

AUTONOMOUS

PASSAGE



intentional  
access

for

/by

mindful  
movements





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# HEY!

*At long last!*

We're tremendously excited to address and share the process of ongoing (and frankly, long overdue) conversations that have been transforming the ways in which we conceive our roles and mindsets as community organisers and individuals. In this brochure, we have collected some impressions, personal experiences, tips and data concerning accessibility in a very basic way. We find it important to note the many different layers and intersections of accessibility on physical, mental, financial & bureaucratic levels, paying close attention to how these factors impact individuals and communities in different depths.

## **Disability Justice**

The term disability justice was coined out of conversations between disabled queer women of colour activists in 2005, including Patty Berne of **Sins Invalid** (and Mia Mingus & Stacy Milbern, who eventually united with Leroy Moore, Eli Clare, and Sebastian Margaret) seeking to challenge social justice movements to more fully address Ableism.

<sup>2</sup> Ableism: discrimination against people with disabilities

<sup>3</sup> Neurodivergence: a brain that is wired differently and functions differently to what is seen as the societal standard or the norm is an important concept for us because it recognises the intersecting legacies of white supremacy, colonial capitalism, gendered oppression and ableism<sup>2</sup>. It is also not a one-off exercise of **Solidarity** but more of an ongoing reflection on access, bodies, wholeness, visibility, rest, loneliness, care work, and mutual aid. Here we have compiled only a brief glimpse of this process and, thus, we invite you to follow, visit, engage with the content found in the latter section of this guide, 'More Resources' & 'Annexes.'

As an international network of grassroots groups, European Youth for Action (EYFA) has been working on a year-long project

visibilizing the structural and societal challenges that young and/or marginalised people with disabilities face within and outside of movements. We hope to encourage activists to question their understanding of accessibility and inclusion with the aim of building and strengthening solidarity practices and allyship. We engaged with various disability justice groups and individuals with invisible and visible disabilities to gather various perspectives that are compiled in this guide. Our previous work in social and climate justice contexts has shown us how much we have to learn about contributing to empowering and accessible spaces, particularly in the context of gatherings, training, parties, concerts, and other events that invite collaboration.

As part of our collective learning journey, and as a group composed of people with and without (in-)visible disabilities, neurodiversities<sup>3</sup> and chronic illnesses ourselves, we are sharing here interviews, articles, comics, tools, and online resources that all have something to say about disability justice. We hope this guide offers insights on how we can better organise ourselves / events / networks and daily life in a way that is more inclusive and accessible to all, regardless of ability, ethnicity, gender, sexuality or class. Enjoy reading!

Love and Solidarity,  
EYFA





**MISERY** is a mental health, harm reduction collective & sober club night centring healing for the QTIBIPoC (Queer, Trans\*&non-binary, Intersex, Black, Indigenous & People of Color) community. Under the motto ,u can cry if u want 2' they have shown to be refreshingly sad, always welcoming in a non-judgmental way, regardless of our high and/or low energy levels (and basically anything around or and/or in between), taking into account our wishes, needs, wild dreams, etc. The collective was born from the urge to create safer spaces for people from marginalised communities, where we can be covered in all kinds of tears while partying and being our weirdo selves ... all-together-now!

We first heard of Misery some years back in an event organised by the CutieBIPoC collective in Berlin. Since then, we've been celebrating the fact that such a collective actually exists and resists in a world that is structured to hurt, neglect and fail anyone that struggles with mental health and precarious lives. The fact that we all have been living in societies with very questionable values and, moreover, some absurd expectations on migrants and BIPoCs, has caused and keeps causing heavy damage in our communities. The high rates of substance use in our communities are not surprising when we think that we have been raised to be numb, and our coping mechanisms are what keep us (sometimes) alive.

We are thrilled to have had the chance to spend some time with them online and get to know better how these healing alliances work and how we can keep growing, strengthening our communities and being there for each other somehow. Here you will find parts of our conversation with them, and we hope it will change something inside you, too. You can cry if you want... Let's be miserable together.

## MISERY PARTY reduced transcript

**Aisha:** Hi, my name is Aisha Mirza. I'm based in London, I use they/them pronouns. And I'm a writer, DJ, and I guess mental health advocate, and person with lots and lots of lived experience of challenging mental health. And in 2018, I guess I began thinking about alternative versions of nightlife that were more open to people with just different needs. I guess I was coming at it more from a mental health point of view, because that's what was familiar to me. And then also from the point of view of people dealing with substance use issues, which was really prevalent in my community of queer people and people of color. And thinking about how we can kind of think about night life in a new way and create some mental health interventions around that. And so from that Misery was born. Misery is a mental health organization, centering the needs of queer, trans, intersex, non binary, black people and people of color.

**Aaks:** One of the stuff was around substance use, but then also, the only places that we have as queer people for gathering, well most of the spaces is nightlife. So there is the drugs and alcohol component to it. There's also something I think really powerful about communal gathering, dancing, creating, sharing space, but because of the fact that the environment is encouraging dissociation rather than embodiment, there's not that integration piece that happens so you can go to a yoga class, and then you can go home and come decompress, or process what's happened, or even like a ecstatic rave experience, or whatever. But we go into these club spaces, maybe entering transformative places, or like having epiphanies or processes or feeling connected to our bodies in ways that we didn't know was possible. And then we're getting fucked up

and then entering back into the world. And this is quite separated. So what is a place where we can bring some of the magic that's there, but really be intentional, encourage presence and allow for us to feel that and it'd be accessible as well. Because, again, that high, loud, fast wave energy, which I love, is also not entirely accessible. And I'm a raver. But then there's also times where I'm feeling really introverted, or overstimulated. And so yeah, wanting to play with that. So we threw parties before COVID and then it sort of evolved. And I think also, it wasn't wanting to throw parties. For me, it was wanting to see what a mental health intervention in our community could look like, to start building communities of care. We were all going to the club, so it was the easiest way. But use it as a way to start building community, because there's community around the club and around the dance floor.

**eyfa:** What was then the specific moment that made you think 'hey, we need to create that kind of space and it needs to be right now'? What is the importance of also making sure that this is a QTBIPOC space?

**Aisha:** I think for me, there were lots of moments. So it's just kind of like a general hum, constantly, people being unwell, struggling to survive comfortably in lots of different ways. And I think for myself, I know that I deal with depression quite intensely, and kind of just feeling how out of sorts I felt sometimes even like in the community that was kind of meant as a safer space for me, because there is still so much focus on being an extrovert potentially or capitalism, or the way you look or a lot of this kind of stuff, you know. I think also just hearing from a lot of people like maybe being out on a Friday and Saturday, having a great time, kind of maybe being intoxi-



cated and then sitting with those same people on Monday and Tuesday and paying attention to the other side of that, which was often a lot of kind of post party anxiety, or community anxiety, or deflation exhaustion, hangovers, you know, lots of other stuff going on. And I was like maybe there's some balance that we can find here or some other options as well that aren't just like, go really hard and fall apart. Also, I have a friend who had a lot of mental health stuff. We used to talk to each other about it a lot. We talked a lot about – I remember they were going through a very intense depressive episode and they were just saying, I wish there was somewhere we could go to be together when we feel like this, rather than having to wait for it to go away. And then kind of get together or pretend to be okay. I wish there was a place I could just be. So it was definitely a conversation with that friend that kind of inspired some of what came afterwards as well.

**Aaks:** The people that we've worked with, were drawn towards, and are doing some form of care work, healing work, whether it just be in relationships, or with friends. And then my friend actually lost someone last week, and I had a moment of a breakdown, because I was just like, it's really not normal that I've known so many people that have taken their life or been sectioned<sup>1</sup>, it's just not normal, you know, and I'm young. And then part of it was lots of the work we were doing was reactive – and actually Aisha has worked in crisis mental health and does different stuff, for me definitely it was reactive, to situations that were happening. And it's also really draining and maybe trying to find a way to put this energy into

something that can be a bit more strategic and more structural. So we are still supporting our friends and our community. It was really about our friends, right? (...) Maybe we can throw a party once a month that all of our friends that are depressed can get together and just be and give the option for ourselves because I know I needed it. (...) Yeah having this burden or want or opportunity, maybe it's not a barrier, maybe it's an opportunity for us as queer people to build new roads but it's also an opportunity for us to do things differently. So I think it's beautiful, this creative drive.

**eyfa:** How did you manage to make that into an actual thing? How did you create the events or the spaces that you were looking for?

