

Lived-Experience Mental Health in Times of Covid-19

with China Mills & Akiko Hart

SAARA [00:00:00] Hello and welcome. This is a podcast on lived experience led mental health support in times of Covid-19 by China Mills and Akiko Hart as part of Through the Portal programme, a community-led health programme created in response to Covid-19, but relevant before and beyond.

SAARA [00:00:32] So to introduce our absolutely incredible speakers today, we've got China Mills, who researches and teaches about global and mental health. She is a senior lecturer in public health and programme director of the Masters of Public Health, MPH at City University of London. And Akiko Hart is the CEO of NSUN, the National Survivor User Network. She has previously worked as the Hearing Voices Project Manager at Mind in Camden and the director of Mental Health Europe. She is a trustee of ISPS UK, the English Hearing Voices Network and National Voices.

SAARA [00:01:18] So I'm going to hand straight over to China, who will be holding the session.

CHINA [00:01:25] Thank you so much Saara for introducing us and for grounding us and just thank you so much to Healing Justice London for making this space possible. It's such an honour to be invited to be part of this wonderful work. So we want to welcome you who are listening into the space and into the

conversation we'll be having today. Just to reiterate what Saara said, our aim is to the conversation to be accessible and meaningful. If we use any jargon, then we'll try to talk about what our understanding of those words mean. We won't be talking about personal stories of distress in detail. And if we feel anything might be triggering in any way, then we'll say so beforehand.

CHINA [00:02:07] So the aim of the session today is to share learning and to talk about organising and mutual aid in relation to mental health in times of covid-19. So we hope also to talk about what makes lived experience work different to other forms of support and the diversity and energy of the lived experience-led, community-led and user-led sector around mental distress in the UK today. So just to recap, my name's China Mills and I'm joined here by Akiko Hart who is the Chief Executive Officer and CEO of the National Survivor User Network, NSUN. So I'm going to ask Akiko some questions and we're going to have some conversation together about some of the key work of NSUN. So, Akiko, would you just be able to introduce yourself a little bit more and tell us a bit about your journey to becoming the CEO of NSUN?

AKIKO [00:03:04] Hi, China. Thank you so much, first of all, for inviting me today. It's an honour to be here. I always find it quite hard to situate myself in mental health because I find it's often a world where you are allowed one identity, but not another one. I find it always a little bit tricky.

AKIKO [00:03:23] I suppose I came to this role because I had an interest and experience in rights based mental health policy, I used to be the director of Mental Health Europe. Just before I was at NSUN, I worked at a medium sized UK charity, Mind in Camden, where I helped set up and facilitate hearing voices peer support groups and networks in the community and in other settings like prisons, forensic secure units, immigration removal centres. So I suppose I came to this work kind of interested in the gaps between mental health policy, practise and research and how those areas don't really talk to each other so well, but also with a really strong belief that mental health is inherently political. And I'm interested in community action and organising and mutual aid and peer support and what happens in those spaces. So I started at NSUN in January this year. I had a few months before covid, and then since then everything has changed.

CHINA [00:04:26] And there are lots of people who were delighted to hear you start at NSUN because you bring such rich experience in that sense to the work. Would you just be able to tell us a little bit more about NSUN and kind of, a little bit about the history maybe in some of the work generally done by NSUN?

AKIKO [00:04:43] Sure. So NSUN is a UK charity and an England wide membership organisation for people with lived experience of mental ill health, distress or trauma, as well as user-led or community-led groups. So we have just over five thousand members at the moment and our role really is to

influence mental health policy, practise and research through amplifying the diverse voices of our membership. And I suppose some of the things we try to do is push back against this idea that survivor knowledge is just located in the individual, but that it's actually, well not just one collective knowledge, but many collective knowledges. And that, what is sometimes called in mental health policy, this kind of service user voice, isn't one voice, but many, and that it's not a monolith.

