



**POSITIVELY UK**

# **Welfare Service May 2020 - April 2023**

## **Evaluation Report 2023**

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# Content

Executive Summary	3
Introduction	4
Summary of Work and Impact	4
Welfare Service Success	4
Recommendations and Future Needs	4
<b>Introduction</b>	<b>4</b>
<b>The Project</b>	<b>6</b>
Positively UK	6
The Welfare Service	6
Target Populations	6
Service Aims	6
Service Activity	6
<b>About the Evaluation</b>	<b>8</b>
Method	8
Service User Outcome Data	8
Staff Interview	8
Service User Focus Groups	8
<b>Results</b>	<b>10</b>
Motivations for Accessing the Welfare Service	10
Challenges in Achieving Support from the UK	10
Welfare System	10
Sources of Referral	11
Service User Demographics	12
Financial Support	12
Impact on Service Users' Mental, Physical, and Social Wellbeing	14
Need for a HIV Specialist Welfare Service	14
Feedback about Positively UK	15
Recommendations for Improvement	17
<b>Overall Project Achievements and Impact</b>	<b>17</b>
<b>Recommendations for Future Service Provision</b>	<b>18</b>
<b>References</b>	<b>20</b>

# Executive Summary

## Introduction

People living with HIV in London commonly experience challenges related to housing/homelessness, income, and employment. Social and economic challenges are particularly present in people from minoritised backgrounds.

## Summary of Work and Impact

The Positively UK Welfare Service commenced in May 2020, with funding received from Fast-Track Cities (London) totalling £215,990.

The Welfare Service provided two key functions to achieve its aims:

- One-to-one support helping people living with HIV to achieve welfare support.
- Workshops to develop knowledge around navigating the UK welfare system and promote personal financial management skills.

## Welfare Service Success

The Positively UK Welfare Service has succeeded in achieving its initial aims and objectives, set out at the initiation. The Welfare Service supported service users to achieve financial assistance totalling £1,786,005.29 during the period of May 2020 - April 2023.

# Introduction

Human Immunodeficiency Virus (HIV) is a virus that attacks the body's immune system, by targeting specific white blood cells (helper T-Cells) that are responsible for leading a response to infections. This leads to overall reduced immune system functioning, which may lead to severe infections and cancer. If left untreated, HIV can develop into life-threatening Acquired Immunodeficiency Syndrome (AIDS) (NHS, 2021).

Globally, 38.4 million people live with a diagnosis of HIV (UNAIDS, 2023). In England, a total of 91,432 people received HIV care in 2021. Additionally, 177 people received a diagnosis of AIDS in the UK in 2021 (UK Government, 2022 [1]).

People living with HIV can access treatment in the UK. HIV treatment aims to reduce the viral load (amount of HIV present in the body) to 'undetectable' via blood test. This reduces the chance of someone living with HIV from becoming seriously unwell due to HIV complications and prevents the virus from being passed on to another person (NICE, 2021).

HIV treatment has evolved substantially since the first reported case of AIDS in the UK, in December 1981. However, despite the substantial progress in treatment options, some people still experience the impact of living with HIV in their daily lives. This includes psychological symptoms, weight loss, bowel/bladder problems, night sweats, recurrent infections, and life-threatening illnesses (NHS, 2021).

The impact of living with HIV may vary from person to person, and people diagnosed and treated early may not experience severe, or any, symptoms at all. Some people who live with HIV today were diagnosed during the 1980's and lived with the virus without treatment, and, as a result, experience significant and long-term challenges to their health, which may impact their ability to work or undertake daily living activities.

Additionally, people that receive a late diagnosis are more likely to become unwell and also experience long-term unemployment (NICE, 2021).

Some people living with HIV might be diagnosed with HIV in another country and seek refuge in the UK for their own safety, but struggle to navigate the National Health Service (NHS) and UK Welfare System (BMA, 2023).

Additionally, some asylum seekers may acquire HIV in the UK. Asylum seekers have no recourse to public funds and experience significant challenges in accessing basic needs such as food and accommodation (NAT, 2022).

