



GROWING TOGETHER FOR
HEALTH AND HAPPINESS

Chiva Impact Report 2023



Company no. 06337017
Charity no. 1122356

Sleep

hope that
will make
friends
and to
have
a good
life

learn more about
HIV

Vibez!

my cousin to recover
his mom my
auntie's death.
xx

Love

MAKING
new friends
♡

What I'm
hoping to
improve

- confidence
- improve in my communication
with new people

favorable

making
new
mem

C.M

Ayudar a enseñarle como
ser un portero.
enseñarle español.

I am hopeful
to get new
friends

to have a nice
time with
my friends

I want to have fun,
meet new people,
make friends,
try to adjust
to new environment
and really have
fun!!!

ABOUT CHIVA

CHARITY MISSION STATEMENT

Children's HIV Association Limited (Chiva) is dedicated to enhancing the health and wellbeing of children, young people, and young adults growing up with HIV. Chiva works to ensure that young people living with HIV have the treatment and care, knowledge, understanding, skills and wider support needed to live well and achieve their greatest potential.

Chiva achieves its mission by providing direct support for children, young people and young adults living with HIV and their families, working closely with clinic teams, and by delivering programmes which offer comprehensive and integrated support to empower young people towards healthier and more fulfilling lives.

HOW WE WORK

Chiva operates its programme of work through a dedicated staff team, supported by volunteers, trustees, steering group members, and strategic partnerships. Through a programme of direct work, Chiva engages young people living with HIV across the UK and Ireland, in distinct projects which aim to address the Chiva mission statement.

Delivering projects at a national level enables young people from diverse regions to attend residential and engage with young people from other areas, building a peer network of support.

Support to young people is also delivered regionally by Chiva staff working closely with clinical teams in those areas.

We produce clinical guidelines and resources to support the work of professionals in this field, and provide opportunities for education and continuing professional development, with access to a professional peer network through the Chiva membership.

Chiva ensures the specialist needs of children and young people with HIV are fully understood, through engagement with research, audits and studies, including representing their needs in the commissioning of NHS services and informing wider policy and service provision.

Chiva creates resources and delivers campaigns aimed at improving HIV awareness in the public more widely, and specifically in relation to children and young people.

There is a strong commitment to the involvement of young people in the organisation and participation is at the heart of our ethos. Chiva has a dedicated participation programme ensuring young people are provided meaningful opportunities to influence and inform the direction taken by the organisation. Chiva ensures young people are provided opportunities to influence and shape wider policy and service development and raise public awareness and understanding of HIV.

Chiva ensures paid and volunteer opportunities for young people and young adults who have grown up with HIV, including co-production and peer leadership and youth facilitation roles in projects. We strive to provide pathways of involvement through the organisation which ensure young people have opportunities to progress from attending programmes into delivery and leadership roles in the organisation with meaningful engagement, consultation, and development support.

ACHIEVEMENTS IN 2023

ACTIVITIES, ACHIEVEMENTS AND PERFORMANCE IN 2023

In 2023 Chiva developed a new strategy through a process of engagement involving staff, trustees and Chiva youth committee members.

Three pillars have been developed to guide our objectives:

- **Life Span Holistic Support;**
- **HIV awareness; and**
- **Research, Evidence, and Evaluation.**

Our strategic objectives outline our commitment to comprehensive support, public awareness, professional understanding, research influence, youth participation, and impact assessment.

ACHIEVEMENTS IN 2023

The number of young people and young adults who were provided with support from Chiva in the year grew considerably in 2023 resulting from an increase in referrals for support and project activity. Engagement data suggests increased awareness of the support and services available at Chiva and is also reflective of the organisation's development more recently, extending support to the young adult population.

327

Overall number of young people and young adults supported, who have grown up living with HIV

119

Hardship support interventions

52

Young adults supported through our young adults programme

18

Young people were Chiva Youth Committee members

47

Family members attended Chiva's first families residential

78

Young people aged 11-17 attended Freedom 2 Be support camp

156

Received support from our regional Support staff

34

Had peer leadership and project delivery roles

25

In person events run for children and young adults who have grown up with HIV

ACHIEVEMENTS IN 2023

KEY EVENTS HELD DURING THE YEAR

MARCH 2023

The 17th annual Chiva conference delivered in London, engaged health professionals and other stakeholders to enhance collaborative efforts in improving care and outcomes for young people living with HIV. 159 people attended the conference (99 in person and 60 online).

