

Centring lived experience voices at the Human Rights Committee's 140th session

Impact report from the British Institute of Human Rights (BIHR) for the Equality and Human Rights Commission (EHRC).

20 March 2024

"I feel that I was listened to, I was respected and more importantly that I was heard" – Kirsten Peebles, Lived Experience Expert

About BIHR

BIHR is a charity working in communities across the UK to enable positive change through the practical use of human rights law. We have a working focus on the rights contained within the International Covenant on Civil and Political Rights (ICCPR) as our primary purpose is the implementation of the Human Rights Act which brings many of the rights in the ICCPR into UK domestic law. We work beyond the courts every day:

- supporting people and communities with the information they need to claim their civil and political rights;
- supporting organisations that have public power to live up to their legal duties; and
- ensuring real-life evidence of the difference civil and political rights make is heard by decision-makers.

Our work directly with people, communities and public bodies puts us in a unique position to call for the development of national law and policy which truly understands people's experiences of their human rights. We hear the stories of people whose lives have been changed in real and tangible ways by civil and political rights protections. We also see the impact when these rights are not upheld. We think it's important that everyone else hears those stories, too, especially our UK Government who have the power to roll back on these fundamental protections or to commit to supporting their implementation through rights respecting law, policy and practice within public bodies. We were

therefore grateful to the EHRC for the opportunity for our Lived Experience Experts to give evidence at the 140th session of the UN Human Rights Committee.

About BIHR's Lived Experience RITES Committee



BIHR's [RITES Committee \(standing for real-life insights, tips, experiences and stories\)](#) is made up of experts by experience from across the UK who have used the Human Rights Act to achieve change – for themselves, the people they work with or their loved ones. From lived experience of caring for family members with complex support needs to working in frontline

public services, each of our experts brings a unique perspective of human rights in practice.

About the funding

EHRC offered funding opportunities to representatives of civil society organisations in Great Britain to provide in-person evidence to the UN Human Rights Committee at its 140th session in Geneva on 11 March 2024. The aim of the project was to enable human rights experts to participate in the Human Rights Committee's examination of the UK's compliance with the ICCPR.

By attending the session, the successful applicants would have the opportunity to share evidence directly with the UN Human Rights Committee on the UK's record on civil and political rights, to inform the Committee's report and recommendations.

BIHR was pleased to see that EHRC's prioritised funding bids from organisations who could:

- enhance the diversity of representation of individuals with one or more protected characteristics.
- enable the participation of individuals with lived experience relevant to the Human Rights Committee's 140th session.

- enable the participation of organisations which would otherwise be unable to attend.

BIHR applied on the basis that provision of funding from EHRC would allow us to invite and importantly support, one or more of our Lived Experience Experts to prepare, attend and decompress. We shared with EHRC some of the members of our Committee whom we'd like to invite to have their voices heard on key ICCPR issues.

- Fairuz specialises in working with women and girls from Black and Minoritised Ethnic communities with multiple disadvantage and complex needs.
- Kirsten is a single parent of an autistic son who, from the ages of 14-18, was held in mental health hospitals and subjected to restrictive practices, including mechanical restraint and long periods in seclusion.
- Charli Clement is a disabled, neurodivergent and LGBTQ+ activist. Charli works with BIHR as a Lived Experience Expert as well as the NHS and other third sector organisations looking at psychiatric care, autism, human rights and sensory needs, after their own admission when they were a teenager.
- Hanna is a young person who spent over a year in inpatient mental health care. She is now training to be a paramedic.

We were awarded £2100 which covered the travel, hotel and sustenance costs of two Lived Experience Experts for two days. This funding was invaluable in meeting those costs, as BIHR would not have been able to cover them ourselves. However, it is important to flag that BIHR did supplement the EHRC funding with our core funding to cover participation payments for Experts for their time. As our experts are not salaried, attending means time off other paid work so we have to ensure their days of time are also paid for. BIHR also supplemented the cost of 2 BIHR staff members to support our experts to prepare and attend. On this occasion BIHR was in a fortunate position to have core funds available to do this; but that will not always be the case. Such an approach runs the risk of excluding other civil society groups from being able to take up the opportunity this EHRC funding opens. For any future funding, we very hope the EHRC beyond the provision of travel & subsistence grants only. For example, funding could be specified for lived experience time payments, for organisational support payments, etc. This is an

important opportunity to further support a rights-based approach to participation.

The impact of the funding – centring lived experience voices

EHRC's funding meant that the Human Rights Committee and all in attendance were able to hear directly from those impacted by rights issues in the UK. Not only is this required by a human rights based approach to policy and practice, our experience over 20 years of human rights work at BIHR tells us that valuing, funding and listening to people with lived experience of human rights issues has the power to change things in a way that hearing from policy professionals alone on the issues simply does not. Our evidence, tells us that hearing from a person directly affected by the action or inaction of our UK Government carries a lasting impression, evokes empathy and is more likely to lead to action. It is not so easy to remove yourself from the testimony of someone who has been on the sharp end of the issue(s).

