailey Heritage Foundation makes is only possible because of our amazing 500 strong team of employees and volunteers, who together support over 300 children, young adults and their families every year across our care, specialist education and community services.

Around 80% of the cost of a place in our services is for staff. The number of staff has increased rapidly over the last five years as the complexity of the young people referred to us has increased considerably; almost without exception, new pupils in our School require at least one-to-one support. Working with young people with complex special needs requires very special people and our dedicated workforce is highly trained to meet the complex learning and health needs of those young people.

The professionalism, compassion and commitment shown to the young people we support by each and every one involved with us truly embodies the Charity's promise **'we will never ever give up working with children, young people and their families to empower them to make their own choices at every stage in life'**.

Over two thirds of our staff are support workers and teaching assistants; those at the heart of everything we do, working daily with the young people, keeping them healthy, and ensuring that they are safe and lead happy lives.



Stepping stone into adult life
In 2010, Chailey Heritage Foundation launched its first young adult provision open to those aged 19-25 and offering a stepping stone into adult life. Futures Accommodation continues to support young adults with complex disabilities with the transition from school or college into adult life, and beyond.

NHS relationship

We are proud to work in partnership with Chailey Clinical Services, part of Sussex Community NHS Foundation Trust.

This unique, on-site relationship enables the young people in our care access to a highly qualified and experienced team of Consultants, Doctors, Nurses, Therapists, Rehabilitation Engineers and Dietitians, as well as various visiting specialists.



Meet Sam

"The minute we stepped inside the School we experienced an overwhelming sensation of family and warmth. A whole new world opened up to us."

Vicki, Sam's Mum



Like many children his age, Sam loves football, computer games and watching TV with his family. He's a keen Brighton & Hove Albion fan and has even played at the club's Amex stadium. For most parents, knowing what makes their children happy or unhappy is simply a part of everyday life. But for Sam's parents, Vicki and Alec, the ability to understand their son's wishes and needs is a breakthrough they will never take for granted.

Sam, 10, has a rare genetic condition called CDKL5, which causes severe seizures and means he is unable to communicate verbally. When Sam joined Chailey Heritage School at the age of four, he had no clear way of making his feelings known – if he seemed unhappy or in pain, Vicki and Alec would often struggle to pinpoint the reason.

Several years on, the picture couldn't be more different. Using a small 'thumbs up' movement, Sam can now take part in conversations, make his own decisions, and even tell his mum how much he loves her.

Vicki says: "The staff at Chailey Heritage have been the key to unlocking our son to us. We can now feel confident that he understands what's going on around him, and that he is involved in his own learning. The fact that he can be understood makes a huge, huge difference to his wellbeing, and we couldn't be more grateful to his teachers and carers for their commitment to making this happen. The ethos at Chailey Heritage is to combine compassion with medical expertise – it's a holistic approach that is tailored to each individual child and works so well."

Communication between staff and parents is also high on the agenda, says Vicki. "I can go to work in the morning confident that all Sam's needs are being met, but I know if there's a problem, I will be contacted. At the end of the school day, we'll read Sam's diary and see photos of what he's been doing all day - I'm constantly amazed to find out about the new things he has been discovering. He enjoys horse riding, loves Patchwork Farm, and especially likes using the computer."

It was while working on the computer with his teaching assistant that Sam was able to communicate 'I love you' to his mum. "It's impossible to express how much that meant," says Vicki.

Sam's two sisters, Daisy, 12, and Zara, 5, also feel part of the Chailey Heritage community; they are able to join in holiday clubs and the whole family can use the specially-equipped swimming pool at weekends.

Much as Daisy and Zara love their brother, Vicki recognises that being the sibling of a severely disabled child has many challenges. This led her to set up SIBS, a Chailey-based group that connects siblings from different families.

"We'll arrange activities such as making dens in the wood or kayaking," explains Vicki. "It's great for the children to get together and let off steam. As families we all 'get it' – we understand the frustrations and get comfort from comparing experiences and sharing information. We come to rely on each other. For our other children, it's much harder but actually they soon realise that there are many other kids out there who don't stare anymore and for whom wheelchairs, feeding pumps and birthdays spent in hospitals are all too familiar."

This year, Sam had his first ever school photo taken. "It's a gorgeous picture and to be able to display it alongside Daisy's and Zara's school photos is something I thought we'd never see. We are just so grateful for his progress at Chailey Heritage and extremely proud of everything he has achieved."

Support for families every step of the way

We are proud to say that we work in partnership with parents and families at every step of their journey with us, providing support at difficult times and celebrating achievements together.

Often the best support comes from peers and the Chailey Heritage community is extremely warm, welcoming and proactive. There are two independent groups, CHIPS – Chailey Heritage Information and Parent Carer Support and Chailey Heritage Siblings Group.

Direct feedback from families is important to how we work and we are always looking for ways to improve. Working with families and our charitably-funded Family Liaison Worker, we co-produced a film titled 'in our shoes' to educate our staff on the challenges families face living with a disabled child.

The Aquamovers+ group was created to give parents of toddlers and young children with disabilities access to expert physio and speech and language therapists in an informal setting. Very quickly it established itself as much more; the feedback from parents is that Aquamovers+ has become an invaluable support network, providing an opportunity for parents to meet and socialise with other parents of children with disabilities, and make friends for life.