A varied programme was delivered which included the latest research on breastfeeding when living with HIV, a youth engagement focused panel, chaired by the Chiva Youth Committee, the latest in treatment developments and the relationship between HIV, co-morbidities and aging.

17th Annual Chiva Conference



159 delegates attended

82% **strongly agreed** that the day was interesting and relevant to their professional needs, with everyone else agreeing with this statement.

"This was the best HIV-related conference I have attended in years. Without exception the talks were engaging, relevant and introduced novel ideas. The work of Chiva makes me proud to be involved in HIV care in the UK. Well done to all involved!"

"I felt the conference was a great benefit to me professionally"

APRIL 2023

Chiva delivered its first families residential, uniting parents / carers of children living with HIV and their siblings. The aim was to provide a safe space where families could come together to share and explore experiences of living with HIV as a family. It was delivered in partnership with women from 4M network. Providing art, creative writing, nutrition focussed cooking sessions, facilitated sharing and social time, the event aimed to facilitate a space for

participation and connection. Sessions encouraged communication and sharing of family stories between parent/carers and children and young people.

The evaluation reported that the opportunity to meet other families, to make new friends, to talk to others in a similar situation and have a safe space to share were most important to participants.

The connections and togetherness people appreciated came through strongly in the evaluation and affirmed the need for this type of event which addresses the social isolation and marginalisation many families experience. The retreat style of the event was also effective in providing a safe and calm space in a natural environment.

A staffed creche and activity programme for the under 8s and dedicated programme for older young people was instrumental to the success of the event in order that whole family groups could attend.

FAMILIES' WEEKEND

APRIL 14-16 2023



- 47 participants (16 families attended)
- Overwhelmingly positive feedback was received
- 100% of parents/carers felt it was very important to meet up with other families also living with HIV

"Loving the space where we freely talk about anything with no judgement."
- Parent/Carer

MAY 2023

The new Blueprint support programme for 18-25-year-olds launched in May. The programme themes are framed around four pillars delivered through a range of activities across a year:

- Supporting confidence and well-being;
- Finance and money management;
- Mental health; and
- Ongoing impacts of HIV.

The four programme pillars were identified through a residential delivered to co-design the programme with young people, reflecting key elements relating to quality of life in adulthood.

ACHIEVEMENTS IN 2023

Evaluation highlights illustrate positive impacts on confidence, well-being, and financial literacy among young adults. Practical tools such as the programme workbook and the shared budget planning tools helped young people with a focus on individual growth and self-efficacy. Growth was also witnessed through the coaching programme and the goal focussed objective setting was an effective tool. The day event on career pathways and getting into work had been an additional element to the programme and was very well received by the young people, recognising the need for flexibility in programme design to respond to emerging needs.

THE BLUEPRINT: SUPPORT FOR YOUNG ADULTS



This new young adults programme delivered:

Zoom
Workshops

One-to-one
support calls

Meet-up
day focusing
on careers

4-day
retreat in
Oxfordshire

52 young adults living with HIV participated in the programme

27 of these young adults attended the end of year residential

“The programme has given me an insight on how to navigate adulthood with money management, CV creations, and LinkedIn. I am also able to deal well with low self-esteem and confidence.”

AUGUST 2023

Freedom 2 Be Camp (F2B) ran for the 14th year, bringing together 78 young people living with HIV for a five-day residential camp. F2B aims to address the significant experience of social isolation many young people growing up with HIV experience, provide support to enhance understanding and acceptance of HIV, and help develop future aspirations through an engaging and varied programme of workshops, outward bounds and other activities.

Topics covered this year included sexual health and healthy relationships, understanding your rights, HIV and nutrition. Music, poetry and arts sessions enabled young people to be creative and express thoughts and feelings connected to this year's theme at camp “Unlock Yourself” which was chosen by the Chiva Youth Committee. The impact of camp on participants is measured in relation to addressing the core aims of camp. Pre and post participant questionnaires are completed as well as interviews with a number of campers carried out by camp leaders.