**Aisha:** It was kind of let's create some kind of mental health intervention if we can, because I had worked in mental health for quite a few years. So we were thinking about it from that point as well. But I also knew that if we could start a party, and importantly, a sober party, which I think is very different, and quite radical as a concept – it shouldn't be, but it was, then that could be a really nice place to start. Because it's approachable. People kind of know what a party is. There are so many barriers for our community in terms of feeling comfortable around the idea of mental health services, you know, not that we are a mental health service, but just the general kind of skepticism that people have around that kind of thing – with good reason. There was like, rather than trying to get people to come to a space and think about their healing or depression, which might be a bit much straight off the bat,

<sup>1</sup> to officially force someone who has mental health problems to stay in a hospital and receive treatment because they might harm themselves or other people



so help out create a space that's familiar, but has some kind of specific interventions in it, for example, having no alcohol being sold, and having kind of activities going on in the space that you might not normally find in there. So that's kind of where we started with as an idea. And it took about five or six months to find a venue that was willing to do it with us because it's a loss for that venue, to not serve alcohol essentially. So they kind of would have to opt into losing money. So it took a really long time, lots of emails, lots of people like, "Oh, my God, this is the best idea ever, It's the best thing I've ever heard but no, we can't, sorry, we can't help you", you know a lot of that. And then we did find a very sweet venue in East London. But it took ages to find a venue that was willing to give up a Friday night spot in East London, to a sober party and essentially lose money. But we did, and it was great. And we just started promoting it in the way that you do, but with a clear focus on mental health and thinking around ideas of sobriety, but from a harm reduction perspective. So this is a space to maybe just take a moment to think about your relationship to sobriety, like we're not judging anyone, and we're not prescribing anything, we're not telling you how to be. So it was also kind of used as an opportunity to start introducing the community to ideas around harm reduction as well & how that can be a really compassionate practice for yourself. I guess we were also thinking, if there is no alcohol there that people use as a coping mechanism, a lot of the time for being outside for social interaction, all of that kind of thing, so what are we offering instead? You know, how are we being mindful of the fact that some people do need that? (...) There'll be maybe a coloring station somewhere if someone wants to go there and kind of zone

out for a second and or zone in. And we also used it as an opportunity to collaborate with healing practitioners in the community. So Tarot readers, and masseuses and things like that. Then eventually, over time, we started working with therapists too to offer a kind of walk in signposting service, where someone could be at the party, but also take 20 minutes out to go talk to this person about a specific issue, question, like about other resources that might be available to them in London. Or just to even try out the idea of therapy because, again, I know there's a lot of hesitance around that in the community. So, we were just playing with the whole thing, really. I think between June of 2019, and February of 2020, we did about five parties. One of them was in Berlin, as well.

**Aaks:** But mainly online content last year (...) basically online stuff, there was people from countries that I didn't know anyone in that country and it was like, how have you heard about this? And obviously, all these people coming, adding this richness that we couldn't have ever ourselves been able to do. It was happening, people just like facilitating each other, holding each other gently in the chats. And it was, that was like the most beautiful parts for me from the skill sharing, but just actually, people were practicing what we think about community care, in this way, on this zoom space, really unexpected without us needing to do any intervention. And I think that was really special. (...) And as you grow there are 300 people and you gotta take care of all of these people and when you become more popular the risks obviously increase that something is gonna happen. But I think moving forward we are thinking a little bit more about proceduralizing that stuff so maybe there are some policies. If

anything gives our volunteers, or whoever is working with us some framework. At the same time it was recognizing that if we wanted to have deescalation as a policy, none of us are trained in that so how are we gonna be confident to equip people to de-escalate if there was harm or violence happening. These are the sort of things that we are grappling with and wanting to have these ideas of transformative justice, but also radical accessibility in a space. If you just wanna help out, that you can help out, you don't need to be an expert on anything.

There was also prevention, so there was like (dinner, no alcohol, small venues), henna, nail polish, tattoos, magnetic sand that you could go play with and different workshops, so it was around the prevention, while getting into the space that there are multiple outlets to try and bring everybody in with intentionality.

**eyfa:** Given the fact that mental health isn't given as much significance in BIPOC communities, how has this impacted your work and your reach?

**Aisha:** Yeah, I think it's been quite easy to connect with people seeing as we're coming at it from a mental health point of view. It's just desperately needed. We've had a conservative government here(...) drastically cutting public services for a period of 10 years now. So the situation is very, very dire when it comes to mental health. There's even recent moves to begin enmeshing police with emergency mental health services as well. It's a really, really bad situation for anyone needing mental health support, much like, and then much less like people of color, black people, queer people, you know, it's a nightmare. So stepping into that space, I think there's a lot of really lovely natural interest.

**Aaks:** I think it's helped us in a way because there's not many alternatives, people have been drawn to us in that sense. And we're not a mental health service, our piece is more about resilience. So if you're not ready to go to therapy, here's a stepping stone in between. Or if you are going to therapy, and you still need your community space, this is a space in between, it's not like, you're going to come and do some psychotherapy in our groups, but it's about facilitating joy rather than trying to unpack trauma.

**Aisha:** I think it was also about creating a space of experimentation to some degree and feeling okay with not having all of the answers. Because there's merits to everything, and there's severe cons to everything as well. And so we don't have that blueprint of what a safe space is. I'm not really sure that there is one on this earth under these conditions, you know. So I think it's more about creating opportunities for experimentation and options, just because, like, another thing that QTIBIPOC have in common, I guess, is having your options just severely limited in terms of what's available to you that is safer. My feeling with Misery was always quite a sort of soft touch I think in that, we weren't prescribing anything specific, it was just kind of like, come and play and bring that part of you that you might otherwise in other spaces have to push down or leave at home or pretend isn't there. You know, the sad part, the traumatized part, the manipulative part, like whatever it is. But yeah, we don't really have any answers beyond that point. Because what does it actually look like when traumatized people do start bringing those parts to a space?

**eyfa:** What are the kind of misconceptions you've experienced, whether personally or collectively, about mental health?

**Aaks:** I think the misconceptions that we found or challenges we've had, both of us have had personal examples of friends struggling with addiction, or suicide, and how other friends have tried to show care has actually made the situation worse. And so misconceptions about how to actually support people in these spaces.

**Aisha:** Yeah, I think that the basis of that kind of misconception is, I think, and this is society wide, is that some people feel like they know what someone else should do with their lives, right? Like, once someone has shown a sign of being mentally unwell or having addiction or, it kind of automatically downgrades that person in terms of deeply infantilising in the way that everyone has been kind of taught to approach that. And that's so violent and it's so scary how that plays out in terms of people's humanity being downgraded then. And other people assume that they know better what that person should do, than that person does. One very simple way that I personally approach mental health work is the idea that everyone does know the answer for themselves. Everyone's the expert in their own lives. So it's like, yeah, it's just a way to empower people, cuz I think when you're in that situation, you can often feel like you don't have any answers. I feel like another misconception is that you are that way because you're 'too sensitive'. And you get that from all directions as well which I find quite painful. You might get that from your family, for e.g., who might have been through a lot in different ways, and just can't believe that you can't get through a goddamn day compared to what they've been through. And then I feel like that's also attached to this idea that you're the problem for not being able to function in this society, as opposed to like the

society clearly being the problem. And people who can function in it without any sort of questioning of it, or critical thought, might actually be the ones that are ill in some kind of way.

**Aaks:** And the self care industrial complex which is like the well-being industry now. So there's the capitalist element of it, you're responsible for your own healing. And yeah, we are, because no one's going to come and help you. But also, no amount of self care will get me well if there's still war happening in the world and if Palestine is still occupied, and you're still living under a state where we have some of the widest wealth discrepancies, right? And then climate change, we probably shouldn't be fucking up the environments and, we see mental health as a thing that's inside your brain. The neo-liberalism part is that we see each other as separate. Queerness and community for me, is complete like we're in this together. For people like us who are kicked out on the margins or been abandoned by our families and we have to find new families and communities you can't just not care about these people. And then we have no blueprint for either, this is a chosen family idea. How do we do it? We know there's blueprints of biological families and unconditional love but there's no blueprints for this.

**eyfa:** And how do you think that these multi-layered experiences of oppression are influencing or shaping the mental health of people that are marginalized?

**Aaks:** Yeah, I think it's war, it's actually this war on our well being. It's constant from experiencing racism and microaggressions all the time to then also being an outcast of your racial ethnic group, because you're queer or trans. Then there's stuff by the state like just all the



rise of fascist transphobia happening and this erasure of identity by state. Then on the biological level there's ridiculously horrifying rates of chronic stress and chronic illness in LGBTQ people of color that's not the case for other people. And I think our communities maybe are still very ableist. I think capitalism is very ableist, which is really sad, because most of us are going to end up with some form of long term illness or disability statistically. The other thing I think about is hypervigilance, like when do we actually get to relax? And I guess it also makes it stickier and complex in a way, you don't know where it's coming from sometimes. You can't step out of any of them. You know, in science, where you isolate one part and you do an experiment and you try and see what changes and you can't step behind and figure out if 'Is it the race stuff? Is it my queerness? If I was this, would it be better?' But I mean, both of us had been involved in political organizing separate from this and maybe even more active politically like organizing spaces. I think this is the revolutionary piece for us, it's the care work and the slowing down and actually, and it doesn't have to be going out and squatting and occupying buildings and like, to also be doing something that is radical, or engendering political change.