CHINA [00:05:35] And just in terms of being mindful about jargon and how we're using words, I'm just thinking, so NSUN is called the National Survivor User Network. Could you just tell us a little bit more about what both survivor and user mean in relation to NSUNs work? Because I know they can mean lots of different things to different people, but just some idea of how you're using those terms.

AKIKO [00:05:58] Yeah, absolutely. I think it's really, really key to so much work in mental health. People... The way people talk about themselves and define themselves, I think is really key, and I think we need to push back against this idea that there should only be one word for defining a very diverse group of people. So some people will talk about themselves as service users because they use mental health services. But of course, a lot of people with personal experience of mental ill health, distress or trauma might not want to use services, might want to use services, but might not be able to access them or might have used services in the past. So some people might also talk about

themselves as ex-service users or as service refusers. The survivor word is really interesting I think if you come at it from outside of mental health, people, often me survivors of what? And it depends. For some people, it's survivors of mental distress or mental illness. For some people, it's survivors of the psychiatric system of oppression. So there's something it deeply political in that. And for a lot of people, it's that and many other things, survivors of interpersonal violence, for example. So we try not to use one word, survivor or services user or people with lived experience, but we try and incorporate as many of these as possible when talking about our membership.

CHINA [00:07:19] Thank you, Akiko. And I think we'll perhaps come back to some of those issues when we talk a little bit more about what NSUN has been doing in relation to Covid-19. I think just for anyone who isn't aware of NSUN's work, I first came across NSUN because of the brilliant publications and reports which are all freely available on the NSUN website. And what especially comes to mind is the brilliant report, which is titled Dancing to Our Own Tunes: Reassessing Black and Minority Ethnic Mental Health Service User Involvement by Jayasree Kalathil who is a mutual friend of both of us. And I'm also thinking about the 4Pi National Involvement Standards, so developed by people with lived experience as part of the National Involvement Partnership Project, which aims to ensure more effective co-production to improve experiences of support. So there's some brilliant resources available if anyone is able to or wanted to access them. And so, the next thing I thought we could talk about in relation to NSUN was that very recently you've launched a fund for micro grants to user-

led groups in response to Covid-19, and also, linked to this, the NSUN website features just a whole series of brilliant short films and blogs which aim to go beyond the mainstream guidance and give a space for NSUN members to speak about what matters to them: how they're experiencing this current period of crisis, how they're reaching out to others, a space to offer ideas, practical resources, connection, possibilities, validation, very similar actually to what Healing Justice London is doing and what this podcast is part of. So Akiko can you tell us a bit more about the Covid fund and how it came to be? Why did you feel it was needed?

AKIKO [00:09:09] Yes, absolutely. So we secured some funding through Mind via the Department of Health and Social Care and most recently a top up grant from Lankelly Chase, which is a grant making trust to award small grants of initially up to two thousand pounds and then up to five thousand pounds to user-led, community led, lived experience led groups in England supporting people living with mental ill health or distress during Covid-19. This came about because the Department of Health and Social Care had awarded National Mind, a larger grant to support small to medium sized charities, working with people living with mental health or distress. And we made the case that a lot of smaller groups and organisations wouldn't be eligible for this pot of money, which is a perennial issue, I think, in funding, and that they had different needs and that we would be able to reach out to them.

AKIKO [00:10:07] So we started off this process, I think, with, excitement and hope and uncertainty, because it wasn't something that NSUN had done before and it wasn't something that I'd done before either. We weren't sure what to expect. I think we thought it could be that perhaps no one is doing anything. Perhaps groups are paralysed because of Covid, we'd heard a lot about... We'd seen a lot about the decline of user-led groups. And we thought maybe there's just not enough activity to justify this funding. So we... And I also thought, well, maybe people will just be applying for money for Zoom, to move their groups online and maybe be quite kind of boring process where we're just paying for lots and lots of Zoom subscriptions. And that hasn't been the case at all. I've been completely bowled over by the entire process. So in total we've distributed one hundred and twenty thousand pounds to seventy nine organisations. 42 percent of the funding has been awarded to organisations or projects led by people of colour. It's been all over England and we've just been completely bowled over by the variety, by the richness, by the imagination, the pragmatism of all the projects we funded. And it has been such a pleasure and an honour just reading the applications and building relationships with the grantees.