People living with HIV in London commonly experience challenges relating to housing/homelessness, income, and employment. Social and economic challenges are particularly present in people from minoritised backgrounds (Ibrahim et al, 2008). Economic challenges experienced by people living with HIV are magnified by a larger National Welfare Policy.

In London, the demand for welfare support currently outstrips many Councils' ability to provide support to people living on a low-income, with many emergency crisis funds exhausted. The impacts of COVID-19 alongside the current cost of living crisis have resulted, and continue to result in, financial challenges for many (London Councils, 2023).

Some people living with HIV may experience cognitive impairment and fatigue. This makes the challenge of applying for welfare support even more difficult. Additionally, some people may not speak English as a first language and thus may require support in providing the required evidence to substantiate a claim (THT, 2018).

In some cases, people receive an incorrect benefits provision, resulting in further financial distress. This is often because of the complex and challenging Welfare System assessment procedures, combined with the psychological impacts of HIV and, in some cases, a lack of 'system' knowledge. All of which create barriers to achieving welfare support. Moreover, the challenges of applying for welfare support can result in significant waits and increased personal stress.

HIV specialist welfare advice services are required to support people living with HIV to access the financial support they are entitled to, enabling them to achieve physical and mental wellbeing, and to live well with HIV.



# The Project

## Positively UK

Positively UK is an organisation founded in 1987 by two women living with HIV. As a response to the lack of peer-led services for women living with HIV, these two women began providing support services from their own homes under the organisation name of 'Positively Women'. Over time, and in response to the increasing need for support across multiple communities, the organisation has continued to evolve and grow. Today, the organisation is known as Positively UK. It provides peer-led support, advocacy and information to all people living with HIV and works to shape and influence policy in the UK.

## The Welfare Service

The Welfare Service commenced in May 2020, with funding received from Fast Track Cities (London) totalling £215,990. The project employed a full-time specialist Welfare Support Worker named Rosa Midheksa-Kinea, who provided advice by face-to-face appointment, email, text, or phone-call depending on the needs of the service user.

The service was a specialist project, encapsulated within the wider organisation that provides peer-led support to people living with HIV. The service was delivered from Positively UK offices in Islington (London) with outreach peer-led services embedded in 16 sexual health clinics across London.

## Target Populations

The Welfare Service aimed to support all people living with HIV, but specifically aimed to provide support to the following populations through the Welfare Service:

- Minoritised communities (particularly where language barriers are present).
- People with erratic clinical engagement (including people with mental health complications and those who experience substance and alcohol misuse).
- People diagnosed before antiretroviral treatment was available (who are likely to have co-morbidities and to experience isolation, grief, and trauma).
- People with unsettled migration status (particularly those people without working rights or recourse to public funds).
- People with high levels of trauma (especially those with negative experiences of the benefits system who are unlikely to challenge decisions and may require advocacy support).
- People who experience difficulties in navigating systems due to a hostile environment (migrants, trans people, and those facing long-term unemployment).

## Service Aims

### Primary Outcomes:

- Increased/secured benefits.
- Loans achieved/managed.
- Reduced/managed/written off debt.

- Secured/improved housing situation or prevented homelessness.
- Secured other goods and entitlements.

### **Secondary Outcomes:**

#### **Health:**

- Reduced stress and anxiety.
- Improved diet.
- Regular appointment attendance.
- Improved adherence to medication.

#### **Social:**

- Increased personal independence.
- Reduced social isolation.
- Improved home environment.

#### **Financial:**

- Increased financial independence.
- Improved ability to navigate the benefits system.

### **Tertiary Outcomes:**

- Improved mental health.
- Improved adherence to medication.
- Improved management of HIV and co-morbidities.
- Improved cross-sectoral collaboration.

## **Service Activity**

The Welfare Service provided two key functions to achieve its aims.