**eyfa:** I think you, Aaks, also mentioned the term radical accessibility earlier, and I like the way that sounds but I'm not sure that I can clearly imagine what that means. Could you give us an idea?

**Aaks:** I think for us, it's like everyone's talking about accessibility, I think by radical accessibility, like this is the forefront right? A will to make things change for the access. If we're doing activities in the space, don't do an adjustment for one person in a wheelchair. Let's

make the whole activity accessible. I think that's it. I think it's about a constant commitment to it. Rather than, we've done wheelchair accessibility, cool. This is constantly like really thinking about it. And I think this is me processing it and figuring it out, as I'm telling you, I think the other part is expanding the idea of accessibility to racism. White supremacy is also an access barrier. Class. Maybe actually economics is something people are now talking more about in access. But I think there's so much more to it.. Colonialism is an access barrier, right? Like if you've got these cultural experiences, religion, all of these things, and then thinking about, okay, oh, let's not do this thing at this time, because it's Ramadan. I think, if we start moving more of our liberation movements into this idea of ableism, and accessibility, I think that would really shift some of the stuff because racism is also about ableism, is that this body is worth less, this body is less productive. It's all about this body is lesser than. There's a norm, and then there's a lesser. So I think it's constantly learning from our communities and participants that way, what are the barriers? And how can we work to overcome them without having this prescriptive answer that we've got the solution and like, we can do 123 things, and then now we're accessible. There's a constant in progress to be accessible, by championing it as an inherent value in the work rather than again, this add on.

**Aisha:** This year we're building a website, we have a lot of hopes for the website around becoming a database for QTIBIPOC facilitators, healers and all sorts of workshop leaders and artists around the world who are kind of dedicated to this sort of work and have some of the same ideas around gentleness, playfulness and harm reduction that we do. We hope to start Misery

*Meets again, which is our monthly online sort of group/art therapy space. It was so valuable, a lot of people have been asking when it's coming back. So we're also thinking obviously the pandemic and online programming has taught us so much about some aspects of accessibility and how amazing it can be to do this work online as well. I'm personally really into herbalism and gardening as a mental health intervention as well as an empowering way to connect with your environment, make your own medicines and play with the way that different naturally growing plants can make you feel so I have dreams for a Misery-Apothecary at some point. I also really want to get the depression cookbook off the ground, a kind of communal zine, but again we need to have money to pay the contributors, designer, publishing everything like that. That's some of the ideas we've had and then I guess at some point parties are fun you know? Always down to do a couple of those.*

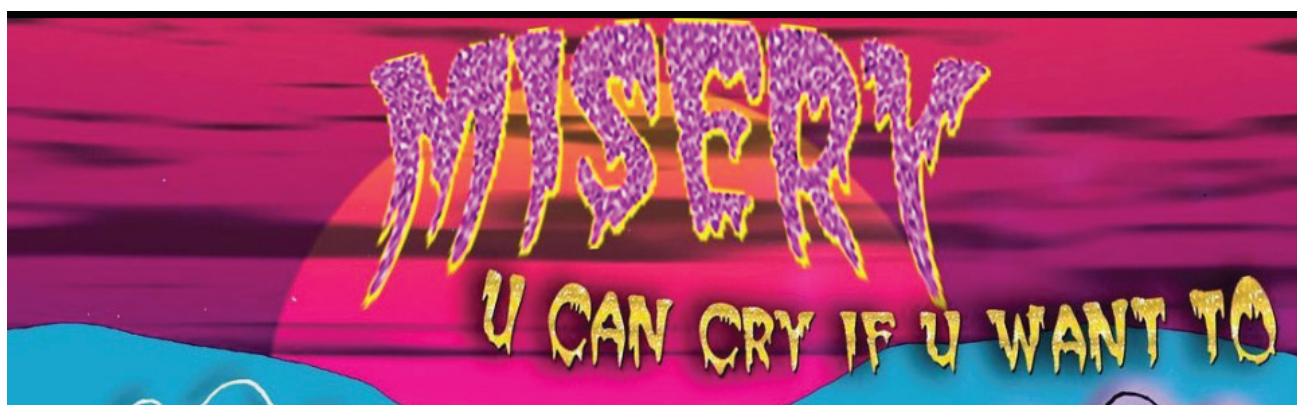
**Aaks:** *I would love to be able to develop a one or two day training online on how to be a better friend basically, how to support your friend if they're depressed and doing some of the training with someone, sharing some of those Mental Health First Aid stuff, but then bringing it into a cultural element and bringing in a peer support person. You*

*don't need to do eight years as a therapist, or a psychologist to learn that we could all just start picking up and sharing it to know what to do when your friends are in a crisis, something around that.*

**eyfa:** *And do you have any tips on how do people get started into being responsible and active allies, to our friends and our community right now?*

**Aisha:** *I mean, money is the first thing that comes to mind. Because I think when allies start getting involved, there's a lot of education and labor that naturally happens to facilitate that. I really feel like the best thing allies can do is structurally support people who already are doing the work to do it in better conditions. If you can't offer money, then admin or just doing things to support the work that's already done without kind of centering your own kind of stuff too much. Then obviously, doing personal growth work outside of that.*

**Aaks:** *I guess it is the cultural humility piece. Like, you're the expert, I'm not some Savior. Actually asking people what they need, and then what you can do for them. I think it's as simple as asking people, what do you need? Can I pick up your groceries? Do you want advice on this? Having that humility.*



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# *RADICAL RESILIENCE*

We have had the chance to get to know Radical Resilience parents, Lian and Delila, many years ago, in one of Efy's Network meetings where we focused on inclusiveness & care practices in activist spaces. Since then we've been building a connection and mutual support where we learn & exchange, gaining awareness and spreading it everywhere we go. Along the way, a new topic came into their lives, bringing other kinds of challenges, reflections and also requiring lots of adjustments: chronic illnesses. This spring we had the chance to talk more about it, on a sunny weekend, by the lake... having delicious food, a hammock, lots of rest and important talks in between. They open up on how chronic illnesses have been shaping their lives, how their activism, among many other factors, has been impacted and how the movement they were a part of has dealt with it.

**Radical Resilience** is a film, a transformative act and also a collective pact on the journey towards caring movements. The film focuses on how to have courageous talks about burn out. And here we are invited to ask ourselves 'how could we better deal with the difficult and painful situations we experience through our activism and in our lives?', How can we heal emotional distress individually and collectively? How can the movement be more inclusive, mindful and open to learning processes, decisions and actions that sometimes sound like an impossible mission, when actually they do not even have to be. All you need to do is listen to people and educate yourself first. Here are some parts of the thoughts shared during our last meeting, so you can also learn a bit more about how they navigate movements, chronic illnesses and care in their activism.



## Radical Resilience reduced transcript.

**L:** we are Lian and Delilah from *Radical Resilience*. What is it about? We make films and a zine and we have a blog. We started making this film *Radical Resilience* which is about regenerative activism, because we noticed a lot of people around us, and ourselves also, being burnt out and also struggling a bit with the trauma from repression. So we made that film, and during that process my chronic illness got worse, so that's when we started focusing a bit more on inclusivity and chronic illness, wanting to bring a bit more awareness on that. That's why we made a zine. And also we do workshops based on the film, often with a focus on inclusivity [...]

**D:** Our focus has turned towards thinking about how to be politically active with disabilities or with chronic illness. Trying to think about how movements could also make that more possible. With our zine we kind of wanted to address movements or activist groups, and saying things are often not inclusive for people with chronic illness, and make some suggestions about how that could be changed. For me I feel like that was the main audience that we had in mind, and that hopefully people could become more aware about things and to the fact

*that there's people with different needs around.*

**L:** While we were making the film my illness got worse, so the way we worked together on the film changed a lot also because of the illness already during the film-making. And then that prompted us to do the zine, because we kind of fell out of all the political contexts that we had been part of and we started noticing a lot of barriers that we hadn't noticed before because we weren't really directly affected. Of course some barriers are easier to notice, but others are very invisible. And then we thought it would be good to have a zine like that, it was also because you, people from Eyfa, encouraged us to do it!

**D:** Yes, at one network meeting of EYFA we shared some thoughts about inclusivity and activism, and then people from Eyfa encouraged us to write this zine to share those ideas more widely. It's kind of where it started but also already in the Deep Waters gathering in Potsdam a couple of years before there was a discussion about chronic illness and activism, which was really interesting, which is also summarized in the zine as well – that was a good moment of networking with other people and sharing some ideas about that, and that was also part of the process of this zine.