However, hearing from lived experience voices does not just happen. It requires, process, infrastructure and lots of support hours to build trust and relationships creating safe and supportive environments for these voices both before and after they share their experiences. At BIHR our Experts are paid to work with us over many years through our RITES Committee and through our programmes work where we cost in Lived Experience expertise in our proposals. This requires funding and we are always seeking funding streams to support this work, EHRC's was a welcome opportunity.

The funding meant that the Human Rights Committee heard directly from:

Fairuz Choudhury on the rights issues faced by women and girls from Black and Minoritised communities

This funding meant we were able to invite Lived Experience Expert Fairuz Choudhury, who has worked in the UK charity sector for the past 17 years. Fairuz has extensive experience of developing, creating and managing services in Gender Equality, Welfare Rights Advice, Legal Pro Bono Work, Mental Health Advocacy, Refugee Advocacy and Violence Against Women and Girls services. She specialises in working with women and girls from Black and Minoritised Ethnic communities with multiple disadvantages and complex needs.

EHRC's funding gave Fairuz a platform to speak to the Committee about the rights issues faced by black and minoritised women. This is an underrepresented group whose voices often go unheard by those in positions of power, yet they are a group at the sharp end of rights issues in the UK and should be represented in these discussions.

Fairuz was able to raise issues important to her community, suggest solutions and ask for change by the UK Government to ensure rights are upheld without discrimination. Fairuz's testimony covered the right to private and family life (Art 8 HRA, Art 17 ICCPR), the right to be free from inhuman and degrading treatment (Art 3 HRA, Art 7 ICCPR) and the right to be free from discrimination (Art 14 HRA, Art 26 ICCPR) across multiple issues including:

- the intersectional experiences of and barriers faced by Black and Minoritised women and girls in having their rights upheld when accessing services in the UK.
- the effect of cost-of-living on intersectional groups and barriers to accessing benefits.
- the rights issues faced by women fleeing violence and abuse.

"These are just a few examples where women felt like they were treated as though they were "undeserving" of human rights. All of these could be avoided, if the public bodies provided proper human rights training to all their staff allowing them to understand how their actions were violating human rights."

The funding meant that the Human Rights Committee heard directly from:

Kirsten Peebles on the rights issues face by Autistic children and their families

EHRC's funding meant we were also able to invite Lived Experience Expert Kirsten Peebles. Kirsten is a single parent of an Autistic son who was locked in mental health hospitals from the ages of 14 to 17. While an inpatient, he was subjected to high levels of restrictive practice and his human rights were breached on many occasions. Kirsten fought for him to be discharged from hospital and receive the right support in his own home. She now focuses on supporting health and social care practitioners to uphold human rights and eliminate harmful restrictive practices.

Kirsten was given space to speak about the rights issues faced by her and her son. Kirsten spoke about her experience but shared that it is not only her experience, but the experience of many families like hers. Kirsten's testimony covered the right to be free from inhuman and degrading treatment (Art 3 HRA, Art 7 ICCPR), the right to be free from discrimination (Art 14 HRA, Art 26 ICCPR), the right to private and family life (Art 8 HRA, Art 17 ICCPR) and the right to liberty (Art 5 HRA, Art 9 ICCPR) across multiple issues including:

- the disproportionate use of restrictive practice in UK mental health hospitals, especially for autistic children.
- the use of mechanical and chemical restraint in UK mental health hospitals.

"I was powerless to comfort or protect him, they wouldn't let me see or speak to him. I used to wonder if he called for me, if he wished I was there to help him. I was angry and afraid every minute of the day. When I knew he was in solitary confinement I wanted to sleep on the kitchen floor, I couldn't bear my comfortable bed. Because I knew he was alone in the dark and I wasn't there for him. They stole my son's childhood. They stole his childhood from both of us." You can read Kirsten's full statement in the appendix.

Funding lived experience voices: The difference it makes

BIHR have long been gathering data on the difference it makes when lived experience voices are funded and supported to be heard. This impact was evident at the ICCPR session, with several members of the UN Human Rights Committee and attendees approaching Fairuz and Kirsten after the formal session to share how impactful their evidence was for them both professionally and personally.

Below we share some data gathered from surveys where lived experience voices have been present on training, events and policy projects.



"A Lived Experience Expert reminds people that we are talking about real lives."*

"I think that what made the workshop be fantastic was that we had someone with lived experience on the training [...] who was brave, vulnerable and authentic about her lived experience and made the training more engaging, relevant and personal."*

84% of staff said that having a Lived Experience Expert in the workshop helped them to think about rights-respecting changes to current practices.

"I found having lived experience very useful. It's hard to think how our work impacts people after they have left the service so having Charli tell us was very helpful."*

*All quotes are from participants on BIHR programmes between 2021 and 2024.