### **1.One-to-One Support:**

The main activity undertaken by the Welfare Service was the provision of one-to-one advice and support. Support included: providing advice regarding benefits and legal rights, support with application processes, and the provision of information regarding the practicalities of achieving financial support. Referral to advocacy support was also arranged in specific situations such as during an appeal process. In certain cases, the team personally helped with the completion of application forms.

People often required support with the following:

- Personal Independence Payments.
- Universal Credit.
- Employment and Support Allowance.
- Housing Benefits.
- Disability Premiums.
- Council Tax Support.
- Mortgage Payments.
- Potential homelessness/housing challenges.
- Food parcels/vouchers.
- Challenges relating to employment/unfair dismissal (related to HIV diagnosis).
- Statutory Sick Pay.
- Issues relating to long-term unemployment.

Monthly drop-in outreach sessions at local HIV charities and sexual health clinics were also provided to offer one-to-one welfare support. This ensured that people who needed support could access it without the need of referral or prior awareness of the service, increasing access to target populations.

### **2.Workshops:**

In addition to one-to-one support, the Welfare Service provided workshops to groups of service users on a variety of subjects. The workshops aimed to develop long-term knowledge and subsequent independence in understanding and navigating the UK benefits system.

Examples of workshops provided to date:

- Social Welfare Reform.
- Benefits Q&A.
- Personal Independence Payments.
- Money Management.

# About the Evaluation

The evaluation was conducted by Jonny Edwards (Clinician and Independent Researcher) on behalf of Positively UK between December 2022 and April 2023. It covers the period of the Positively UK Welfare Project from May 2020 to April 2023.

## **The purpose of the evaluation was to:**

- Provide a summary and evaluation of work undertaken by the Welfare Service.
- Provide a summary of the impact of the Welfare Service on service users compared to the initial service objectives.
- Collect and reflect on feedback that may improve the service moving forward.

## **Method**

Ongoing data relating to service users and outcomes relating to the welfare support was collected by Positively UK since the commencement of the Welfare Service in May 2020.

Positively UK partnered with Jonny Edwards, in December 2022, to undertake an evaluation of the Welfare Service. Work was undertaken to decide on the aims of the evaluation and identify any existing gaps in data collection. Qualitative data was then collected between February 2023 and March 2023. Data for evaluation was collected from the following sources:

- Positively UK service user outcome data.
- Staff Interview with the Welfare Support Worker.
- Service user focus groups.

## **Service User Outcome Data**

Data was provided to Jonny Edwards, which was reported by Salesforce. The data provided a detailed analysis of anonymised demographic data and information regarding individual benefits/awards received by service users.

## **Staff Interview**

A staff interview was held on 24th February 2023 with the Welfare Support Worker. The Welfare Support Worker provided details of their role and their experiences of working in the service. Topics of discussion included reasons for accessing support, the impact the service has on service users, and suggestions for building on the service provision moving forward.

## **Service User Focus Groups**

Three focus groups were undertaken. In total, 18 service users were recruited (6 per focus group), however 9 people did not attend. In total, 9 service users participated in the focus groups. One focus group was held online on the 4th March 2023 (2 service users). 2 focus groups were held as face-to-face groups at Positively UK's head office on 20th March 2023 (4 service users attended at 1pm, and 3 service users attended at 3pm). The combination of online and face-to-face groups ensured maximum accessibility and opportunity for service users to take part. Focus groups lasted 1 hour and service users were reimbursed for their time and travel.



Focus groups were jointly led by a Peer Support Worker employed by Positively UK named Janine Read (face-to-face groups) and Shiraaz Sidat (online group), with Jonny Edwards. At the commencement of the evaluation, planning meetings were held to ensure the achievement of maximal participation with minimal bias. It was felt that utilising Peer Navigators would maximise participation from service users, in contrast to utilising an independent researcher exclusively.

To reduce bias and ensure independent evaluation, Jonny Edwards formulated the focus group topic guides, attended focus groups, and independently evaluated and analysed the data collected from the focus groups. A training session was delivered to the Peer Navigators in advance of the focus groups to ensure standardised approaches and adherence to ethical principles.