CHINA [00:11:36] That's so, just wonderful to hear that the energy is still there, despite very difficult conditions which started long before Covid, right? But, have certainly been exacerbated by them. Do you think you could give us a little bit of a taste, of some of, what kinds of projects and what kinds of ideas and you saw in the applications and that you funded?

AKIKO [00:11:56] Yeah, absolutely. I mean, there's been a real variety. So I think some of the smaller applications have been for just under two hundred pounds and those being tended to be for mutual aid or peer support groups to move online. And that's been quite straightforward. But then we've had really wonderfully imaginative projects, for example, a project to develop a podcast for socially distant walks, based on... So this is FruitCake Creatives led by Michelle Baharier who used to run the Largactyl Shuffle Walks around London. And so this was for a co-created podcast that all the socially distanced people within the group could share while they walked. So, again, just this wonderful sense of community, of creation, of creating something kind of long lasting together that kind of came out from that. And that was just really, really practical as well. So that was a nice example. Another nice example for me is... So this was a little bit further on in the process because obviously the situation changed with Covid because at the beginning it was complete lockdown and it was very, very new to people. And I think a lot of people didn't quite know what to do with the money. At the beginning there was a lot of, there were a lot of calls for food, for example, and for that kind of more emergency type need. And then obviously that shifted well, whilst people kind of got to grips with the situation. And then obviously the lockdown has lifted, but it hasn't lifted for everyone. So it has changed over time. And a more recent application has been from Adira, which is a Sheffield based project supporting black women living with mental distress in Sheffield, and that was for a mobile hairdresser to go to acute mental health wards to do the hair of black men and women who are detained within services. And it spoke to me so profoundly. The... Ursula who runs the project said that

when she was sectioned, one of the things that upset her the most was, to be, for her hair to be so wild, that she would be seen as a stereotypical mad black woman. And for her to be able to have her hair under control and to feel like herself was deeply connected to her sense of self and also her sense of history, her sense of personal history. And she wanted to give that back to other women and men. So that was something that really spoke to me.

CHINA [00:14:32] Thank you. Just amazing examples of personally and locally meaningful kinds of projects. And is there a way of, are you documenting those projects as they go through and as they use the funding?

AKIKO [00:14:45] Yes, absolutely. So Alison Faulkner, who is a very renowned survivor researcher, is evaluating the project. We've got a number of videos that are coming out once a week. So the Adira one, I think, is coming out today. So we can share that. And there will be a report that will be written up, I think, in September or October. We're really keen to learn from this, so for us, it's not just about amplifying these amazing projects, but also for us as an organisation to reflect on our processes and what we could have done better and what we've learnt, because it hasn't been straightforward and it certainly hasn't been what we thought it would be.

CHINA [00:15:27] And are you're able to, to share with us kind of what, what has been different from perhaps what you were expecting or what were the

surprises or some of the sort of key learnings that you found from this process? Because I know you said that this is quite a new process for NSUN and for you.

AKIKO [00:15:44] Yeah, absolutely. So I think that there's a number of things. One of them is around, I think, language, but obviously, like with anything to do with language and words, it's about a lot more than that. So I think we started off this, this project talking about reaching out to user-led organisations, to ULOs, which is what, that's the jargon, who were supporting people living with mental health. So mental health projects essentially. And what we found in this process was that very few of the people who applied referred to themselves as user-led that just didn't speak to them at all. There were clear generational divides where younger kind of activist groups didn't tend to use that terminology, but also groups and organisations led by people of colour didn't either. So that was super interesting. And people didn't talk, didn't necessarily talk about their work being about mental health. So on a really practical level, this kind of matters for us, because if as an organisation we're trying to reach out and connect with user-led organisations who are doing mental health work, and that doesn't speak to them in any way, we're not talking to the right people, if that makes sense. We're not talking to as many people as we could. It matters on a policy and funding level because, again, a lot of this terminology is also reflected in funding and funders if, if they are trying to map the sector and work out who is doing what, they're going to be missing a huge amount of work as well, because their words won't match what is actually happening on the ground. But it's something more than that as well. So if, for example, so Colin