**L:** Back then we changed our way of working in the sense that it is all based on my health now. Before, the project and the deadlines were the most important. I mean, we didn't have many deadlines, but we had a lot of pressure about when we wanted to show the film.... and then I got sick. Now we try to have my health as the main factor and, whenever I feel a little bit good, I can do a little bit. But we try to adjust the project to me rather than me adjusting to the project. And that is quite challenging because some things are fixed and you can't change them. For example, if you organize a film screening and a workshop you need to somehow fix that time, and sometimes it happens that I am doing really bad at the time and then it's a bit difficult. So, some things we haven't really found a way to work around so well, but generally we are more based on "ok, now I have energy, now I do a little bit", and trying to set up boundaries also. And that's what we are struggling with a bit now, because we are now living together and Delila helps me a lot and we also work together, so sometimes it's hard to find the boundaries of like 'ok, now we got this email', 'can you answer?'...'oh no, now I'm resting'. We are trying to work that out, to center well being at the first step, because if I don't do that then I crash really badly and we're

not making any progress. So this illness has really taught us to respect boundaries. [...]

**D:** yeah... even planning a talk can be difficult cuz sometimes the illness will just flare up unexpectedly, you can't really see why it flares up... and it's always good to try and find a way to plan with that, and to find people that are a bit aware of that without getting too impatient with us. Most people haven't got too impatient, so that's been nice. But we have always tried to explain it as well to people so that they know what to expect or not.

**L:** But when we started the film I had so much energy, we hardly planned anything, and we just thought "oh yeah, it's gonna work out, it's gonna be..." and we did it with so much energy! Now I'm like "how much energy did you waste? ". So currently we are planning everything really well. When we go anywhere, then I need two weeks rest before and then two weeks of rest after, and I will need a resting place there. It's a lot about boundaries. At the moment we have a rhythm that doesn't feel so bad, but it's also always depending on some external things that we don't have so much control over. There are also parts where you are only struggling with surviving – and with having to go to medical reviewers who question your sickness and

having to see all these doctors that all takes so much energy, and then there's nothing left for anything else.

**eyfa:** How was the transition for you and how did the new situation affect your plans, your activism, the relationship to friends, comrades, house mates and so on...

**L:** I mean, we were living on protest sites for quite a few years in France. I was living quite a lot on forest occupations and I really loved it. I was already making films then but it was also quite a lot – life had to do a lot with living there and protesting. So our whole life was in some way political and collective. And then I got more sick – I started to get sick there, and it was not a good place to be and then I got really sick so we had to move from there completely. It had several reasons but being ill was the main one. Being ill and not having the right place or support there. Which had to do on one side with life already being harder but also with us not putting much emphasis on support and care. That was just not a place to be sick. We were kind of telling each other if you're sick you need to leave, which in hindsight wasn't good. So we kind of dropped out completely and we ended up being completely isolated from the political context and from friends. We had some friends here also but

when you get ill it's quite a common experience that you lose friends. And that happened to us also.

What helped a lot was corona – with all the horrible things it brought for me it also brought a lot more things being online and me being able to be part of things again from bed, which for me is great. So we've been getting involved with stuff, like now the Zapatistas coming. We also do a lot of film screenings and workshops based on the film online. That's actually been feeling really nice, to be in connection with people again even though we are still living quite isolated [...] and I hope it continues like that, with things being online. In every group that I am in, I am like “keep it online, keep it online, don't kick us out again” or at least keep it in both online and offline formats. Hybrid.

What we want to do now is to make a film about disability and activism, or how to be politically active with disabilities because I think a lot of the barriers that exist don't have to exist. I think the first step is awareness. If people were more aware it would already be so much more accessible. Some things are harder to put in place but a lot of things are quite easy to put in place ... that's why we want to make films, to raise awareness and also for us to be in connection with



other disabled people. I think I am longing for that, for exchange and empowerment.

**D:** I think the contexts that we were in before, were very much focused on action and when people were not able to keep up with that level of action anymore the tendency was more to drop out of that context rather than to have some kind of support within those contexts. Now we try to do that differently, even though we haven't really found a wider community of people to keep that up with. But that's kind of what we would be looking for, more of an emphasis on supporting each other, not only this one kind of action. I think that's a change of the situation for us. And it's also that there are so many things that we have to rethink about about how to do things. Where it comes from. What kind of values it's reproducing. A lot of the same things we were exploring with our film – which was dealing with activist burnout and regenerative activism – all these things that people were talking about, we noticed that in relation with illness or disability, especially with chronic illness where you have very limited energy resources, these things are like 100 times more important. Maybe you don't pay attention to these things, you don't work on these things and okay you might get burnout for a few months and then you continue

again but when you're chronically sick ...there just isn't a way that you can't pay attention to these things because otherwise you can't do anything at all.

**L:** I mean it was obviously not an easy time because I was feeling really bad, we didn't know yet what it was. The doctors weren't being helpful, they were being rather horrible, a lot of them, and then you're also fighting with the government assistance. It was all not easy. I think it was a bit of a mix because we had to move away from the place where we were based and it was like 1000 km away so it wasn't so easy to keep up the relationships, and also at that time there were no smartphones around, at least people at that time were very security conscious, not like now, and also it was at a time when there were huge conflicts in the group and a lot of our friends also started moving from the place and ended up spread all over Europe because of those conflicts. [...] It still felt like being really alone in a really shitty time, like even though there's explanations of why, even though there were some friends who were really nice and really supportive but it still felt a bit like that. The problem is also that the movements are focusing on the political work rather than the relationship with each other so as soon as you are

no longer productive, or you can't really do the political work anymore then you are out of the group. I think the main focus should be how can we live well with each other, how can we be inclusive to everyone, how can we be good together. I think that should be the main focus of any group. That's what I think about it now, but back then the focus was a lot on 'yeah, we need to keep the space, they are gonna attack us again [...]' 'climate change is so bad' 'we need to be so fast' – it's a lot. This is all true but also groups can decide the focus of things and I think that care should be a big focus. That's the experience I made (and a lot of other people): as long as you are productive it's all sorted out because we only want productive people. This is a really capitalistic logic that we really don't wanna reproduce in our groups. But it is also not good for a group if people keep going away all the time, it's not politically efficient or effective. I think it's good to change that.

**eyfa:** Do you mind sharing more on the personal difficulties and changes that came with getting ill?

**L:** Being chronically sick has to do a lot with grief. Like I had to change my life completely and I miss my old life very much. I miss being able to do things I love, climbing trees, swimming, dancing, be-

ing outside, meeting people, organizing, it's all very limited what I can do. Like even on good days I spend most of the day resting in bed, so the sickness itself limits me a lot already and that causes grief. Your whole life disappears in a way and that sucks and obviously the friendships have to change as well, like I just can't do the same things together, and with some people the friendship changes and stays with you, some other friendships come in, but also many disappear and that hurts. It makes you feel you were not appreciated as a person but for the political work you did, and that is painful.

For me the biggest barrier is the sickness itself. Because I have so limited energy, it makes it hard to participate and sometimes it's so bad that I just can't do anything. Even if the movement was the most inclusive it could be.... some limitations are just posed by the illness itself. It could be more inclusive for me if people would be generally more aware of different kinds of disabilities. When I ask for accommodations, for example, it's always quite hard. I have to make myself very vulnerable, I have to say that I have this sickness, I need this and this, and I always feel like I have to expose myself a lot, always with the risk of being judged. And I think that it would be better if everybody speaks about their

needs, because everyone has needs. And if it became more commonplace to speak about those, then it would be easier to address them for chronically ill disabled folks.

And yes it would be good if it became more common for groups to think how they can make things more accessible, like there are some barriers that require more work and resources than others, so it should be normal to look for solutions collectively

**D:** I think there needs to be a big shift of mindset, about everything. I think we're brought up with a lot of conditioning that shapes how we view, what is individual and what is collective, and who's responsible that we're all doing fine or that we are all able to take part. There's still a lot of capitalist values that say you are responsible for your own well being. It's you that has to take care that you're able to take part in something and if you have other needs than the majority of people or of the people that aren't even necessarily the majority, but are more the mainstream, if your needs are different than the mainstream needs then you are the one that is responsible for making things another way, so it's a very different view of collectivity and individuality.