Service users were provided with a participant information sheet that detailed the purpose of the evaluation and the focus group process. Service users were advised and consented to how their information would be used and stored, and that they could withdraw at any point during the evaluation. Reassurance was provided that all focus group data would be collected and used anonymously, and that their responses would not impact any future support from Positively UK.

Service users were asked the following questions by a peer support worker:

- Would anybody like to share some of the reasons that they accessed the Welfare Service? What support did you receive?

- As a result of using the Welfare Service has your financial situation improved?
- Has receiving welfare support improved your mental health and social life?
- Has receiving welfare support improved your physical wellbeing and HIV care?
- Thinking about the Welfare Services you received from Positively UK, did you prefer receiving the advice from a specialist HIV organisation compared with a general welfare/benefits service? If so, why?

To ensure confidentiality and enable participants to speak openly, the Peer Support Worker left the focus group and Jonny Edwards asked the following question:

- Thinking about the future of the service, how can Positively UK build on the Welfare Service it offers? Is there anything you would change?



# Results

## Motivations for Accessing the Welfare Service

Service users accessed the service for a variety of reasons. Many people were in crisis when they first accessed the Welfare Service with some people struggling to access food and shelter, having received a life-altering diagnosis, or needing to reapply for benefits due to a change in personal circumstances. Some service users had uncertain immigration status and had no recourse to public funds. The welfare service acted as a safety net for many people living with HIV who were experiencing extreme challenges.

Illustrative Quotes:

“

*I felt lost, I was not looking after myself.*

*I was left in a really vulnerable situation.*

*I spent a long time looking for employment and I was put in touch with someone who had experience with a work agency. I applied to this work agency, and I needed help getting uniform for work. She [Rosa] helped me to apply for this grant.*

*As an asylum seeker and refugee, I didn't know what to do.*

”

## Challenges in Achieving Support from the UK Welfare System

Many service users experienced challenges in accessing and navigating the welfare system. People often felt that The Welfare System was designed to make it hard for people to achieve support. Service users reported that the cognitive and psychological impact of living with HIV, prevented them from advocating for themselves in both written and verbal communication. The Positively UK Welfare Service was seen by participants as a key support in overcoming the hostile environment, and achieving the financial support they were entitled to.

Illustrative Quotes:

“

*We learn how not to fall in the potholes and they [Department for Work and Pensions] learn how to make the potholes bigger.*

*Some of us are not able to fill in the form - we don't have the right words to express ourselves in writing.*

*Anyone coming to the UK with a language barrier, social barrier and stigma - it's a lot.*

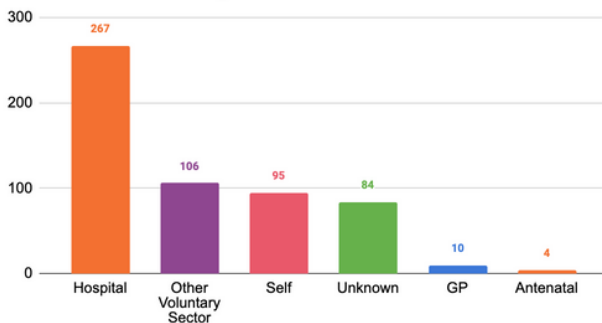
*It's so difficult, it's so stressful.*

”

## Sources of Referral

Positively UK have established cross-sectoral relationships with a variety of organisations that provide referrals to the Welfare Service. This includes Peer Support Workers based in NHS sexual health clinics, local HIV charities/voluntary sector, GP's and antenatal services. The majority of referrals received by Positively UK were from NHS sexual health services (hospital), other voluntary sector HIV services, and through self-referral.

