Huntington's Disease Association

HDYES

Our Year One Story

June 2024

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Disease
Association

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.

HDYES is a three-year project with a total value of almost £1m. We are bringing £305,430 of existing resources to the project plus £240,925 raised by the amazing gaming community through Jingle Jam 2022. In June 2023, we received a major funding boost from The National Lottery Community Fund, securing a grant of £418,360 over three years. This is helping us to develop and grow HDYES.

Over three years we want to support:

300 children and young people

150 parents and guardians

200 professionals

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

What have we achieved this year?

We have provided intensive, direct support to **190** children and young people. This includes **47** children and young people who are new to the service.

We have **doubled our HDYES team** from two to four **Youth Workers**. Children and young people across England now have a dedicated Youth Worker for their region. Between them, our HDYES Youth Workers have delivered **482** support sessions for children and young people this year.

We also created a new role of **HDYES Project Officer** to help manage our project, including our activity programme. We ran **six activity days** for children and young people. These events included watersports, bowling, mini-golf, crafting and a circus workshop.

Working with our Specialist Advisory team, we also delivered **two online** and **two in-person events for young adults**. Together, we discussed physical and psychological wellbeing and the transition from HDYES into our adult services. New members have joined our WhatsApp group for young adults.

We supported **45** parents and guardians through **75** support sessions and our online courses. Seven parents and guardians with children aged 18-25 attended our **Parents of Adult Children at Risk course**, which included a Narrative Therapy session. Ten parents and guardians took part in our new **Navigating Huntington's course** for those with children under 18 years old. **44** people signed up to our new e-newsletter for parents and guardians.

> I feel less desperately alone after this.

A young adult who took part in one of our events

> I started off with very low benchmark scores in terms of confidence and found myself learning a huge amount about how to deal with the emerging challenges. Just seeing and hearing other families and their experiences made it all feel less overwhelming and frightening and helped to ease some loneliness. I really appreciate the team's kindness and patience.

A parent who took part in our Navigating Huntington's online course

We ran **23** training sessions for professionals this year, attended by **127** people. This included teachers, pastoral care professionals, Special Educational Needs Coordinators, school governors, genetics teams, children's psychologists and therapists.

HDYouth Voice

HD Youth Voice is our youth leadership and co-production group. **Three new members** joined HD Youth Voice this year. We now have **13 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 **2-night residential** this year. This was an opportunity for peer support, co-production of projects, community activities and spending time together.

You can read Iris's blog here.

HD Youth Voice has a huge impact and helps me feel less alone, which means I can combat everyday life with Huntington's disease head on.

Charlotte

HD Youth Voice has taught me that just because someone may be quiet doesn't mean they're alright. HD Youth Voice has given us a space to talk about similar experiences we all have.

Joe

Our amazing HD Youth Voice members are changing the landscape for children and young people in the Huntington's disease community. This year, the group co-produced our **You are not alone film**, which has been viewed more than **1,400** times on YouTube. They also played a huge role in producing our social media and online content, including social media takeovers and blogs our HDYES content has received **60,000** views online. TIKTOK data shows that at least a third of our audience on the platform is aged 18 to 24. HD Youth Voice members have recently taken part in a focus group to shape our HDYES website.

Following specialist training, HD Youth Voice members are delivering **virtual peer support** sessions for children and young people in our community. The sessions include fun activities and opportunities to talk about issues and challenges.

Raising awareness and building partnerships

We raised awareness of HDYES by presenting to the UK Huntington's Disease Network, the Predictive Testing Consortium, and at Neurogenetics Calman training day. People attending our Certificated Course for Professionals and our Overview of Huntington's Disease webinars learn about HDYES. We signed the Young Carers Covenant, which is led by Carers Trust.

We met up with colleagues from the Scottish Huntington's Association Youth Service to discuss ways of working that best support children and young people in our community.

What difference are we making?

We are tracking the difference that HDYES makes over time. People in our community are helping us to do this by completing surveys at different points in their journey.

We've worked with an independent evaluation consultant to set up an impact measurement framework and establish baseline data. We started collecting survey data in November 2023 and our evaluation is at an early stage. Only small groups of people have completed surveys so far, but we are already seeing some early signs of change.

29 children and young people completed multiple surveys this year:

- **30%** agreed or strongly agree that they have a better understanding of Huntington's disease
- **56%** agreed or strongly agreed that they are less isolated
- **17%** agreed or strongly agreed that they are more resilient. Although this is a low percentage, this is early data from a small group. Our evidence shows that support from a Youth Worker is helping children and young people feel more resilient, particularly after four or more sessions.

Our Youth Workers only begin talking about the future with children over the age of 13. We asked children in this age group about whether they feel more prepared for the future because of our support. **42%** of 19 children who responded agreed or strongly agreed that they do feel more prepared for the future.

18 parents and guardians completed multiple surveys this year. Between 9 and 15 people responded to each of the following outcomes:

- **100%** agreed or strongly agreed that they have a better understanding of Huntington's disease
- **87%** agreed or strongly agreed that they can better support a child/young person who is affected by Huntington's disease
- **89%** agreed or strongly agreed that they are less isolated
- **67%** agreed or strongly agreed that they are more resilient
- **89%** agreed or strongly agreed that they are more prepared for the future

40 professionals completed a post-training survey:

- **100%** agreed or strongly agreed that they have a better understanding of Huntington's disease
- **100%** agreed or strongly agreed that they can better support a child or young person who is affected by Huntington's disease.

What are our plans for Year Two?

We are now in Year Two of our HDYES project. In this second 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 a residential for those aged 8-17. There has been huge demand for this event and all places are already filled.

HD Youth Voice will continue to meet monthly and will come together to celebrate their achievements. Because the group wants to spend more time together, our HD Youth Voice residential will run over three nights. HD Youth Voice will continue to develop and deliver its peer support model. The group will also co-produce a HD Passport document that children and young people can personalise and share with the professionals who support them, such as teachers and employers.

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

Our HDYES Youth Workers will be trained in family trauma, because we know that Huntington's disease affects whole families.

We'll continue to provide psychological support, rolling out a new approach called LOHA Digital Systemic Therapy. Through LOHA, parents and guardians work through a digital toolkit with their children. This empowers parents and guardians to help their children identify and understand their feelings, emotions and behaviours.

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 amazing HD Youth Voice members.

Thank you to our volunteer-led local branches and support groups who have supported our activity programme.

Thank you to Jingle Jam and the gaming community.

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 1986, 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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