King, his organisation is one of the organisations we funded. So Colin King is, he's many things. He's an activist. He's, he's a social worker. He's, he's an academic community organiser, amazing person. And one of the many, many things he does, is that he does, he does lots of work in London with young black men in the community doing football projects. And if I take that from a kind of like policy or kind of funders perspective, that fits into, I suppose, like a youth work box and a community work box and a sports box, but it doesn't kind of scream mental health. But it is fundamentally a mental health project because you can't, you can't divorce the experiences of racialised people from either the criminal justice system or the mental health system. And it immediately positions mental health as a political, in a political space and positions his work as a political act of resistance. So that, I think, is potentially what we miss if I think we're not, if we're not attuned to the way in which people are describing their work for themselves and if we try to kind of impose our own kind of labels or definitions or structures upon them.

CHINA [00:18:55] And did you notice, what kind of language are people using in this work then, if they're not using terms like mental health or user or survivor? Was there just a whole plethora of different kind of language being used or did you have any sort of patterns?

AKIKO [00:19:13] Yeah. So I think it'll be really interesting to see, when we go through the evaluations to kind of pick up on patterns. I think there's just a real mix, so... And I think that's good. So I mean, people do talk about mental health,

they talk about mental wellbeing, talk about all sorts of things. Some people talk about organising, community organising, community-based. But what we found, because one of the steps through our process was that we would only fund what we were calling user-led groups. So we had a process whereby we had a grants administrator contact shortlisted applicants to kind of ask them that question, as well as other questions. What we found is that, it was so obvious to people that they were user-led or what we were calling user-led, that they didn't even think of describing it as such in their application because they were doing the work for their community and they came from that community and that it almost didn't have to be said. And that was interesting.

CHINA [00:20:14] I find the whole discussion about this kind of language in terms of organising that's happening in forms of mutual aid and community organising so interesting because, as you know, quite a lot of my work is around what might be called global mental health or critical approaches to global mental health. And I've spent quite a lot of time with, with organisations that I guess we could describe as being user-led, but might not use that language themselves, particularly in India. And I've had some really interesting discussions with folks there about this kind of language particularly, and how important say it's been to organise around an identity of psychiatric survivor, for example, and how that often has a very inherently political kind of understanding, often organised in relation to the human rights abuses that some folks experience within the psychiatric system or the mental health system more broadly. But how that doesn't always speak to experiences of people who either

for various reasons of discrimination or also because of where they live, might not be able to experience that system. So I'm thinking a lot of folks that I met in India hadn't experienced the psychiatric system and so couldn't necessarily organise around being a psychiatric survivor in the same way. It also makes me think about and the wonderful organisation and network of the Pan African Network of People with Psychosocial Disabilities and how they used to be called the Pan African Network of Users and Survivors of Psychiatry, and how that name change really sort of reflects how important that language is in terms of getting that community buy-in, I suppose, but also reflecting people's actual lived experience of either surviving systems or and also what psychosocial disability has offered a lot of people as a kind of identity category, I think, and I'm thinking especially around lived experience. Did you see that kind of mobilisation quite a lot within the fund? Because I know within mental health there are some times, debates about using the terms lived experience just because it doesn't, it can be a lot of different things. As an example, I've got lived experience of having quite a few of my family members go through a quite violent psychiatric system, but I myself have never gone through that system. And so the way I live, you know, and there is, those experiences are linked, but they're also very different from one another in certain ways. And I, as a family member, could never claim to speak on behalf of someone who themselves went through that system. Do you see lived experience being used in that kind of way or sort of creative ways in the food that you've been running?

