Huntington's Disease Association

COMMUNITY FUND

HDYES

Our Year Two Story

June 2025

What is HDYES?

HDYES is our Huntington's Disease Youth Engagement Service. Through HDYES, we support children and young people aged 8 – 25 who are impacted by Huntington's disease. We also support parents and guardians. We train and educate professionals to help them get a better understanding of Huntington's disease and better support children and young people who are affected.

In June 2023, we received a major funding boost from The National Lottery Community Fund. A grant of £418,360 over three years is helping children and young people to thrive.

Over three years, we want to support 300 children and young people, 150 parents and guardians, and 200 professionals.

This is the story of what we've achieved in the second year of this project.

What have we achieved this year?

Supporting children and young people

Since the start of the project, 292 children and young people have received direct support from a Youth Worker and 109 have attended an event. 40 children and young people aged 8 – 25 were new to the service this year.

Our HDYES Youth Workers delivered 663 support sessions for 240 children and young people this year. Since the start of the project, our team has delivered 1,219 support sessions for 292 children and young people.

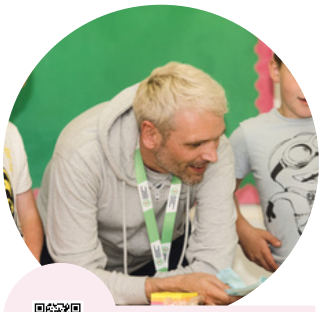
Our Youth Workers received training in intergenerational trauma. All team members have been trained to the level of Designated Safeguarding Lead and have also received training in suicide awareness and prevention.

Supporting pathways into our adult services, we worked with our Specialist Huntington's Disease Advisory service to co-deliver support calls and a one-night residential for young adults up to the age of 40. We continued to bring new members into our WhatsApp group for young adults.

Use the QR codes to visit our HDYES web pages

Our page for 13 - 17 year olds

Our page for 18 - 25 year olds



Our page for parents and guardians

Growing our activity programme

We continued to deliver fun and engaging activities this year, including 17 in person events based on what children and young people told us they want. Events included Go Ape, escape rooms, Lifesized Monopoly and a Bake Off day. We also delivered six virtual events. We had 220 attendances by 84 unique children and young people at events this year.

Since the start of the project, we've delivered 25 in person and seven virtual events, with 341 attendances by 109 unique children and young people. For some children and young people, coming to one of our events is the first time they've connected with HDYES.

We've learned that in person events are more popular than virtual events. Children and young people tell us that they make friends and connect with others when they meet in person. This year, we ran a residential summer camp for 30 children and young people aged 8 – 17. Demand was high and feedback was excellent. Children and young people who attended the camp told us:

> "Chatting to people my own age reassured me and made me feel less alone."

> "I really enjoyed the camp. I have made lifelong friends in the same boat as me. I hope to come again next year so I can meet them all again."

> "This summer camp is a very good place to make friends and have a brilliant time and it is overall a smashing experience."

" A huge "THANK YOU" to HDYES for providing an amazing few days of camp for Harry & Bella-Rose. They connected with loads of other young people, and have had such an incredible time. They haven't stopped going on about the amazing adventures and connections they made with other children who just "got it". WOW words are beyond me.. I'm just so lucky we have you in our lives!" Hannah

Supporting parent and guardians

Since the project began, we've had contact with 162 parents and guardians and delivered 179 support sessions, 78 parents and guardians have had a one-to-one support session, attended an event or taken part in a course. We welcomed 12 parents and guardians who were new to the service this year. We ran our online courses Parents of Adult Children at Risk and Navigating Huntington's. 83 people are now signed up to our parents and guardians e-newsletter.

> "Listening to the experts and the real life experiences of other families made the whole idea of communicating with our daughter less daunting."
> Parent who attended our Navigating Huntington's course.

Supporting professionals

We ran 16 training sessions for professionals this year, attended by 75 people. This included teachers, family support workers, pastoral care professionals, a social worker, a safeguarding lead, staff at Barnardo's, a SENCO, carers, a domestic abuse team, genetics team, children's psychologists and therapists. We've supported 177 professionals since the project began.

