The Chronicle Sunshine Fund



Address: NCJ Media Ltd, 2nd floor Eldon Square, Percy Street, Newcastle upon Tyne, NE1 7JB Registered Charity Number: 1133293 Website: www.thesunshinefund.org Telephone Number: 0191 201 6090



# The Sunshine Fund Christmas Appeal 2023 Harry Havelock



**16 million** people in the UK live with a disability.**11%** of these are children.

According to research conducted by Newcastle University, **1 in 57 children** in the UK are on the autistic spectrum.

As of June 2023, there were **143,119 patients** with an open referral for suspected autism. **83%** of these referrals had been open for at least **13 weeks**.



# Meet 4-year-old Harry from Newcastle...

Harry is a very happy little boy whose favourite things to do are bouncing on trampolines and being pushed on swings. He's becoming increasingly fond of his iPad and though he doesn't quite understand TV shows, he enjoys Super Simple Songs and Hey Duggee.

Harry's parents describe him as very pure, in that he likes what he likes and doesn't like what he doesn't like; he likes to get on and do his own thing. He never complains, he isn't mean and he never intentionally misbehaves – he's just himself, he's just Harry.

Harry has autism, delayed motor skills, sensory processing difficulties and PICA (eating non-edible items), amongst other additional needs. He received his official diagnosis of autism spectrum disorder on Wednesday 26th July 2023, which was where our journey with the Havelock family began...

The same day the Havelocks visited their GP surgery to receive Harry's anticipated autism diagnosis was the same day we were at Cruddas Park Surgery hosting one of our sensory session days.

> We first saw Harry, a very smiley, energetic boy enter the room, with his parents, Lauren and Richard, who (and I'm sure they won't mind us saying), were at a bit of a loss. Lauren has family who work at Cruddas Park, many of whom had mentioned our charity to them, and so they decided to drop by, which was the start of our relationship with them.

We're sure many parents who have received that autism diagnosis, or who have waited and waited for an official diagnosis, can relate to the struggles that can come with this journey. The feeling that until you receive an official diagnosis, your world can feel like it's hit a wall.

The Havelocks had expected the diagnosis after years of identifying **traits of autism (spinning, stimming, lack of eye contact and not responding to his name)**, and after Harry was flagged by staff to be put on the pathway for an autism assessment at his very first day of playgroup in 2021.

Lauren worked hard over the years to **make physical contact and build a connection** with him, that connection that so many of us take for granted. In Richard's own words, **"no child loves their Mam more than Harry loves his"** – and this special bond was so immediately obvious the moment we met the family.

The family were able to obtain a DLA (Disability Living Allowance) for Harry early on which provided 15 hours of 1-on-1 support per week. While the government provide 30 hours of free childcare, the staff couldn't look after him without it being 1-on-1.

The process of getting Harry to school was nothing short of a nightmare; his Educational Health Care plan (EHCP) didn't reflect Harry's needs and he was subsequently recommended a mainstream school with some additional funding, and because of this, he didn't have an official school until the day before he started in September. Harry's ECHP had a customised learning plan and while the school was great, they simply didn't have the resources or staffing to look after Harry for more than a few hours each day, and they couldn't create or implement the learning plan that his ECHP had suggested. The general consensus was that he was better suited to a specialist school.

It was during this time that we first met the Havelocks at our summer-themed mermaid sensory session. As well as providing activities for children with additional needs to get involved in, our family events also give parents the opportunity to talk to our team; whether it's for advice or guidance, or to simply have a friendly chat or vent with **people who just get it**.

Our Families Co-ordinator, Bev, and our Strategic Partnerships Officer, Rachel, sat with Richard and Lauren for a good hour, and listened to their story. They voiced their concerns about Harry's EHCP, and how they felt failed by the Local Authority, and really just wanted to know, **"what do we do now?"**. We empathised with their situation and Bev advised that they contact SENDIASS immediately, as well as providing details to someone who could offer more specialist advice.

The family did what was suggested and ended up going through mediation, and with the help of SENDIASS, had the EHCP rewritten, which was when a new school was recommended. After what seemed like a never-ending battle with the Local Authority, Harry finally got a place at a specialised school for children with autism, which he started on 6th November 2023. His school days are tailored to him and provide the support he needs, it allows him to be himself and engage at his own pace, and he will be looked after until the age of 18.



# And what does Harry think ...?

"He absolutely loves it. He likes riding the bus to and from school every day, as he can see everything go by. They have swimming, trampolining (rebound therapy) which Harry is very much enjoying. It is a huge relief that he is now in the right place for him. If we hadn't talked to Rachel and Bev on that day, I don't think Harry would be where he needs to be today.".