AKIKO [00:23:01] Yeah, it's a really interesting one lived experience, isn't it? I mean, to go back to psychosocial disability. I don't think I saw that maybe once or twice in the applications, but I don't think that will surprise you because I don't think that's used so often I think in the UK, psychosocial disability, you hear it a lot less. Lived experience, yes we saw that a lot more. I think it's, it's a mixed term, isn't it? I mean, no term is... Every term is deeply imperfect and lived experience has got lots of critics, but perhaps there's something expansive about it, which is also why people criticise it, but expansive enough to feel comfortable for, for organising. What I was really, really interested in seeing was how, how so much of the kind of grassroots campaigning work I saw that I hadn't been particularly aware of... So I'm thinking here more of perhaps kind of just slightly younger kind of activist groups, I guess, are... Were not single issue. So they weren't just talking about mental health, but they were doing mental health and anti-racism work, for example, or mental health and environmental activism. And I think that that's something that we're seeing coming up quite a bit, which is different, I think, to a different generation of campaigners who were perhaps more focused on specific issues because things changed. What I'm really, really interested in doing at NSUN is trying to bridge that generational divide a little bit and trying to create spaces where that learning can be shared. I think that would be really, really rich.

CHINA [00:24:45] I think it's so important because something that I have sort of become very aware of, hanging around, I guess, in a lot of these spaces over the past few years, has been that a lot of organising... I mean, and I completely

see why, and I think there's been amazing achievements here. But a lot of organising in the UK and perhaps in some other places as well around mental health has been based on people's contact more with psychiatry or with the mental health system, let's say. Not necessarily just psychiatry. But of course, not everyone who's experienced distress has had contact with the psychiatric system. And those who have will have had very different experiences. So people don't experience the psychiatric system and mental health system in the same ways. And I'm thinking about very different experiences around, say, choice or coercion. For some people, rightly so, I think there's a real concern about kind of over medicalisation, if you like, but then also for others, absolute lack of access, people not being taken seriously and people in crisis actually having nowhere to go. And I'm thinking, obviously, that that reflects the different positions, people's different positionalities, the different kinds of privilege that they're able to access, different intersecting forms of discrimination that they might experience. And so it's really exciting to hear that that you and that NSUN are interested in kind of engaging beyond that I suppose, and thinking like you're saying about the more creative ways that people are organising around mental health.

AKIKO [00:26:27] Yeah, I think so, because I think, as you pointed out, it can feel sometimes within this kind of campaigning world that there's a divide between people who are campaigning about abuse and then, other people who are campaigning about neglect. And obviously they are two sides of the same coin. And as you say, not everyone has personal experience of mental health

services, partly because of austerity and cuts, because a lot of people can't access support. And obviously mental health services have changed over the last 30 years. What I'm interested in, I suppose, was the energy that I found in the groups who were doing things. And I think that just seems to me a really fruitful area for NSUN to be focusing on. How do we facilitate that? We can't do it on behalf of. That's not the point, it's how do we facilitate that? How do we support that? How do we connect different groups together? How do we think together about sustainability, about about healing, about, about burnout?

Because I think, I don't know if this speaks to you. My experience of activism, of organising, is that often the work is held by a small number of individuals and it's always the same people kind of doing the heavy lifting. And often those people are the most marginalised within their communities and that, that labour is invisible. If I think about our Covid Life video and podcast, our video and, and blog series, we have thirty four videos and blogs. Everyone was either, a woman or queer or trans or a person of colour or disabled, and that wasn't intentional, but I think that pattern reproduces itself across kind of organised, community organising and activism, where it's, where that work is taken on quite often by people with more marginalised identities and lives within, within their communities. And I'm interested in thinking about how we can... How we can guard against burnout. How, how that kind of learning can be shared. One of the groups that we funded, Kunsaka, which is a group supporting African elders in London, what I loved about their proposal was that they were really keen to think together about how to share the learning that was held and the experience that was held by the elders within their community and how they

were still doing a lot of the work. And how they could share it with younger activists who were coming up within their community and kind of bridge that gap. And so that the few people who were doing the work weren't completely burnt out and didn't just leave.