Raising awareness

We presented at the HDA Northern Ireland conference and attended the international HDYO Congress. We presented a poster at the European HD Network conference, which was published in the Journal of Neurology, Neurosurgery & Psychiatry. HDYES content is included in our Certified Course for Professionals and our Overview of Huntington's Disease webinars.

Use the QR codes to read our blogs

Q&A with a Youth Worker

EHDN Conference 2024

Talking with children - guidance from a Youth Worker

HD Youth Voice

HD Youth Voice is our youth leadership and co-production group. Eight new members joined this year and we now have 17 inspiring young leaders aged 16-27 from across England in the group. A member of HD Youth Voice is also a Board member for the Huntington's Disease Association. Another member is also a Young Adult Executive Committee Member for the European HD Network.

HD Youth Voice meets online monthly and came together for a three-night residential this year. This event was an opportunity for fun, peer support and co-production of projects. The group also took part in social media and content production training.

Read Amye's story here

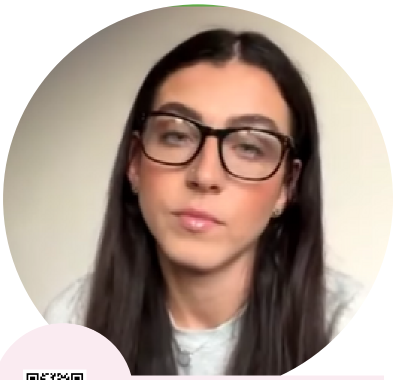
Amye joined HD Youth Voice this year after discovering HDYES through our social channels.

She told us:

> *"I had my first residential, which was an amazing experience to get to meet so many people who are affected by Huntington's disease, and getting to speak about my experience with them. It helped me feel a lot less alone. I really wish I got involved sooner. HDYES is really important for young people, because I think it helps people to raise awareness and become positive advocates. It also helps people have a voice and to share their experiences like they wish they would have known at the time to help them, so they can use their own experiences to help others."*

Use the QR codes to hear more from our HD Youth Voice members

Ava and Ayme talk about finding support



Instagram Live "Talking to others"

Joe talks about what HD Youth Voice is

This year, HD Youth Voice has co-produced:

- Our refreshed guides for children and teenagers and the new **HD Passport**. Children and young people can personalise this document and share it with the professionals who support them, such as teachers and employers. The **HD Passport** can include information such as caring responsibilities and the support they need.
- Social media content and blogs, including our first Instagram Live
- Our **Behind the Gene** campaign for Huntington's Disease Awareness Month 2025
- Following specialist training in peer support and safeguarding, HD Youth Voice members now lead **HD Connect** bi-monthly virtual peer support sessions, which include fun activities and discussion topics.

Following consultation with HD Youth Voice in Year One, this year we refreshed our website content for children and young people, creating a **HD Youth Voice web page** and refreshing our **HDYES web page.**

This year, our HDYES content received over 284,966 views online. Since the start of the programme, our HDYES content has received over 344,966 views. Tiktok data, which can be segmented by age, shows that 12.3% of our views on this channel are from people aged 18 to 24.

Our **You are not alone film,** which was co-produced by HD Youth Voice last year, was a Finalist in the Smiley Charity Film Awards. The film has now been viewed more than 2,400 times on YouTube.

Chloe's story

Chloe is a founding member of HD Youth Voice and a Board member for the Huntington's Disease Association. She grew up knowing that her grandad had Huntington's disease but without knowing that the disease was genetic or you could be tested for it.

Chloe describes finding out about her own risk as "a big shock. My mind went into a spiral, not just worrying about my own health and future, but also what it might mean for my closest relatives."

Eventually seeking support from HDYES, Chloe connected with James, one of our Youth Workers. She told us: "I was really nervous before I talked to James, but he was so friendly." "It was the biggest relief just talking to someone who understood my situation, gave me factual information and reassurance, and validated my feelings."