Camp is delivered by staff and long-term associates and relies on the commitment of volunteers and partners to support delivery. Many young people return to camp as volunteers when older. The Camp Leader volunteer programme provides dedicated roles for youth peer mentors who have grown up with HIV, and the Key Worker volunteer team increasingly includes young adults who formerly attended camp.

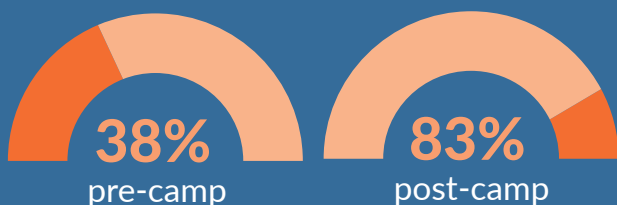
ACHIEVEMENTS IN 2023

HIV RELATED KNOWLEDGE



Participants demonstrated a **significant increase in HIV-related knowledge** over the week, getting more questions about HIV correct post-camp and attempting to answer more of them.

Understanding of U=U:



TALKING ABOUT HIV



pre-camp only **23%** were comfortable talking about HIV

By the end of camp, this had tripled to **69%** being comfortable talking about HIV



GAINING CONFIDENCE



Participants made friends and became more confident:

“ I felt comfortable for the first time in myself, and I feel good about myself. ”

“ I love the involvement of everybody in this camp and how everybody comes together as a unit, as a community. And you know, I just love how it is all the time. ”

Parent / Carers saw a positive impact on their young people:

“ My son was very happy. He informed me the camping was very informative and since he came back from the trip he is a changed person, proactive with his medication and he looks much happier and bright. ”

Parent / carer of camp participant



ACHIEVEMENTS IN 2023

PROGRAMME ACTIVITY THROUGH THE YEAR

EXPANDING SUPPORT TO YOUNG PEOPLE AND FAMILIES LOCALLY

Chiva extends support to young people and their families through the year, via a regional support programme delivered by Chiva specialist support staff working in different regions of the UK. Staff are located in London, Birmingham and Sheffield covering those regions, with core team members based in Bristol covering Bristol, the South West and Wales.

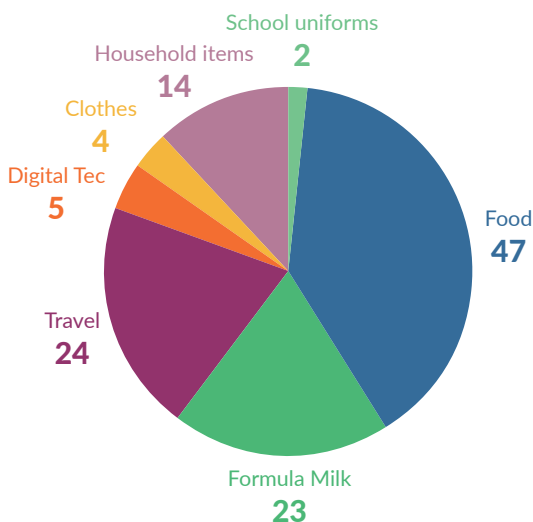
HARDSHIP SUPPORT



We have had a large increase in demand for our hardship support programme, with the number of interventions doubling from 2022 to 2023.

Total number of interventions:

119



This programme works closely with the medical teams in those locations to provide further support via clinic attendance as well as undertaking work in the community and collaborating with other agencies to deliver support and provide advocacy.

Staff engage in home visits and organise regional peer meetups through the year to enable peer support networks to grow locally and deliver HIV education activities aimed at building self-efficacy skills. Staff also provide access to the Chiva hardship support provision meeting essential needs with practical assistance.

Regional Support

Chiva delivered **12** regional peer meet ups in Birmingham, Bristol, London, Wales and Yorkshire in 2023



“ Thank you so much for today. You have opened up our journey with [redacted] to so many wonderful people and new friends. For the first time in three years we don't feel alone in the journey. You and your team are amazing! ”

– Parent who attended London parents and little ones meet-up

The regional support work has provided a valued additional support to the clinic teams and builds a holistic support model around clinical care. Chiva staff provide critical support, helping with issues such as medication adherence, maintaining engagement with clinical care and transport to clinic.