CHINA [00:29:34] I think just amazing work and would you just tell us a little bit more about the Covid Life series of blogs that you have, I had a quick look yesterday, and there's so many of them and they're so rich. But I was also struck by a similar... By what you've just talked about in a way, but yeah, any more snippets to get people to have a look at them and have a listen?

AKIKO [00:29:57] Oh, I love them. I love them. And for me they are NSUN. Rather than like me, talk about what NSUN is, to show people that series of videos with these very kind of different voices and perspectives and experiences. There was so much love and rage and energy within all of those different different clips. It really, really speaks to me. So we've got, you know, lots of different types of organisations like People First, which is a user-led learning difficulties charity. We've got Wish, women in secure hospitals, someone from Freed Voices, which is the expert by experience arm of detention action, talks about what it's like, what it was like in an immigration removal centre during Covid-19. So we tried to kind of reach out to as many people as possible. And also, I think at the beginning of Covid, we were only hearing a certain type of... Well, certainly I was only catching a certain type of story in the

media in terms of like my experience of lockdown. And I think we were trying to kind of just amplify lots of different experiences of lockdown and Covid.

CHINA [00:31:15] And hopefully, I guess that a lot of these issues have been, have maybe come into visibility or a bit heard about more in relation to covid, but have been much more long, longer going issues, if you know what I mean. In the sense that I'm thinking particularly about, say, the work of detention action and other groups in relation to immigration removal centres and the long and amazing campaigning work that's been done there, as well as the work around hearing voices groups, etc. in those carceral spaces, that some of these issues are long standing in terms of detention, but are perhaps coming to the forefront a little bit more now because of Covid almost in a way. So Covid does present new challenges, but kind of on top of a much longer existing challenges. And so there is an opportunity in a sense, I suppose, to bring that into people's recognition and visibility a little bit more.

AKIKO [00:32:14] I hope so. I mean, certainly from a policy perspective, I'm hearing a lot of warm noises about, you know about community work, about how there needs to be a paradigm shift in how we do mental health. You know, about trying to work more locally, and then obviously, you know, since the murder of George Floyd that we had ramped up kind of rhetoric around kind of anti-racism. But I think the worry is always, you know, is it just words? What does that look like in terms of action and within the charity sector, certainly. You know, there seems to have been, you know, a real, a kind of wider reflective

exercise about, you know, the whiteness of the sector and the kind of structural racism within it. And Charities So White has done amazing work around this. But again, what does that look like in terms of actual change on the ground? I'm not so sure. And I think it's an opportunity. Yes. And I hope we we seize it. But yeah, it worries me as well.

CHINA [00:33:22] And I guess we see that, yeah, the language potentially of community led, lived experience led, user-led the kinds of things we've been talking about, that being co-opted in that sense or of it changing at least as it as it starts to be used within those kind of policy circles, I suppose. And I guess just thinking about your amazing, long experience in this kind of work, but also your exposure more recently to the, to the fund and to the Covid Life blogs. What, what do you think it is, or when drawing on your experience, what do you think it might be that makes that kind of lived experience, community led sort of work and in a way different, qualitatively different or meaningfully different than some of the other work that's going on? And because it's important to capture that, I guess if we're concerned about the potential co-option, as if that language is going to be used more, say within policy, it's important that we have a sort of distilled idea of the richness of what makes that work different. And obviously, it's not one thing because, as you said, there's not one homogenous kind of user or survivor etc. Do you have any thoughts on what makes that sort of work special or different or to stand out?