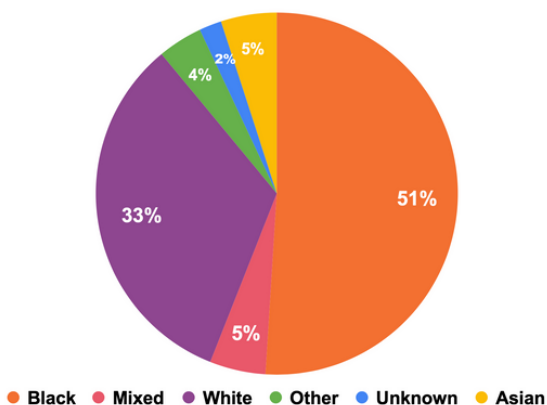
Referral Pathway into the Service:



## Service User Demographics

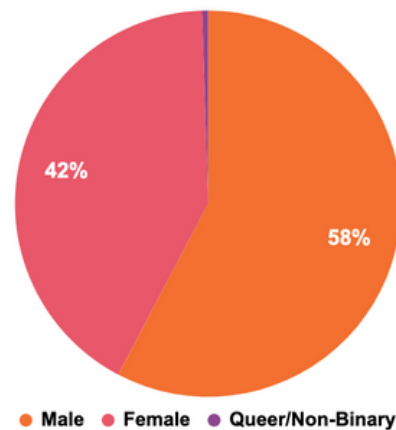
During the period of May 2020 - April 2023, The Welfare Service supported 566 service users totalling 1,181.25 hours of support. The service offered a safe, inclusive, and non-judgmental environment for people to seek help.

### Ethnicity:



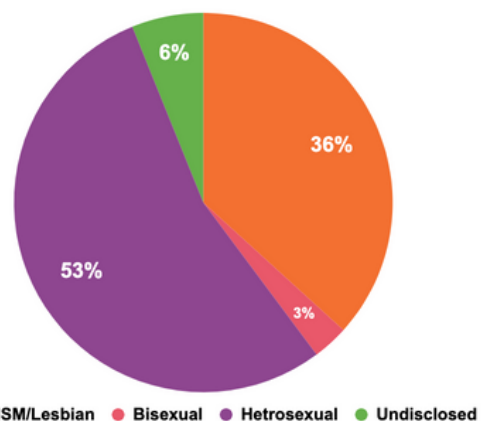
Service users represented a wide range of ethnicities including 288 Black service users (51%), 189 White service users (33%), 28 Asian service users (5%), 26 service users with mixed heritage (5%), 24 service users who identified as 'other' ethnicity, and 11 service users who did not disclose their ethnicity (2%).

### Gender:



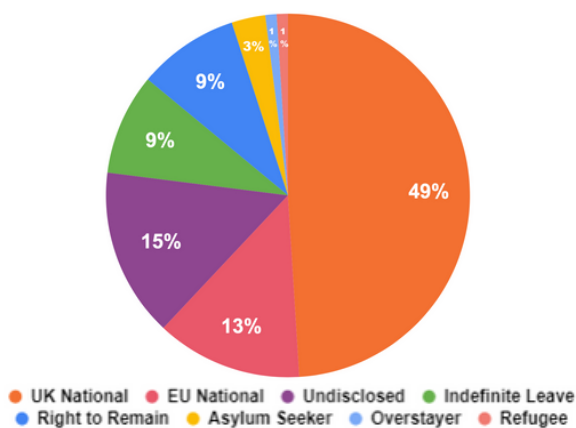
The Welfare Services provided support to 326 male service users (58%), 237 female service users (42%) and 3 queer/non-binary participants (less than 1%).

### Sexuality:



Service users represented a wide range of sexualities including 311 heterosexual service users (53%), 205 gay/MSM/lesbian service users (36%), 33 service users who did not disclose their sexuality (6%), and 17 bisexual service users (3%).

## Immigration Status:



Service users represented a wide variety of immigration statuses including 277 United Kingdom Nationals (49%), 71 European Union Nationals (13%), 88 participants who did not disclose their immigration status (15%), 51 service users with indefinite leave to remain status (9%), 50 service users with right to remain status (9%), 17 asylum seekers (3%), 7 overstayers (1%), and 5 refugees (1%).

## Financial Support:

The Welfare Service supported service users to achieve financial assistance totalling £1,786,005.29 during the period of May 2020 - April 2023.