Chiva staff regularly follow up with young people who have missed appointments, address welfare and housing issues and provide mental health support. Chiva staff are increasingly supporting young people who have had complex childhood experiences and adversities such as parental bereavement, which can result in increased support needs in early adulthood with risks to health and wellbeing.

Last year a number of young people were provided intensive support from regional team members following extended stays in hospital to help them resettle in the community and engage wider services and community resources as needed.

ACHIEVEMENTS IN 2023

The work completed by the regional team is increasingly revealing the complexity of needs among young people which, if unmet, would result in detrimental impact on their health and wellbeing. This support, focused on preventing future harm as well as addressing presenting needs, is also releasing some pressure from statutory services with noted difficulty around resourcing and staff capacity.

Provision such as essential psychological support for young people is frequently impossible to access from public services. Chiva have funded psychological support privately for a number of young people in 2023 to ensure their critical need for mental health support is addressed whilst ongoing advocating for the need for psychological support to be available via health services.

PARTICIPATION

Participation opportunities for young people within Chiva include the Chiva Youth Committee (CYC), Camp Leader programme at the annual support camp, peer leaders at regional support peer activities, youth speakers at conferences and education events held by Chiva and wider organisations, engaging with media and other public forums.



The CYC comprises twenty young people living with HIV who are aged under eighteen when joining the committee. They meet regularly throughout the year with sub-committees within the group leading on different aspects of work.

Members of the CYC took part in the **“My Medicine My Health”** working group, a co-production project Chiva delivered in 2023 to develop medicine information resources for young people.

Summary of other key achievements by the CYC in 2023:

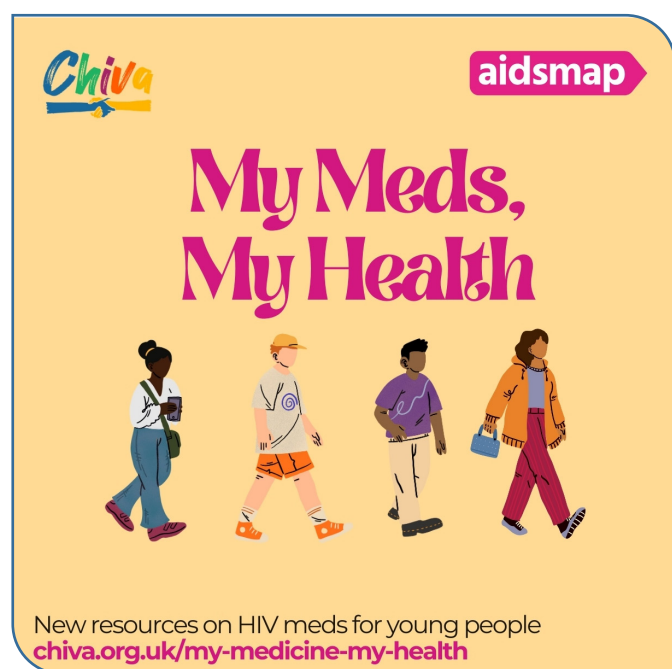
- Provided consultation on the Chiva camp programme development;
- Delivered a symposium on youth involvement at the annual Chiva conference;
- Informed a review of the Chiva website, and updates to Psychology and Sexual Health guidelines;
- Delivered a session at The National HIV Nurses Association (NHIVNA) Conference, for HIV specialist nurses;
- Provided consultation on long-acting injectable HIV treatment;
- Spoke at an HIV education event at an NHS Trust event; and
- Held meetings during the year with the international group, Committee of African Youth Advisors, to explore experiences of HIV stigma, medicines and how best to provide accessible health-based information to young people.

Evidence collected through exit interviews and ongoing evaluation of engagement illustrates how being a member of the CYC not only provides valuable participation benefits for the organisation and delivers wider campaigns aligned with Chiva’s strategy, it also supports young people in their own growth and development and helps with their relationship with their HIV, leading to increased confidence and coping skills.