Inspired by the support she received, Chloe now uses her experience to benefit other young people. Chloe told us: "As young people, we can have a huge impact on how the next generation deals with this condition. By speaking up, we have the potential to change lives."

Read Chloe's story here

What difference are we making?

In Year One, we established our impact measurement framework and began to collect data. In Year Two, we aimed to increase the number of surveys completed to strengthen our impact evaluation – and have achieved this.

This year, we exceeded all expected outcomes for children and young people. Of 119 children and young people who responded to a survey this year:

- **85% [101 of 119]** agreed / strongly agreed that they have a better understanding of Huntington’s disease. Our target is 70%.
- **73% [87 of 119]** agreed / strongly agreed that they are less isolated. Our target is 60%.
- **72% [86 of 119]** agreed / strongly agreed that they are more resilient. Our target is 60%.
- **73% [54 of 74 aged 13 or above*]** agreed / strongly agreed that they are more prepared for the future. Our target is 50%.

*We only start to deliver content around preparing for the future from the age of 13 onwards.

We exceeded three out of five outcomes for parents and guardians. Of 38 parents / guardians who responded to a survey this year:

- **61% [23 of 38]** agreed / strongly agreed that they have a better understanding of Huntington’s disease. This is below our target of 70%. However, some respondents already had significant knowledge and lived experience of the disease before engaging with HDYES.
- **87% [33 of 38]** agreed / strongly agreed that they can better support a child / young person who is affected by Huntington’s disease. Our target is 70%.
- **62% [23 of 37]** agreed / strongly agreed that they are less isolated. Our target is 60%.
- **58% [22 of 38]** agreed / strongly agreed that they are more resilient. Our target is 60%.
- **79% [30 of 38]** agreed / strongly agreed that they are more prepared for the future. Our target is 50%.

We exceeded all outcomes for professionals. Of 22 professionals who responded to a survey this year:

- **100% [22 of 22]** agreed / strongly agreed that they have a better understanding of Huntington’s disease. Our target is 70%.
- **95% [21 of 22]** agreed / strongly agreed that they can better support a child or young person who is affected by Huntington’s disease. Our target is 70%.

We have continued to work with consultants Trust Impact to capture longitudinal change for children and young people who have experienced ongoing support from a Youth Worker. In Year One, we identified positive signs of early change. In Year Two, this trend has continued with patterns of positive change seen across all key outcomes in line with the support received from a Youth Worker. Knowledge appears to be the area of quickest and greatest change, while resilience appears a more complex area to affect - although users still experience improvements. Connection to others and future preparedness both show greatest, or more consistent, change in the medium-long term (20+ sessions with a Youth Worker).

What are our plans for Year Three?

We are now in Year Three of our HDYES project. In this third year, we will continue to provide support for children and young people. We'll also deliver more activity events for children and young people, including two residential camps.

HD Youth Voice will continue to meet monthly and get together for a residential and a celebration event. The group will continue to deliver its peer support model and co-produce social media content and blogs. Group members have told us how much they want to give back to the charity. HD Youth Voice will become more involved in fundraising with support from our experienced Fundraising team. They will also co-produce a Wellbeing Box that can be sent to other children and young people who need support.

We'll continue to provide support for parents and guardians, including our online courses. We'll continue to train, educate and engage professionals.

Our funding from The National Lottery Community Fund runs until September 2026. This year, we're also looking at ways that we can continue to fund HDYES and sustain the impact it creates with and for our amazing community.

Thank you

A big thank you to all the children and young people, parents and guardians, and professionals who have worked with us this year. Thank you to our inspiring HD Youth Voice members. Thank you to our volunteer-led local branches and support groups who have supported our activity programme. Thank you to The National Lottery Community Fund and players of the National Lottery.

About us

HDYES is delivered by the Huntington's Disease Association, the only charity that supports people affected by this rare genetic disease across England and Wales. Established in 1971 as a peer support group and registered as a charity in 1987, we have worked with and for the Huntington's community for over 50 years and remain community-led.

Get in touch

If you'd like to know more about HDYES, we'd love to hear from you.

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