The impact:

In Kirsten's own words:

"I am really glad to be here today to give evidence and testimony to the UN Human Rights Committee. It was great as a person with lived experience to be one of only two people who were talking about their own personal experience. To be able to be heard by the UN on the treatment of my autistic son as an inpatient and to highlight the plight of him and many other families like mine who are subject to high levels of restrictive practice and to solitary confinement and to inhuman and degrading treatment. I feel that I was listened to, I was respected and more importantly that I was heard. I'd like to thank BIHR for that wonderful opportunity and let's hope it makes a big difference."

[You can watch Kirsten explain the impact in this video.](#)

In Fairuz's own words:

"I am really glad to be here today to give evidence in person of the intersectional experiences of women fleeing abuse, especially women from black and

minoritised communities. How their human rights are violated when accessing basic services like housing and social security, benefits and legal aid. This could be improved by educating frontline services and officials.”

[You can watch Fairuz explain the impact in this video.](#)

Summary and next steps

BIHR would like to thank EHRC for the opportunity and for prioritising funding for lived experience expertise and diversity. We hope to see many other equality and human rights funding streams take this approach.

BIHR intends to follow-up with the Committee ahead of its concluding observations in regard to both the testimonies of our Lived Experience Experts and the evidence we were able to share in the informal briefing. We hope to be able to reinforce the messages shared at the session and provide further information and examples that speak to the points raised and the questions asked by the Committee.

We have also been able to connect with other civil society groups working on issues closely connected to BIHR’s work. We have seen (particularly in recent years, as civil society was mobilised to come together to resist attacks on the Human Rights Act) the power of unified voices from across the third sector, and attending the session in-person was a great opportunity to develop these vital relationships. We intend to explore future opportunities to work together with the other NGOs in attendance.

Similarly, Kirsten and Fairuz will be sharing their experiences with our wider RITES Committee, to inspire and support other Lived Experience Experts to further engage with public and policy work relating to human rights in the UK.



Appendix: Full statements

Fairuz's Choudhury, Lived Experience Expert:

“The lack of adequate knowledge of human rights law has continued to limit human rights for women in UK, in particular Women from Black and Minoritised communities with intersectional experiences face discrimination at multiple levels. Women fleeing violence and abuse from these communities face grave violation of their human rights, to the point that they feel human rights are only for the privileged not for women like them.

Women who feel hopeless and talk about going back to their abusers, simply because of the way they are treated by housing services, who refuse to re-house them in safe accommodations, adult social services who refuse to provide adequate care to terminally ill victims of abuse, enabling the abuser to continue to psychologically and economically abuse the victim and women with disabilities whose disability benefits are rejected because they are considered to be fit enough according to the DWP assessments, these are just a few examples

where women felt like they were treated as though they were “undeserving” of human rights. All of these could be avoided, if the public bodies provided proper human rights training to all their staff allowing them to understand how their actions were violating human rights, in these cases, the right not to be treated in an inhuman and degrading way (protected by both the ICCPR and our UK domestic law, the Human Right Act).

Women from Black and Minoritised communities in UK, with insecure immigration status fleeing abuse, or women with mental health issues or those with contact with the criminal justice system or women who are tireless fighting for the custody of their children in family courts, all these women continue to face intersectional barriers in accessing basic human rights, because of the front-line public body professionals lacking proper knowledge of human rights, contributing to the rigid and oppressive mechanisms and systems that simply do not acknowledge the human rights of women with intersectional experiences. It is crucial to make human rights accessible and inclusive for all in UK, including women facing multiple barriers due to intersectional experiences.”

Kirsten Peebles, Lived Experience Expert:

“My only child is autistic and when he was 14 he was sectioned in a mental health hospital. Read without knowledge or understanding of human rights law, the UK Mental Health Act gave legal powers to give my son so many drugs they turned him into a zombie. It gave powers to put him in metal handcuffs to go for a shower. It gave powers to transport him in a cage from one hospital to another.

My child was not a criminal, he was just autistic, in distress, frightened and alone. Worst of all it gave them powers to put my child in a solitary confinement cell for weeks at a time. When they put him in there, he was restrained by several members of staff, stripped naked and forced into stiff non-rip clothing. Because the hospital staff didn’t know about, or protect, my son’s human rights, he acted like a ‘caged animal’. He believed he was less than human, unvalued in society. Sometimes he experienced hallucinations from sensory deprivation. As his mother I was powerless to comfort or protect him, they wouldn’t let me see or speak to him. I used to wonder if he called for me, if he wished I was there to help him.

I was angry and afraid every minute of the day. When I knew he was in solitary confinement I wanted to sleep on the kitchen floor, I couldn’t bear my

comfortable bed. Because I knew he was alone in the dark and I wasn't there for him.

They stole my son's childhood. They stole his childhood from both of us."

The British Institute of Human Rights is a registered charity (1101575) and registered company (4978121).

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Please note: we do not work at this address and the office here is not open to visitors; the address is for correspondence only. E: We work remotely, and email is therefore the best contact method; general queries can be directed to info@bihr.org.uk. T: 020 3039 3646 (a voicemail facility which is checked daily).

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