ACHIEVEMENTS IN 2023

HIV AWARENESS & UNDERSTANDING

“My Medicines My Health” was a resource development project delivered during 2023 which involved co-producing with young people a series of new comprehensive medicine resources, with support from Aidsmap. Young people held key roles in script writing, content development and design.



The resources include:

- A comprehensive medicine handbook;
- Information sheets on specialist topics including PrEP and PEP and developments around HIV cure;
- An animation series which explores different aspects around HIV related health, medicines, and growing up living with HIV; and
- Video content for sharing on social channels.

TWO PODCAST SERIES WERE RELEASED IN 2023

“Positive Advice” was developed from Chiva’s oral history project, Positively Spoken. The series explores life growing up with HIV, using stories recorded at the International AIDS conference in Montreal, Canada in 2022 combined with discussion from expert guests. The series explores topics from the life story recordings such as mental health, experiences of health care and medicines, family life and school.

“Don’t listen to my HIV, listen to me!” was planned and recorded by the CYC, a powerful and frank sharing of feelings and experiences growing up with HIV from the youth committee members with a particular focus on mental health.



POSITIVELY SPOKEN

Chiva’s oral history project in partnership with the British Library and funded by the National Lottery Heritage Fund, formally ended at the end of 2023. In total, 34 individual life stories have been recorded during this project and will be archived in the British Library sound archive.

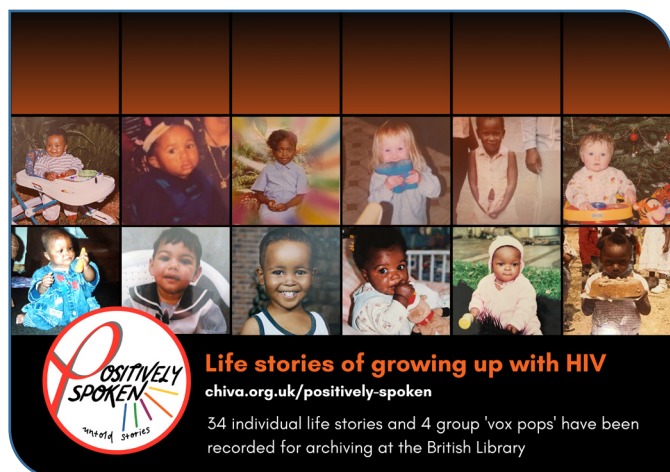
Young people were trained in oral history and conducted interviews with their peers, supported and mentored throughout by an oral historian with an extensive background in recording life stories around HIV.

ACHIEVEMENTS IN 2023

The project was celebrated at an event at the British Library on 1 December, World AIDS Day. Interviewees and partners and colleagues of Chiva were invited to the event to hear some of the clips, listen to musical pieces created by a group of young people responding to the clips and working with musician Awate.



Bespoke pieces of art created by Bristol based artist Cai Burton based on the life story clips were displayed alongside the audio clips which had inspired the pieces. The clips could be listened to alongside their corresponding artwork for an interactive and engaging exhibit to celebrate this project.



SOCIAL MEDIA AND COMMUNICATIONS

Chiva has a strong presence on social media and uses different channels to communicate with partners in the HIV sector and wider stakeholder organisations and individuals, as well as raising awareness and challenging myths which can prevail in the public domain, including on social media.

The platform serves to communicate our work activities and deliver campaign messaging. Chiva has two Instagram accounts with targeted audiences, one being in the public domain used for awareness raising and general promotion and one private aiming to reach young people and families who may wish to engage with our programmes and resources.

The Chiva website has been regularly updated with news and information. Offering a hub of resources, for clinical use and to support wider understanding of HIV. It also provides HIV related information for young people and parent/carers and highlights projects and support offered by Chiva and how they can get involved.

Chiva produces a quarterly newsletter for its professional and affiliate membership. The newsletter provides updates on current Chiva activities, information concerning wider events of potential interest to members, recent research and publications.

Chiva website and social media in 2023

Website

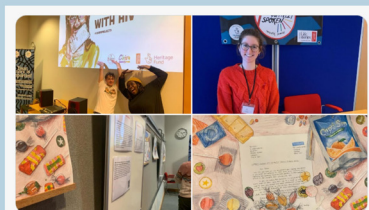
8,000+ unique visitors to the Chiva website.