Service users experienced significant benefit from the support they received from the Welfare Service. Achievements ranged from assisting people in crisis to accessing emergency grants, food, and clothing, to securing long-term financial independence, and improved quality of life through access to benefits and housing.

## Total Financial Support Achieved May 2020 - April 2023:

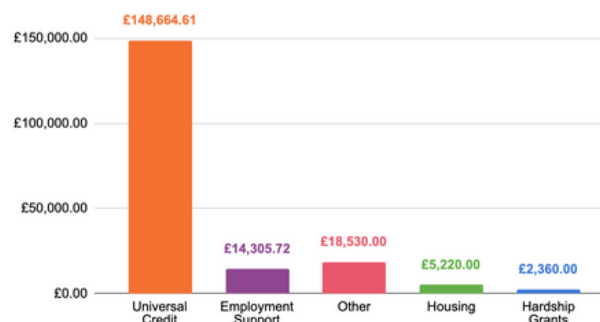
**Summary of Financial Support Received by Service Users**



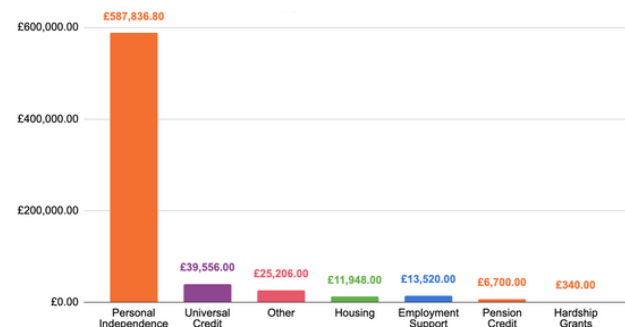
\*The value represented in year 3 is a provisional representation of the total achievement, as many service users are awaiting confirmation of an award, and as such the year 3 figure is likely to be significantly higher.

Service users were awarded support to the value of £732,144.03 in Year 1, £685,106.52 in Year 2, and £368,754.74 in Year 3. Personal Independence Payment in Year 1: £543,063.34, Year 2: £587,836.80 and Year 3: £279,066.38 represented the highest total value of awards secured by service users during years 1-3 of the Welfare Service.

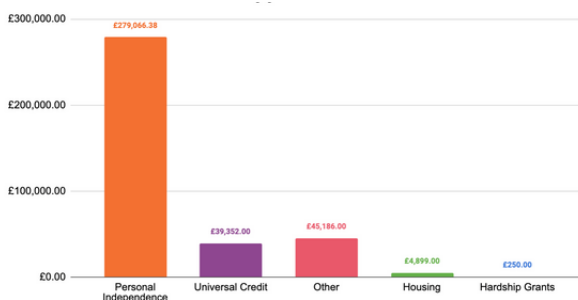
## Breakdown of Financial Support Achieved in Year 1:



## Breakdown of Financial Support Achieved in Year 2:



## Breakdown of Financial Support Achieved in Year 3:



Service users commented on the significant impact that the Welfare Service had provided to their psychological and physical health. The impact was attributed to an improved financial situation, and additionally to referrals to external organisations which enable people living with HIV access to wider support.

Service users were referred to external agencies in circumstances where a wider health need was identified by Positively UK. Service users were often referred to the YMCA Positive Health Programme, which provides a 12 week exercise programme, including supervised gym sessions and access to complementary therapies and nutritional advice. Additionally, service users were frequently referred to The Food Chain who provide groceries, offer cookery classes and nutritional education specifically for people living with HIV.

Additionally, service users discussed the impact of the Welfare Service on their social wellbeing, including accessing travel passes which enabled people to travel freely to social events, medical appointments and HIV related workshops and socials which promoted wellbeing.