- Richard, Harry's Dad



Our family events are so important for both children with additional needs, but also for the families, too. We put on several events throughout the year, and these can range from sensory sessions and messy play, to trips out to the farm or cinema. It's our mission to provide activities where cost and accessibility aren't barriers, and to allow families to make special memories in an inclusive, comfortable environment. They also build a community and allow families to meet other like-minded parents, to create friendships.

Since meeting the Havelocks at our mermaid session, we've had the pleasure of seeing them at a couple of our other family events since then, and it's been so lovely seeing their confidence as a family grow.



The last time we saw the family was at our Halloween sensory day at the Metrocentre Community Hub, where we had a variety of different areas and activities. This allowed Harry to interact with some of the activities at his own pace, whilst having the option to dip in and out as he also wanted to walk around the shopping centre.

This session took place just 1 week before Harry was starting at his new school, and it was truly wonderful seeing how far the family had come since we first met them, and how much happier they were. We were all so excited for Harry to start at his specialist school, and we are so genuinely pleased to hear how well he's settling in. In August, the family attended our beach day at South Shields, where we invited families to spend the day exploring and playing on the beach, as well as participating in surf sessions, too! There was something for everyone as we had group surf sessions and 1-on-1 adapted surf sessions with a team of highly trained professionals from South Shields Surf who use specialist equipment. We worked with Beach Access North East to test out their beach-friendly wheelchairs, which Harry enjoyed whizzing around in!

Richard told us how Harry has a younger brother, 1-year-old Theo, who's also on the pathway for an autism diagnosis. The pair are very different in personality, and because of this it can be tough to find an activity that focuses on Harry and provides the best environment for him.



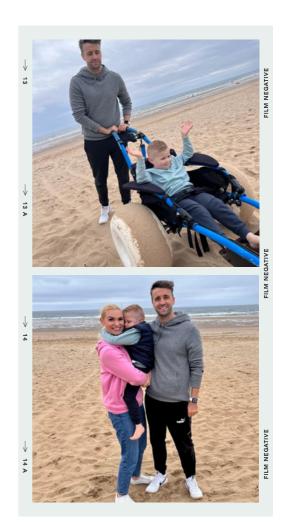
"I would say the beach day was the most fun Harry has ever had being outside with others. he absolutely loved it – we were both emotional afterwards because of how great it was to see him this happy. The events in general are great as there isn't any judgement, something that can happen when we're out at the park or Metro Centre, or with friends and other children."

- Richard, Harry's Dad

It was here that Bev encouraged them to apply for equipment that isn't available through the NHS or Local Authority. We explained that the equipment can be anything that provides enrichment and improves quality of life. They went home and looked through our website, watched our application tutorials, and applied for a fort/swingset for their garden, which they have made as safe as possible using what money they have, so this will be a fantastic addition that will be used for years to come.

#### The swingset costs a total of £501.98.

Harry loves playing on swings, but just like so many children, visiting public parks can be an overwhelming, overstimulating experience and just isn't possible for some families. Having somewhere he can play at home is massive for him because it will also help him to self-regulate and release energy.



Here at The Sunshine Fund, we believe that every child deserves the chance to have fun and play, and it's these items that provide enrichment that can have just as much impact on a child's day-to-day life as any other piece of equipment. We are thrilled that Harry's application has now been approved.

This is just one of so many families we have got to know and support, and the Havelock's journey is just one of many that we have been part of. We've loved getting to know the family and it's success stories like these that remind us of why we do what we do. We can't wait to see the family again at one of our next family events where we can hear all about how Harry's getting on at school, and we can't wait for them to receive their equipment and see it in action!

Harry's swingset is one of a list of outstanding items on our waiting list. Our most recent equipment round costs upwards of £30,000, and we need £320,000 each year to provide hundreds of disabled and terminally ill children in the North East region with the equipment they desperately need.

However, as a small charity that receives zero statutory funding, we rely solely on the generosity of our supporters and donors to continue our work, and to fund these items to the babies, children and young adults who are waiting so patiently for their equipment. Children like Harry. So please, if you can spare anything this Christmas, consider making a donation to The Sunshine Fund, and make an impact this festive season.

If you or somebody you know relates to the journey this family have been on, we are here to help. Please visit our website at <u>https://www.thesunshinefund.org</u> or call our Families & Applications hotline on 07593 298 541.

# Find out how you can help other children like Harry on the next page...



# How you can help... Your Gift to Us

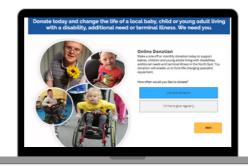
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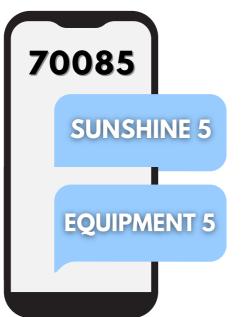
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