**L:** yeah, because care somehow plays into how we sup-

port each other. Now it's possible for me to do political stuff because Delila does the house work for me and cooks, and often I feel like there is a split, like this is the political work that you do and then the illness, that's your personal stuff that you have to deal with. I don't know, in my utopia it would be more like we all live together, there's not this separation and we all support each other because it's the thing to do, it's no question. Often I feel like I am seen as a burden if I ask for accommodations, even if they are not really big accommodations, and I don't like this way of looking at things. It should be more like well, that's how it is, some people have less capacity to do this, other people have more capacity... that's just life, no? And it shouldn't be like 'oh yeah you're the special thing and you're the...' it shouldn't be so discarded. Most likely all of us will become disabled at some point in our lives.

**D:** It's also very political how we care for each other. A lot of things don't get seen as political in a group. In my experience I was in a lot of campaigns that were focusing on a single issue, maybe that's also something to do with it. We say "ok we want to stop some kind of environmental destruction happening in this place, and more than that of course we want to stop environmental destruction in



general, and more than that we also want to stop capitalism". But there's still the focus on the one thing and often it wasn't a very intersectional view of things. Also because there were a lot of different opinions on different things and the one thing that we all agreed on was that we want to stop this environmental destruction happening here and that was the thing that we focused on as well. I think that's maybe one aspect. But at least for me I was not brought up to see these things very much, how care is happening. I also wrote about that a bit in the zine, a tendency to see care as a private thing and not as a collective thing [...]

**L:** The movements that we were part of were quite direct action focused. Most people there were quite able, quite young, sporty, and a lot of the groups I know are also like that. Like, if you can't run then you are basically already out. I feel like at the moment we do mostly focus on care subjects and I consider that totally political, for me that's clear.... and it's not that most people in those movements wouldn't agree in theory, but it's just not the focus. It's really what you put the energy in and what you also value, no? And I feel like in the movements that we were part of, this direct action and this fighting, and also other things, like build-

ing, a lot of things were getting more value than actually looking after people. And I think there is also some sexism in it. Who does the care work [...].

**D:** A lot of times really transformative stuff happens when people start realizing ok we actually all do have an opinion about this, we all actually are affected by this. And often we don't even notice because it's hard to see and because it's something that's often typically thought of as a personal or private thing. There's sometimes a taboo about talking about care, so talking about different needs and bringing up that there's a problem is already a good start. As well as that, making an effort to listen to the voices of different people and to actively look for which people are not in this movement and to find out, to read stuff, to watch videos, or even to get in contact with people directly and ask them.

**L:** It's a really good practice what you just said, to look in the group who's not there and ask the people why they are not there and then they will probably tell you what barriers exist for them. Sometimes they are also just not interested and that's fine, but sometimes there are also just barriers. Learn from each other, be curious. We are all oppressed and we oppress in a lot of ways [...] Like with

regards to ableism, it's so huge, there are so many different illnesses people have, so many different disabilities and so many different accommodations they would need. There's so many different experiences. I also just speak from my perspective with chronic illness, but for someone who's deaf, someone who uses a wheelchair, there are very different challenges. But i think it's good to ask people, to ask people what their needs are to take part and to make it a usual thing. Not that the one person who is disabled always has to come forward and say, 'I have this', and then fight for the accommodation. I have the feeling often it's also a fight, even if I say I have this need it becomes a fight and people say this is annoying, or this is exhausting, or people even unconsciously, when I come with my hammock because I can't sit, they say oh this is such a posh thing to bring, or such a german thing to do. It really annoys me, it upsets me if every time I bring something that's really needed for me to be part of something I get a comment like that. A lot of things that are very basic for disabled people are declared luxury items...

I find it hard sometimes to ask for things because some people see it as a distraction from the real work, now we have to put a sofa there for you and at the same time we

could be doing something to stop this thing, or to do this towards the aim of the group. I sometimes wonder if I really want to be part of that group because I'm seen as such a burden. It's good to give people the feeling that they are not a burden. As chronically ill I already think a lot of myself, and I find it really hard to ask for help. It's already so hard to ask so it's nice if people make it easy to be done.

**D:** Also because these are unconscious behaviors and values. We really need to come up with techniques and structures that we can put in place to make a transition until it becomes internalized in everybody, that it's just a normal way, or that's just how we behave, that's just our values. We actually need structures to address each problem, to remind ourselves collectively how to change that. Have those kinds of collective structures to make this care more possible, as something that's available for people collectively.

**L:** how can you make a political group more inclusive? there's certain things you can do but for me the bigger question is how do we organize care [...] For me it's possible to be politically active because Delilah does care work for me, but it's like again in this partnership thing, it's not like a collective way of

looking at it. I think If you really want to be inclusive as groups then we also have to look more at how we care for each other. Also in our daily lives. At the moment a lot of the care is done by FLINTA\* (Women, Lesbian, Inter, Trans, Non-binary, Agender) and that obviously would need to change.

**D:** I feel that often a big problem is the lack of valuing for people who maybe can't necessarily do some of these kinds of activities that get more recognition within the movement, or the kind of activities that are seen as more valuable. There's a lack of recognition. Care work generally is one of the things that gets less recognition from people, and care for yourself gets even less value than other kinds of care work, and actually for people who are chronically ill they need to care for themselves and that's something just as political and valuable as any other kind of activities... they do deserve to get just as much recognition.

**L:** What allies could do or what I'm always happy for is to help me meet my needs at a place. For example, if there's a camp and it doesn't meet my needs for some reason, then it's good if I have a group that I can turn to and that helps my needs being met, because I don't have the energy to fight for that when

I'm already so low. And it's good if it's not always the partner only doing it. We've been thinking about what we could put in place, we thought we could make a group that's responsible for responding to what people need. That you can easily ask and that can help you ask for your needs. It's really tiring. You meet so much resistance, if you have to do it for yourself it gets really hurtful sometimes because it feels like rejection.

There are obviously many things that need to change, changing how care work is done, how different kinds of activism get the same value (a lot of disability activism is happening online, and it often gets devalued by others), and also structural/physical things (making places wheelchair accessible, put sofas for resting, organizing sign language interpreters...)

And it all starts with learning from each other, learning about different disabilities, about ableism (and obviously also all the other systems of oppression that put us down). Let's support each other and fight for disability benefits and ultimately create a utopia where we can all live and fight together well, where we value each other for who we are and not what we can or can't do, where everyone can meet their needs without having to fight for them!





# WINVISIBLE

## *WOMEN WITH VISIBLE & INVISIBLE DISABILITIES*

**WinVisible** is a multi-racial community group of women with visible and invisible disabilities: polio, sickle cell anaemia, osteoarthritis, mental health issues, cancer and etc., from different backgrounds: asylum seekers, refugees, other immigrants, UK-born.

For over three decades, the London-based group have advocated for and defended the rights of disabled women facing discrimination of all kinds while offering advice, emotional support and information on accessing benefits, health care, transport services, employment, etc.

Women with disabilities globally face significant challenges such as stigma, violence & abuse, financial barriers and exclusionary attitudes & policies that

impact their lives and their health even further. The group shared how experiences of disadvantage and inequality are amplified by multiple dimensions of identity that make it even more difficult to live a dignified and secure life.

During our online talk, there was a lot to learn and reflect on from their experiences, and it was clear how their activism work is closely tied to their everyday life experiences and the ways in which that empowers them collectively to keep fighting for justice and equality.

“Through WinVisible, disabled women meet and support each other, overcome isolation and discrimination, and often win what we are entitled to”

## WinVisible reduced transcript

**eyfa:** *Could you give us a short introduction on how the group was created, the main idea behind it, how you've been shaped by the different persons that have joined you over the years and what are the different identities, needs and wishes present in the group?*

**Claire:** *Well, we started in 1984. Some women with visible and invisible disabilities had taken part in a grassroots women's conference, organized by the Wages for Housework Campaign, as it was then. And it was about immigrant women's experiences, bringing together UK-born and immigrant women. For that event, some of us wrote our personal stories as disabled women for the first time. And then after that conference, Selma James, who started the Crossroads Women's Centre where we are based, and who started the Wages for Housework Campaign, said 'you should form a group to put forward disabled women's demands'. So we started from there and another founding member was Wilmette Brown, an African American woman who'd been*

*in the Black Panthers & who was a cancer survivor. So our group was always dealing with multiple discrimination, as disabled women, as immigrant disabled women, as disabled women of color. We had a difficult experience in the mixed disability groups we've been in, because they never prioritized women's experiences and, on the other hand, the women's groups – except for at the Women's Center or a few elsewhere -- didn't address disability and didn't regard disabled women as colleagues. And at best, they only considered accessibility and they thought that if the meeting was accessible, that was enough, they didn't consider that disabled women should be contributing to their policy, to their discussions and their demands. So that's how the group started. And we also started from the basis that we are entitled to money and services because in an inaccessible society, coping with disability and your health is hard work. It's not work that we want to do, we want that workload to be lessened. We want it to be recognized. Welfare is what we're entitled to, because it's very hard work to cope*

with day to day life with all the discrimination we have to face. Our lives are made very difficult because of poverty & health inequality, which comes from the discrimination and the deprivation. And that's why we want income. Not a basic income, but a Care Income for everyone who is caring for people and the planet. Including looking after ourselves and others, because as disabled women we're not separate from other women, we still do caring work for other people.