## Illustrative Quotes:

“

*Without this support, I wouldn't have been able to concentrate on anything else.*

*I was connected to The Food Chain.*

*I am not struggling for food now, I am okay - but before I was going to food banks.*

*It is better to go to Positively UK, better than a psychiatrist from the NHS.*

*I am still moving forward, coping, believing I will be fine.*

*They referred me to another organisation - Doctors of the World, and I had a full medical check with them.*

*They supported me, as I was in a panic situation.*

*The staff [positively] impacted my mental health and wellbeing.*

*They applied for a bus pass for me. I can go anywhere if I want, just take a bus, which is very, very easy for me.*

”

## Service Impact on Service Users' Mental Physical, and Social Wellbeing

### The Need for a HIV Specialist Welfare Service

The service users who took part in this evaluation unanimously reported a strong preference in favour of receiving financial advice from a Welfare Service that provided peer-led support and specialist HIV knowledge.

The peer-led service enabled people to discuss their health experiences, without feeling judged, in a confidential and welcoming space. Service users highly valued the empathy provided by the Welfare Service and felt safe to ask questions as well as discussing personal, and occasionally embarrassing, details related to their health and finances.

The HIV specialist knowledge, provided by the peer-led Welfare Service at Positively UK, enables the Welfare Support Worker to provide highly accurate and detailed support to service users who are applying for welfare support, particularly in relation to the bio-psycho-social aspects of living with HIV. The Welfare Support Worker often supported service users to include information about their health and wellbeing, that they may otherwise have neglected to include, which may have resulted in an inaccurate or rejected application.

Additionally, the speed of access to support from Positively UK, in comparison to other, more general Welfare Services was highly valued.

### Illustrative Quotes:



*It is good to know someone in the organisation understands us and helps to fill out the form.*

*It was the empathy that helped, the heart-to-heart chats.*

*Positively UK is more person-centred and holistic.*

*When I pick up the phone and hear Rosa's voice, it's a relief, it's a weight off my shoulders.*

*No better place than Positively UK.*

*I am so grateful, thank you so much, I was in a state.*

*Positively UK makes you comfortable.*

*Positively UK is great, everybody can testify to this.*

*I can't even imagine Positively UK not being there, it would be horrible.*





## Feedback About Positively UK

Participants highly valued Positively UK as an organisation and recognised the help and support it provided them. Service users found the charity to be a reliable, friendly, comforting, and safe space, particularly in times of crisis.



*Positively UK has been a friend and a support system.*

*Coming to Positively UK is the best way to escape from isolation. We live with a condition and some of us are not able to associate with other people. Coming to Positively UK is like therapy to fight against stigma and discrimination.*

*I felt I wasn't alone, I had someone to share my problems with.*

*You find a family [at Positively UK].*

*I always find very good people who try to help me in a very good way.*

*They try to put themselves in your shoes, they try to get the most out of the appointment with you.*

*Positively UK was that comforting source.*

*Being in the building with staff from Positively UK, my well-being came back to me, it made me feel alive again.*



## Recommendations for Improvement

Many service users preferred face-to-face support. This was sometimes related to the practicalities of completing forms (such as access to a photocopier), or simply because they had a personal preference for in-person contact. Additionally, some service users would value a planned review after their initial contact with the welfare support worker, to ensure that they are progressing forwards, and did not require any further assistance.

Whilst some service users were unable to work due to long-term ill health, other services users were keen to find a job, or develop a career. However, some service users struggled in accessing support relating to CV writing, or job/course applications and would value mentorship from Positively UK to help them achieve their employment goals.

Service users reported that they would have preferred the Welfare Service to act in a more direct way, providing advocacy on behalf of service users, as they often felt that they were powerless against a hostile environment.

The existence of the Welfare Service (as a specific service within the wider Positively UK offering) and the help that it could provide, was not widely understood by service users. The need for accessible information about the service was identified and services users recommended that posters or leaflets about the service might be helpful.

Finally, service users were keen to be involved in shaping the future service provision and suggested undertaking a specific Welfare Service survey to explore future service needs. Service users were also keen to be more widely represented at annual general meetings and decision-making meetings.





# Overall Project Achievements and Impact

This evaluation analysed the service achievements and impact by comparing the service's activities and outcomes with the service's initial aims. The results of this evaluation demonstrate that Positively UK has achieved its initial aims, which were developed at the initiation of the Welfare Service.