AKIKO [00:34:42] Yes. First of all, I mean, I'm totally in agreement with you about the potential co-option of these terms and I'm already seeing it when I talk about user-led work within policy and actually mental health spaces, it's quite often, more often than not conflated with kind of small to medium sized charities. And I was talking to a founder the other day who said that it's also conflated within funder's worlds. And that's hugely worrying because they're not the same thing. It doesn't mean that one is better than the other, but they are different. Some overlaps, perhaps, but they are different. So it's almost the sense that if it's small, it's kind of the same thing. It's almost like a size judgement. So I think the co-option is very much happening and I also think that because, the terminology around social justice is kind of gaining quite a lot of traction, especially within the voluntary and community sector. There's a lot of enthusiasm towards kind of terms like grass roots and community. And I think that's quite dangerous if we don't quite clearly set out what is different about the sector. And I think it is a sector. I think that's one of the things I'd like NSUN to kind of work on is, is to present it as a very diverse, but, but as a sector. I think, one of the things that came up quite a lot during the fund, during the process of... during the grant making process was, is this application in the spirit of the fund? Because there were so many really, really good projects that applied and they weren't in the spirit of the fund. And we tried to work out what is it, what is this thing that we're trying to get at? And as you say, it's not one thing. There was something about, about that shared experience that the people doing the work had a shared identity or community or experience with the people that they were doing the work with. That for me is quite important because it turns this

kind of helper-helped kind of diad on its head. And that's so strong within mental health services that you are either being helped or you are a helper. And actually within mutual aid, within peer support, within community action, you hold both those identities and many more, so that that felt key. Equality, I guess, again, so thinking about the power dynamics are one of the questions we would ask people is... was, not just other people doing the work, do they have the shared identity, the shared lived experience, but also the people with the power within the organisation, the governance, the people on the management committee, the trustees, what's their make up? What does that look like? You know, because if you've got an organisation where the trustees don't have that, for example, this is a very typical example, refugee and asylum seeker charity where the people may be doing the work at a more junior level, might have that identity or have that shared experience. But the more senior people are white and don't, and certainly the board is white. That's really, really common within, within that sector. But it's also relatively common within the disability world as well and also within mental health. So that's kind of what we were looking at as well. So, yeah, something about power. Something around equality, mutuality, I've missed loads of things, but, yeah. What about you? What do you think is qualitatively different?

CHINA [00:38:34] I think, yeah, power is a massive, massive issue there and you're sort of, as you said, I suppose I find it quite frustrating, though understandable, when those who have the ultimate power, such as the kind of trustees or the people who are running the organisation or indeed where the

funding is coming from in it sometimes, really, in my opinion, kind of conflicts or contrasts with what it claims to be doing I guess. I think it's quite important that we see the deeper roots of an organisation also be committed to the message of social justice say, if that's what what's being done. I'm also really interested, and this is a bigger conversation than we can have right now, but around the, the really important but really, really troublesome and problematic work of doing some of this kind of more lived experience led work in a really quite inhumane spaces. So like in immigration removal centres, in prisons. So I'm thinking, how do... Because I can think of some brilliant examples of that work that is being done, and I also think Freed Voices, part of detention action, are fantastic. But, but, yeah, doing that lived experience based, really important work, but in a really inhumane carceral system, I think poses some incredible challenges, which I would look to, kind of look at more and learn more about I suppose. So how do you do that work within those spaces, but also seek to get rid of those spaces entirely, to have a kind of abolition stance on something, but also try and support people who are actually living through those, those spaces, I guess, in those contexts.

CHINA [00:40:24] But what I find just so, exciting about what you've said is that especially because of so long of austerity and cuts and really incredibly hostile government policies to disabled people more broadly, people who have mental health diagnoses, users, etc., that there is still that that energy there and that some of these organisations are still managing to, not just managing, but perhaps thriving and doing that work. And at the energy is there, I find really,

really positive. Because I tend to hear the other side of that, the cuts side and which is incredibly important. You know that's also the context of those organisations, too. But I find that very rich from from what you've said. A really kind of positive message I guess.