**eyfa:** As some of you are mothers, single mothers, part of the LGBTQIA+ community, Black and PoC & migrants living with disabilities, what would you say accessibility is like in activist spaces? I mean, not only the physical access but also considering that people have multiple identities and that no one should be reduced to a single identity. How is it for you to access spaces being who you are?

**Ebere:** I am from Nigeria, and I've been in the UK for like 10 years now. I'm going to just summarize it, and in a story. I was born disabled. And I have polio. I came from a wealthy

home, my dad was a politician but in the 80's when you are born with disability, it means bad luck. Yeah, bad omen to the family. And I suffered so much abuse from them, continuously, and it impacted me and my mental health. I survived sexual abuse from my uncle and this continued until I left Nigeria to come to UK, I had to run away. When I came to this country, I saw what Black disabled people & queer people experienced, so because I saw these barriers I became an activist. Then I was with WinVisible for a long time. Then I was moved to Derby and was invited to join the equality and diversity committee in Derby that addresses disability issues. I joined them. And I said 'Please, we need a gender neutral toilet, to make it accessible for the queer people and transgenders'. And they said 'Oh, no, we can't do that. We just need a generic toilet'. They shut me down. You know, I was not being listened to, that really impacted me. I was like, then what am I doing here? If as a disabled person, you're not hearing me, as a queer person you're not hearing me. So what's the need?

*Ok, I have Post-Polio Syndrome. My nerves are going down. And I requested for an electric toilet because I just fell down using my normal toilet I used to use before. And they say, oh, that's a luxury. I said, How can washing and dry toilets be a luxury to me? It's a basic right.*

*And also, during the COVID I was invited for a conference. And the theme of the conference was how COVID impacts people of color? How COVID exposes the marginalization of people of color. So I attended the conference, and they brought so many professors and others, and doctors and they were talking and talking and talking, by the time they finished, and it was Question Time, so I said, I have a question. They said Yes. And I said, Please, you've been talking all of this and that but nobody mentioned how COVID impacts disabled people of color, how COVID impacts queer people of color, how does it impact Black women? And nobody said anything. Just to prove to you that we are not considered important. When they normally do updates about COVID on TV, there's nobody to do sign language. No*

*one does sign language! That's why everybody stigmatizes us, because we are not being respected.*

**Claire:** *And some of the benefit campaign groups, they don't address the rights of immigrant people. And since the 1990s people seeking asylum have been excluded from the main benefit system.*

**Ebere:** *As an asylum seeker, when I was in London, nothing was provided to me. Then I was moved to Birmingham, then Birmingham to Derby [then they provided my support]. Then I lost my case, they withdrew their support from me, and they told me they're gonna kick me out of the flat, and then withdrew my health care services. (...) I got a letter telling me that I had to leave my accommodation. I didn't know what to do. How can someone who is in a wheelchair be getting kicked out to the streets because you lost your immigration case? It took me seven years, and finally I got my papers.*

**eyfa:** *X, could you tell a little bit about your experience as a parent? What your experience has been as a single parent*



*living with disability, dealing with the state and how the state handles that.*

**X:** *Oh, gosh, it's very difficult, because I have an issue, like, mentally, and I have physical problems as well. Every time I end up in a hospital for treatment, social services come and get involved in my children. And they ask them a lot of questions, they put them in a separate room. Just to find something... Because I have problems related to mental health, doesn't mean that I treat my children badly -- but they are very quick to jump into that conclusion..*

**Tasha:** *I just think, as soon as you become disabled, that's when the battle starts, basically. Many of us have other caring responsibilities. People believe that the state cares for us without having to put up a fight. But as members of minority status or multiple minority statuses, we seem to be placed at the top for any budget cuts. And then when it comes to prioritizing support for mental health and well-being we're put at the bottom.*

**Claire:** *Under the pandemic,*

*we've had a terrible series of policy decisions against us, which has resulted in a very high death rate under COVID. The government was making plans of who was disposable. And, for example, they had a policy of sending patients with COVID into residential care homes for older people, which is majority women, which resulted in an enormous number of avoidable deaths. They were also issuing Do Not Resuscitate notices against people with learning disabilities.*

**Sue:** *During the Covid 19 pandemic I experienced a situation where it seemed that disabled people were not being treated equally around the provision of spare parts for our ventilators. I use a ventilator 24/7 and at the very beginning of the pandemic the hospital informed me that they were no longer going to be supplying filters. The filters were anti bacterial but also anti viral. All the people that were on home ventilators were discriminated against and what was behind it was this policy decision that the hospital had made because there was a shortage of filters in the country. So I*

had the support of WinVisible. Disabled People Against Cuts recommended a law firm who helped me write an official complaint. The hospital decided to send me some filters in the post and because they sent me four filters in the post it meant that I no longer had legal grounds. It was a tactic to get them out of having to go to court. The hospital also agreed that they would start supplying patients in the community again.

**Heulwen:** One of the things that I've become very aware of recently is the ignorance of professional people about autism. It's just unbelievable. So many times I had to deal with doctors who knew nothing. When I explained my son's behavior, they reacted as if they were insulted because I knew so much more than they did. That's it really.

**Sarifa:** There are a lot of issues for people with English as a second language from the BAME (Black, Asian and Minority Ethnic) community, in hospitals, because again, interpreters are not allowed. And some of my deaf community were complaining about BSL (British Sign Language) not

being there. In Britain, there is a big issue around racial inequality in healthcare, as well as social care and everything else, even inclusive education. There's a big, big issue. We find from my group (Parents for Inclusion), we're disabled parents with hidden disabilities, and with disabled children, is like a double whammy. It feels like you can't be a service user or a woman with disability and a carer, but a lot of my community are and sometimes 'sandwich carers' (for children and for parents). But it's like the system won't recognize us, especially if we've got hidden disabilities. Carer's Allowance is a pittance and is canceled out by retirement pension. And there's Islamophobia going on as well. So it's really, really tough. I had two children and they wanted to take them away, they wanted me to have an abortion, and this kind of practice is still going on, because they said the baby would be disabled, and it would cost the state too much. So let's have an abortion. But this is also what's going on, on the quiet.

**Claire:** We are pressing for resources for any woman to

have the children that we want. Where the baby is expected to have a disability, the mothers are often the first defenders of the baby. And we're also concerned that a lot of women are prevented from having wanted children, because of the economic circumstances, like, you know, the bad housing situation now, has stopped a lot of women from starting a family. WinVisible hasn't sided with the feminists who have promoted abortion as enabling women to keep in waged work and who have put forward cost arguments against disabled children. And we're not pro-life, which has focused on the baby to the exclusion of the mother. Instead, we are promoting resources for women to have the children that we want, and to decide, not doctors and other state agencies. And if there was a Care Income, then obviously, women of any situation would be able to have the children that we want. And it would just completely change the whole priorities of society. Jean, who spoke at our disabled mother's workshop said that her child was taken because it was seen as child abuse that her child would have to look after the mother. That is

due to the lack of support.

**Sarifa:** That's the biggest issue that I was talking about. As disabled mothers, I feel it's a strength when we come out and we say we need support in our role as parents and to support us in that, but the system at the moment just puts us on to child protection

**Didi:** For women with refugee status, the whole process of applying for benefits, you have to relive the physical violence and mental trauma that has caused you disabilities. We have helped women be able to bring out their experiences.

**Claire:** We do succeed in helping women to get their benefits without having to do interviews. And we use the "exceptional circumstances rules" very often where the stress of the assessment is causing the woman to deteriorate in her mental health or physical health.