Service users typically accessed the service during periods of poverty and crisis. Frequently, service users had experienced challenges in independently achieving benefits awards and struggled to navigate the national welfare system, often experiencing the system as a hostile environment.

The service offered a safe, inclusive, and non-judgemental environment for people to seek help. Service users highly valued the specialist HIV knowledge provided by the Welfare Service and benefited from accessing welfare advice from a service that is encapsulated in a wider peer-led HIV charity, which enabled the provision of holistic and integrated support.

The Welfare Service enabled service users to increase their personal and financial independence by achieving financial support including grants and benefit awards. During the period of May 2020 - April 2023, the Welfare Service supported 566 users totalling 1,181.25 hours of support hours and supported service users to achieve financial assistance totalling £1,786,005.29. Additionally, the service provided support

with mortgage payments, potential homelessness or housing challenges, food parcels and vouchers, challenges relating to employment/unfair dismissal (related to HIV diagnosis), statutory sick pay and issues relating to long-term unemployment.

Accessing the Welfare Service and achieving financial stability reduced stress and anxiety for service users and promoted psychological wellbeing. Service users benefited from cross-sectoral collaboration with outside organisations such as the YMCA and The Food Chain, which supported service users to increase their physical health through exercise, improved nutrition, and access to healthy food.

Financial independence and stability enabled service users to travel to medical appointments. Improved ability to travel, reduced isolation, and enabled service users to access peer-led support, socials, and HIV specific educational sessions.

Workshops provided by Positively UK, alongside one-to-one support enabled service users to develop the skills and knowledge to navigate the UK welfare system, further increasing independence.

This evaluation demonstrates the significant and ongoing need for the specialist HIV Welfare Service delivered by Positively UK.

# Recommendations for Future Service Provision

All participants discussed the significant benefit they had received from accessing the Welfare Service. However, Positively UK service users were not always aware of the scope of the Welfare Service, or how to access it. Additionally, people who had accessed the Welfare Service were not always aware that they had accessed the service. This evaluation recommends an increased promotion of the Welfare Service to existing Positively UK service users and people living with HIV who do not currently utilise Positively UK services. Wider engagement with social media may also be of benefit in promoting the Welfare Service to a wider audience.

Participants often discussed a preference towards face-to-face advice sessions and workshops. This evaluation recommends a regular drop-in clinic, to facilitate face-to-face support. Information relating to the drop-in clinic should be advertised to both people who have used the Welfare Service and may need further support, alongside existing Positively UK service users and other people living with HIV who do not currently access Positively UK services.

Participants frequently explained that they would have benefited from a planned review to ensure that they were progressing as planned. Where possible, and on an individual basis, this evaluation recommends that future service provision considers including follow up contact with service users after initial support has been provided.

Additionally, an Information leaflet or email should be provided to people who access the Welfare Service (including information regarding confidentiality and how to access the service in future).

Service users experienced significant challenges in navigating the UK welfare system, council services, and the National Health System, and often experienced a hostile environment when seeking support from Government agencies. Some service users highlighted a preference for more advocacy on behalf of service users. This evaluation recommends that early referral to advocacy services should be considered in individuals who may require additional support.

Some service users were keen to gain meaningful employment, but experienced challenges in finding work. Positively UK, as an extension to the existing Welfare Service, is well placed to support people living with HIV to find suitable employment. This might include the provision of workshops such as how to write a CV, or the provision of information on where to look for employment. Additionally, workshops might include information on how to discuss their health with a prospective employer including requesting reasonable adjustments where necessary. Linking to one-to-one work-related mentors, outside of Positively UK may also be useful.

Finally, the evaluation recommends exploring service user involvement in planning the future service provision of the Welfare Service. Additionally, the evaluation recommends wider promotion of opportunities for service users to attend annual general meetings and other decision-making meetings, to ensure that service users are represented during the design and planning stages of Positively UK services.



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