Instagram

Posts on new Instagram account had a reach of 3,000+

X

Tweets had 147K impressions



Positively Spoken

Our event celebrating our oral history project, Positively Spoken, was shared across social media platforms and we launched Positive Advice - a podcast based on the recordings

ACHIEVEMENTS IN 2023

WORKING WITH PROFESSIONALS

This area of Chiva's work is led by the Chiva Steering Group. The steering group meets twice a year and expert groups within the overall group meet ongoing to work on specific areas which focus on providing resources and support to professionals working in HIV.

CONFERENCES, EDUCATION MEETINGS AND EVENTS

In addition to the annual Chiva conference described above, Chiva also delivered four education meetings to provide access to specialist topics of interest for Chiva members and wider stakeholders.

Three meetings were held online and one in-person, with expert speakers presenting information on key topics such as specialist clinics supporting refugee health, highlights from an international conference on retroviruses, best practice around talking to children about their health, and research on the impact of Covid on children.



CLINICAL GUIDELINES

In 2023 the clinical guidelines group had new co-chairs appointed from the Steering Group to lead this expert group. A schedule of all clinical guidelines developed at Chiva are monitored and peer reviewed by the group who meet through the year.

Updates are undertaken by group members and additional expertise sought as required. Guidelines being reviewed and updated currently include Developmental monitoring, Sexual health, and HIV & TB co-infection.

The Chiva Standards of Care are also due for review and update, and this is planned for 2024 to align with completion of the new service specification for NHS clinical services for children and young people living with HIV.

AUDITS AND COMMISSIONING

The key activity in the year for this group involved taking forward an audit of the transition from paediatric to adult HIV care. It also involved establishing a partnership with NHIVNA to deliver the audit with adult clinics, as well as planning for a qualitative study of the experiences of children and young people with HIV who have been adopted or spent time in care.

Chiva holds a place on the British HIV Association Audit (BHIVA) committee and is involved in the design of their annual national audit.

Chiva took up a position on the Clinical Reference Group which manages the specialist commissioning of HIV clinical services nationally. Chiva also formed a working group for updating the service specification on paediatric HIV clinical services, working with NHS England to provide recommendations for the ongoing specialist provision of this service and to ensure these decisions on service delivery and care quality decisions are informed by key stakeholders at Chiva, including consulting with the Chiva youth committee.

ACHIEVEMENTS IN 2023

HEALTH ASSOCIATION LINKS

This group leads on links with other health organisations, coordinating responses to consultations and engaging with Chiva membership to share practice-based experiences and evidence to support policy and service development. In 2023 Chiva coordinated a response to a NICE quality standard on transition enabling Chiva members to feedback views on this.

Ongoing collaborative work has continued with other key HIV partner organisations. Exploration of opportunities to raise the profile of HIV among other paediatric infectious diseases was addressed in a meeting with The British Paediatric Allergy, Immunity and Infection Group (BPAIIG) which is an affiliated speciality group of the Royal College of Paediatrics and Child Health (RCPCH).

PROFESSIONAL GROUPS

In 2023 Chiva has increased the number of professional groups coordinated to facilitate peer engagement to discuss current priority issues in professional practice. HIV paediatric nurses and paediatric psychologists now have regular professional group meetings, and a new group has been started for adult clinicians delivering youth specialist clinics.

Supporting these professional groups is an important function of Chiva's professional support work to maintain a network and ensure people have opportunities for support and guidance from their peers, whilst ensuring Chiva is kept abreast of current key issues in professional practice.



PLANS FOR 2024

PLANS FOR 2024

Chiva plans to continue its current work programme of activities in 2024. This includes a direct support programme delivered across the UK, collaborative working with clinics in the NHS and wider services, and providing educational activities, support and resources to professionals.

Specific workplan priorities are aligned around our strategic objectives to provide comprehensive holistic support for children, young people and young adults who have grown up with HIV, raise public awareness and address ongoing HIV related stigma, enhance professional understanding and develop best practices, influence wider research, ensure effective and meaningful youth participation, and ensure effective monitoring and evaluation of the impact of our work.







GROWING TOGETHER FOR
HEALTH AND HAPPINESS

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