**eyfa:** So how we can think of accessibility as a practice as a daily practice in our minds, not just thinking about how we can put a ramp when we are having an event, but more to do with how we can

*incorporate it in how we think about including everyone?*

**Claire:** *I think one thing is to pay attention to what is being discussed in the disability movement. And to work out how that can be incorporated. For example, we are supporting a campaign called Kill the Bill, a campaign against more police powers. And we're very, very worried about that. And a lot of people are killed at the hands of the police, usually when those in mental distress, and it's disproportionately Black men.*

**Didi:** *Also if you're a woman facing very heavy domestic violence, or someone threatening to kill you, you call the police, and many times the police just don't come. And during lockdown, there was an increase in the number of women killed. (...) Things are structured, yes. And the other thing is that it comes back to the money. The root of a lot of the distress that people are going through is not only the isolation, that of course is adding, you know, and it has been made worse during Coronavirus. But it's also money, because poverty – not having money is very*

*stressful. Not having good housing is very stressful, not being able to travel, to afford to travel because the travel is too expensive to go and see your friends or family is very stressful. There are disabled people who can't go online, can't work on a computer or don't have a smartphone or can't afford broadband. With claiming benefits online, people are blocked from getting basic money to survive. And there's so many more homeless people. And a lot of women basically, do sex work to survive or to support a disabled child or partner. And that's because they can't get proper support from the council or government. Women in the English Collective of Prostitutes are fighting for decriminalization of sex work. As the poverty has increased, more and more women are having to do sex work.*

**Claire:** *And, regarding accessibility as a practice instead of just an add on, we have campaigned for Accessible transport and also against people's interest being pitted against each other. Like for example, with bus design, only one wheelchair user can travel per bus. And wheelchair users*



are put in competition with mothers who have buggies, so we want these concerns to be looked at together instead of being pitted against each other. And obviously, it's to everyone's advantage if transport is made, accessible, non polluting and affordable or free. So we've done things like written letters to the press about transport and access. And we work with some of the other access groups on trying to put forward women's interests like as mothers, we are buggy users, as well as wheelchair users. So we don't see those as clashing with each other.

Talking about the connection between different issues and how we need to sort of take everything into account, you know, across different situations to be really

representative, we need to take all of those things into account.

**Ebere:** For example, I was asked to come and give a talk in London. I think, is UCL or something. And I went, and where the panel sits, there are steps. And there was nothing that could help me go up on the steps. So everybody was able to see me and they were like Let's borrow the lift, this movable lift and bring it over here, then you can take her up and she can go on top of the panel. So it took some time, because I had like 45 minutes to give that talk. Why am I saying this? I'm saying this because, when we're trying to organize something, there should be a disabled person, there should be a Black person, there should be a queer person, there should be a LGBTQ representative.



# *DISABLED AND MAD PRIDE PARADE BERLIN*

## *WORKSHOP NOTES*



Disabled and Mad Pride is a yearly parade, by and for people reclaiming their agency as Mad and Disabled, as well as those who are not directly affected but wish to fight for a world where nobody is excluded. By taking to the streets to celebrate, center, and uplift our community with pride, it is a part of a global movement that is challenging the prejudice and shunning that

is so normalised in modern day society. It took off in Berlin for the first time in 2013, with the aim to make mad and disabled people more visible in society, inspired by the 70s and 80s Cripple Movement (a radical group in Germany) and the first Mad Pride events in Canada and the US during the 90s, as well as the feminist and civil rights movements, by emphasising the existing

intersections of disability and class, race and gender.

It was founded on the following principles:

- Self-determinism and autonomy for everyone
- A society that does not exclude based on health issues, where everyone can participate as a part of a whole
- Respect for every individual's capacity without external pathologies taking precedence over/in our perceptions or livelihood

The parade is organised as an alliance of groups and individuals without hierarchies, in ways that allow people to engage from their own capacities, with no profits earned by the team, or financial support from the state to influence the work. It is a political action to raise public awareness and spread information about the experiences, exclusions and demands of mad and disabled people. It is also a space for mad or disabled people to show their confidence in the streets of Berlin, and represent ourselves genuinely.

Disabled and Mad Pride is also a protest against the fetishisation of work and efficiency. It criticises the pressure to be normal, and to adapt to arbitrary social norms. By bringing together voluntary activist work, protest and a collective celebration of diversity, the organisers of this event seek to include people who usually don't feel comfortable at demonstrations. The parade welcomes everybody who is excluded as disabled, mad or "not normal", as well as people who want to show their solidarity, inviting the attendance of thousands of participants yearly.

Online self-organised events and adaptability are nothing new to our community; as the Corona Crisis poses a great health concern for many, and gathering in large numbers is something most of us are avoiding to the best of our abilities, the 2020 celebration of Disabled and Mad Pride was restructured to take place online through a movie/livestream— thus amplifying narratives and voices in ways that have been able to reach many people even outside of the context of Berlin. You can find the movie with English subtitles on Youtube!

## **Mad Pride: Barrier Frei!**

### **Study notes and accessibility toolkit from our workshop**

On the 12th of July, our orga team from the Berlin office had the fabulous opportunity to meet and have a small private workshop with two members of the Mad and Disability Pride team, Tob and Sven, who shared a lot of insight with us regarding the broad topic of accessibility. Having participated in Mad Pride parades in other cities in previous years, and feeling the weight of isolation from this community over the last couple of years, I was ecstatic at the prospect to meet with them in person, and especially curious to learn more about the perspectives and experiences from the Berlin context.

We met at Aquarium, a beautiful and very accessible event space just a few blocks from our headquarters, and shared some precious hours of learning with them, in which we got to reflect on our knowledge and experiences as individuals; our structure as an organisation; and learn practical tools to put to use immediately in our quest to remove barriers in our projects as well as our daily lives!

Here are some of the notes and take-aways we would like to share with you. Hopefully these will be as helpful to others as they have been for us moving forward in organising better and more inclusive events

(Content warning for slurs and ableist/medicalist topics ahead)

### **How structural discrimination works: Parallels between society and medicalism**

#### **In Society**

**Initial Perception:** When someone sees a person, the first thing they perceive is their physical appearance, body language and speech patterns, which leads to...



➡ **Group Assumptions and blanket statements:** With limited information, people have a tendency to try to categorise individuals into identity groups, from which they make general assumptions usually based on stereotypes. These are determined/used to determine...

➡ **Societal norms, through binary thinking, biological essentialism and imposition of lifestyle expectation, which are used to assign the worth and value of people, all of which causes...**

➡ **Discrimination, barriers, exclusion.**

In Medicine, a similar trajectory follows as such:

**Initial perception:** When people have experiences that differ from what is perceived as the norm, be it physically, emotionally or cognitively, these are examined through a clinical lens, often omitting external factors or the complex histories of each individual, which lead to...

➡ **Symptoms, which are categorised in groups, and can vary in degrees or change even at an individual level. This metric often relies on general assumptions and personal biases, yet it is how the medical services determine...**

➡ **Diagnosis/Pathology.** A diagnosis in theory is a categorisation used to determine forms of necessary care, but like all labels and identity groups, they are loaded with stereotypes and oftentimes harmful stigma, and these result in ...

➡ **Institutionalization, personal responsibility, social expectations, discrimination, barriers and again, exclusion.**

This is a form of structural discrimination that is generally accepted and regarded as a functional part of the system. Medicalism and pathologisation have always been used to justify harm, by taking away peoples agency and labelling them as unfit to participate in society. We ask you to question how you perceive medical

institutions, and how they have influenced your perception of other people's experiences!

## **Four Critiques of Pathologisation**

1. Diagnoses are based on societal norms and assumptions
2. Pathologisation is bio-essentialism based, function focused/ utilitarian and individualistic; lacks perspective outside of systems of productivity yet are used to define people as “ill” (which comes with negative connotations all around)
3. Creates differences in worth/value of people, by defining individuals through the aforementioned parameters
4. This all only serves, and is determined by capitalism

Pathologies and their standards carry an inherent social bias as they are determined by cisheterosexual white men from academic, western backgrounds. They do not consider many factors such as social cause, nor are they adequately assessed through scientific means beyond normative contexts. These pathologies are what make up the **DSM II** and the **ICD XI**, which are the two main texts used by doctors to give “official diagnoses”. Diagnoses are a prerequisite to receiving social/state support in most modern societies.

## **Models of Disability**

The following are some of the models used to determine disability. This is a non-exhaustive list, but they are the main ones historically used in chronological order:

### **Medical Model**

Generally defines the perspective of disability as a physical, cognitive or emotional deviation from the social norm which must be treated, “cured”, corrected or intervened so that the person can integrate with society. Inability to do so effectively results in removal of the individual from participating in society.

## **Social Model**

The social model looked at the characteristics that the medical model defined as “deviations” and integrated them as part of the norm, attributing a margin of possible variation; however, what is standard is defined by the experiences of the majority, and so society is shaped to meet the needs of that majority (which still results in exclusion)

## **Bio-psycho-social Model, aka Human Rights Model**

Based on the social model; Deviations from the norm in a physical, psychological, cognitive and psychosocial way are cross-checked for relevant impact in the quality of life of the individual, before making the assessment of “disability” in order to provide adequate assistance for quality of life improvement

...however, how these assessments are made and the lack of structural and systemic changes still result in barriers and exclusion. The existing models created by the medical community are thus still not enough, by failing to consider individual experiences, structural and social challenges that we are fighting for in our own ways. There is still a long way to go for our communities to achieve justice, and perhaps the way to do so cannot be modelled in a one-fits-all approach.