Working closely with parents is one of our most important partnerships and this collaboration has reaped many rewards. In response to issues raised by parents about school meals, we embarked on a project to improve school meals, resulting in a production kitchen being installed within the Dream Centre, together with a Chef, to ensure pupils can have food cooked 'from scratch' rather than frozen meals.



Chailey Heritage Foundation is a proud supporter of the Disabled Children's Partnership, a major coalition of more than 70 organisations campaigning for improved health and social care for disabled children, young people and their families.



"Since arriving at Chailey Heritage, we have built strong friendships and we get emotional support from other parents. Chailey Heritage is the only place I leave my child, knowing I don't need to worry ... it is our life ... it's like our second home so thank you."

Parent

Meet Ellie



"Connecting with other parents via the Chailey Facebook group has been so helpful. It means a lot to be part of a community that understands."

Liz, Ellie's Mum



"Chailey is unique in every way – just like Ellie!"

Liz, Ellie's Mum

With her cheeky smile, irrepressible curiosity and keen sporting talent, Ellie is a little girl who is most definitely going places.

Despite suffering from complex health conditions including cerebral palsy, autism and severe epilepsy, 11-year-old Ellie has made amazing progress since becoming a pupil at Chailey Heritage School two years ago.

She loves to ride on her favourite horse, Tod, excels in wheelchair sports including boccia, curling and table cricket, and has a fascination for the animals that live at Patchwork Farm (especially the tortoises!). Taking part in team sports has awoken a competitive streak in Ellie, and she now has dreams of competing at the highest level.

Watching Ellie interact with her teachers and fellow pupils, it's hard to believe that she once found the classroom a very daunting place. At her previous school, she had become withdrawn and insular, and as her epilepsy worsened, it was clear that more specialist support was needed.

Ellie's mum Liz explains: "A nurse told us about Chailey Heritage Foundation and as soon as we began researching the school, we felt sure it could be the right place for Ellie. On our first visit, we were bowled over by the warm welcome and friendliness of the staff, the wide variety of activities on offer and the fact there was so much medical expertise on-site.

"We were very fortunate to secure a place, and from the moment Ellie joined Chailey Heritage in the spring of 2017, she has never looked back. When the school minibus picks her up in the morning she always has a smile on her face.

"Ellie now follows a ketogenic diet and we think this has helped to control her epilepsy. Although she still has profound challenges, to know that these are being managed by experienced nurses on-site – with an NHS Consultant always on call – is just an immeasurable relief. It's fair to say that Ellie lives each day with a huge amount of drive and zero self-pity – we couldn't be more proud of her."

Knowing that Ellie is happy and confident has had a positive effect on the whole family. Ellie's new school hours mean there's more time for Liz and her husband Terry to take their sons Bill, 9, and Daniel, 8, to clubs such as karate and swimming. And Liz has been able to return to her job working four days a week as a Registrar.

"Chailey Heritage has been the best thing ever - not just for Ellie, but for all of us," adds Liz. "The boys are able to take part in so many more activities, which means we don't have to feel guilty that they are missing out. And Ellie's happy too – in fact she's in her element, and we feel quite blessed to know she's being cared for so brilliantly."

Making dreams come true

"We always strive to create a family-like environment for the young people and the Dream Centre will enable us to come together in one place to celebrate individual achievements, as well as for drama, sport and music performances."

Carol Llewellyn, Teacher



"This project would not have been possible without the phenomenal support of the sponsors, trusts, foundations, local businesses and the general public who have helped raise the funds needed for its design and build. Many of the activities that the children and young people will be able to take part in will be ground-breaking and will really broaden their horizons and enable them to develop new skills. A big thank you to everyone who helped us achieve our ambitions."

Sally-Anne Murray, Development Director

The Dream Centre is the latest chapter in the story of Chailey Heritage Foundation, which has been changing the lives of young people with disabilities for more than a hundred years.

The Dream Centre is a modern, accessible facility which gives young people with complex disabilities the opportunity to get the most out of life. The new centre has doubled the size of the redundant Grace Kimmins Memorial Hall, opened in 1958. This £3.1 million project was completed in the summer of 2019. The Dream Centre nods to our heritage and our Founder, Grace Kimmins, whilst looking forward to the future with a facility that uses state-of-the-art technology to create stimulating and engaging environments for themed learning.

The Dream Centre has an indoor sports court for accessible sport such as wheelchair football (inside for the first time), boccia, new age kurling and table cricket all year round. The new trampoline, which is built into the stage to make the most of the space, has transformed rebound therapy. Previously held in our cold and inaccessible 1950s hall, we now have a permanent home for rebound therapy, which has become such an important part of the physical programme for all the young people on site.

Beneath the sports court is a built-in tracking system which is used for our powered wheelchair driving school. As all of the young people use a wheelchair for some or most of the time, this addition enables

them to learn to move independently and practice using different terrain in a safe environment.

Perhaps the most innovative aspect of the Dream Centre is the immersive experience zone in which real world environments are simulated. Simulations include being on a roller-coaster, trekking the desert and swimming under water, which brings brand new experiences to the lives of the young people, who may never be able to experience these scenarios first hand. It also forms the backdrop for drama and the school's World Culture Fridays, allowing the pupils to be fully immersed within a chosen culture, using interactive sensory cues.





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