[00:41:16] It surprised us because like you, we'd heard more about the cuts and the decline of user-led... And so many groups have been decimated. That's the thing. So I think both stories are true, but we just weren't expecting this kind of explosion of energy. But I will say that one of the themes that came up again and again was the precarity of the, of this work. Because people are doing this work... Most people aren't paid, and if they're paid, it's very, very little. There's no capacity for, for planning, for funding. And so when Covid hits, people were just completely overwhelmed with the demands, but with no extra capacity. And, you know, it's really something, I think that, that funders need to think about because a lot of funding has been made available over the last few months for, for technically community groups. But actually, they haven't been eligible to apply. So groups, so first of all, lots of groups don't, aren't big enough to apply so their income is too low and that the cut-off point is too high or they're not constituted in the right way. So they're not a registered charity, for example, so that they're not eligible to apply. But also, actually, you need to hear about these opportunities. And I think this is where something like, someone like NSUN can come in here and kind of support that networking element. So many funding opportunities that I've applied for, I've heard about through my personal networks, and that shouldn't be the way it happens. So how do we spread this

information, but also support organisations to fundraise when they're already doing the work and try and influence funders to make their processes more straightforward and more accessible? And I think that, that's the work that needs to be engaged in, or part of it.

CHINA [00:43:24] And so in terms of that kind of, as we sort of close this, I guess I'm thinking that anyone listening might be interested in how they might sort of get involved further with NSUN, especially at what sounds like a really exciting time as you kind of start to think through some of these things. And you know, in terms of how you might better support the capacity of smaller, more lived experienced led groups, organisations, how you might support their infrastructure, what that support might look like. Do you think you could just briefly give us some idea of how people can get involved with NSUN?

AKIKO [00:44:01] Yeah, absolutely. So we want to hear from you. Membership is free. You can join on our website. If you don't have a website www.nsun.org.uk, you'll see a membership join us tab so you can join through that process. You can also find us on Twitter @nsunnews or you can email me, I think my email will be linked to the podcast so you can contact me directly. But we want to hear from you because we have an inkling of what the different user led community lived experience groups out there might need or want. But we're not 100 percent sure and we want to find out. So we're starting a process from around now, where we want to reach out to you and kind of ask you what is most useful for us to do, us NSUN. Do you want support with finding out about

funding opportunities? Do you want kind of governance support? You want us to lobby on your behalf? Do you want us to connect you with others? Do you need, do you need kind of like support internally? Because the work is actually really, really hard, you know? So is it more that kind of emotional kind of support that you need? I don't know. So we want you to tell us what what is most useful for you. So, yes, please contact us.

CHINA [00:45:16] Thank you so much Akiko, and yeah I would just really recommend having a look on the NSUN website, the National Survivor User Network website, and look in at the Covid Life blogs and videos that have been telling us about which it is just fantastic. And also the brilliant, older and up to more recent reports and publications at NSUN, which I personally find incredibly useful. And so thank you so much Akiko for your generosity and sharing just such rich experiences. It's been so lovely to talk to you. And as I just close this and pass over to Saara, I just want to say thanks so much to Healing Justice London again for giving us this space and thank you all for listening and for being here with us. Thank you.

SAARA [00:46:06] Thank you so much. China and Akiko, for such an incredibly rich session with just so much learning and so much to take forwards and to think about, that was absolutely amazing. Just thank you so much. We're really honoured to be in conversation with you both. And it's going to really benefit both our team and our community. So thank you from the bottom of our hearts. And to stay in touch with both Akiko and China, they are on Twitter, it's

@AkikoMHart and China is @chinatmills. And you can follow NSUN @NSUNnews. And just to reiterate the NSUN website, it's www.nsun.org.uk who are doing absolutely incredible work. So if you'd like to tweet about this session, we're using the hashtag #ThroughThePortalHJL, and we're going to be having many more podcasts, workshops, talks within Through the Portal, so do stay in touch and keep up to date through our newsletter, social media and website.