## **Language approaches**

Ableist language is embedded in our day to day speech, and recognising it and changing it is an important step. In general, there are two main prescriptivist approaches when it comes to speaking about individuals. It's better to ask the person directly what their preference is, as this can change depending on context or personal opinion.

- People-first (or people-centred) approach i.e. Person with disability

This approach centers the personhood of the individual, placing conditions as secondary information

- Identity-first approach i.e. Disabled person

This approach accepts conditions as a part of an individual's identity, rather than something to distance oneself from

Within these approaches, some people prefer descriptive (i.e. person who hears voices) or ambiguous terms (i.e. person with special needs/abilities/interests).

Some terms that have been created to make it more “politically correct” to speak about disabilities (such as handicapped) are also harmful, as these tend to downplay and sterilise the challenges that individuals face.

## **DOs**

Ask people what they prefer; people first or identity first approaches, describing feelings/experiences instead of diagnosis, reclaimed words (always depends on context and background, i.e. crazy, loon, cripple, etc)

## **DONTs**

Calling people by their diagnosis, slurs and other dehumanising terms (i.e. psycho, retarded, lame, spastic, neurotic, hysteric, hypersensitive, handicapped, etc.)

When it comes to talking about health related issues of any kind, if it's something you have no personal experiences with, the most respectful thing to do is to acknowledge not knowing and asking questions without assumptions -- and of course, be mindful not to ask for any personal or intrusive information that you would not ask of your neurotypical/abled friends!

## **Accessible Communication Guidelines**

- Let people finish speaking without interruptions (keeping in mind that people sometimes pause in sentences even if they're not done expressing what they want to say)
- Listen carefully. Think carefully before speaking.
- Focus on your own learning (sharing suggestions is ok, but it's



best not to tell people what they should do!

- Practice self-care in your communication. Be aware of your body and headspace, and keep yourself grounded
- Respect diverse experiences and opinions
- Ask questions!
- Be mindful to use simple language and self-determination. Speak from your own experiences
- Speak up/lower or slow down. Reflect on how you're choosing to express yourself, and whether the other person is able to listen
- Make space in conversations for processes/processing. Allow pauses and quiet moments before changing topics

## Writing in easy/accessible language

It is ideally best to commission text revisions and creation by experts and people with personal experiences to ensure long lasting impact and adequate, simple terms and communication. Here's a few rules to follow:

1. Use clear, distinct terms, and avoid compound words. If you must use a compound word, make use of the hyphen.
2. Avoid foreign terms, words in other languages and technical jargon if you must, use defined fonts and provide short definitions.
3. Avoid abbreviations.
4. Avoid genitive and nominative clauses, use verbs instead of nouns where possible (I am guessing this means in regards to German sentence structure)
5. Avoid large numbers, use words to describe amounts
6. Use positive instead of negative constructs (i.e. pro- instead of anti-)
7. No idioms, slang, etc.
8. Only use short sentences, and structure them line by line. Align text to the left and use plenty of paragraph breaks and punctuation
9. Avoid sarcasm, irony and rhetorical questions.
10. Don't use self-referential sentences, complex, unexplained references, etc..

11. Use size 14 fonts, sans and serifs; dark fonts on bright/light backgrounds and avoid shocking colours and contrast

12. Use images that directly illustrate clearly what related text describes. Write image descriptions in online publications for ease of use with screen readers.

Remember that for a lot of people it's easier to understand spoken word better than text, and likewise, other people will struggle more with auditory processing and will prefer reading

When writing invitations and event descriptions, always include a simple text version, and especially/specifically when you make events that are accessible to people who are the target demographic for simple language

## Accessibility Inventory for Organisations

- What does our organisation do? For who?
- What does the organisation stand for?
- Where do we want to go in the future?
- Who is missing? Why?
- What does the group of disabled or crazy people in the organisation look like? What do they have in common? What sets them apart?

## Practical Accessibility Assessment Inventory

This inventory contains some practical considerations that we brainstormed during our session. It's a good place to start, but it's not a complete guide, as much as a starting point— as you read it, perhaps you might think of more ways to accommodate the needs of people who you might want to attend your events. Feel free to add your own, and we encourage you to always ask people to reach out to you to communicate if there is anything that would make it more possible to participate in your future projects!

## **I. Framework conditions**

Money/funding, free entry for accompanying persons, childcare, legal support, time management, frequent breaks, basic needs (non-allergenic food and drinks)

## **II. Rooms/spaces/places**

Quiet rooms, accessible non-gendered toilets, comfortable and non restrictive seating, private accommodation, scent free spaces, proper doors, childcare space, ramps, rails (no steps or obstructions for movement) adequate lighting, lateral flow, personal space, transport/parking

## **III. Communication/speech**

Simple language, translators/interpreters (signing, spoken language, etc), paper/pen, captioning, clear enunciation, adequate acoustics

## **IV. Awareness**

Awareness team, flyers, posters, clear signage, regular announcements, further resource materials, free info, bar/security training

## **V. First Aid**

First aid kits, medics, sweet snacks (various degrees of sugar), transport...

## **And remember...**

Accept new experiences and embrace imperfection, especially with yourself when you're trying to do better

Document for posterity to expand on that knowledge, and accept all relevant feedback

Don't be discouraged! It's a learning process :)

# Queers Need Spaces to be Sober, Sexy and Sad at the Same Time

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*Why We Need More Sober Spaces  
for Marginalised Communities*

*by Aisha Mirza*

If we want to get serious about intersectional mental health, we first have to create more sober spaces for queer people and people of colour.

The last few years have seen the queer landscape in London and other parts of the UK transformed by collectives and party-throwers such as Pxssy Palace, BBZ, Hungama and many more. They have held space for



bodies that are othered -- for not being straight, not being white -- spaces in which we can chat, dance and act like fools together, shielded, just for a moment, from an imperial gaze. Curating public shared space for people of marginalised communities in an era of rabid privatisation of social services is life-saving work.

This year, some awkward peers and I joined forces to try and build on this work, bringing together our skills as organizers, nightlife lovers and mental health nerds, with our experiences of addiction, sobriety, neurodivergence, psychiatric wards and routinely not being the hottest person in the room. We wanted to create something structural that could support the mental health of our community, because the thing is, life shielded from white supremacy, though joyful, still feels its impact. That's to say, now that we have demanded and

are normalizing this gift of spaces that center queerness, transness and Blackness, now that we can lean back and bask in the torsos glittering like galaxies, revel in the joy that we have found each other on these English soils; now we are left with the reality that this is not quite utopia either, that many of us are frequently miserable.

Through MISERY, we are trying to make structural, non-judgmental healing accessible for QTIBPOC who fancy doing that kind of work. We run sober club nights with the help of MISERY resident DJs GIN (founder of Resis'dance and Nite Dykes) and Basmati (resident at Pxssy Palace). At our parties you can expect healing movement workshops, massage, facilitated art and tactile play corners, quiet areas for those who want a breather, vegan south asian food by our chef, Rajiv Bera aka Queer Masala,

performances, genderless nail bars, signposting for local mental health resources and a good amount of grinding. As we grow, we're curating more events outside of a nightlife context, but still providing therapeutic experiences based on ancestral modes of healing such as foraging herb walks, twerkshops, and cooking classes – “What to eat when you're too depressed to move”, for example).

It's not that we set out to do a strictly sober vibe, but the more we thought about it, the clearer it became that if we were trying to make some kind of real mental health intervention, we'd need people to be present for it. The reality of trying to run a sober rave in an accessible venue in London on a Friday or Saturday night is that you will be laughed at. Nightlife and venues are completely beholden to alcohol sales, hence the lack of sober spaces readily available. Sober

spaces aren't just a health asset, but an anti-capitalist one too, which, call me dated or whatever, but feels important.

There is a bunch of research confirming what we know, that problematic substance use is much higher in LGBTQ communities compared to other demographics. We're living on a melting planet and sharing memes about wanting to die for sport – it's a hard time for everyone – and harder still for those of us that are different, for whom society was not designed to accommodate, let alone nurture. Harder still for QTIBPOC, who may experience even further despair, isolation and oppression within our often white-dominated LGBTQ umbrella minority groups. For many of us, moments of freedom are often facilitated by a kind of dissociation and self-medication that can only be provided by alcohol and other drugs. We deserve some other options too.

We've built **MISERY** as a non-judgmental space. We do not police anyone's relationship to substances or what they do before or after our events. Everyone is welcome, whatever their relationship to substance use and sobriety. We understand people's trepidations about sober spaces. Sober rhetoric has historically been chock-full of judgment, moralism, unhelpful and unrealistic goal setting, and inherently shaming language peppered with terms like "getting clean" or the idea that you can "love yourself" out of potentially destructive patterns.

We're careful not to replicate any of these sometimes well-meaning but ultimately damaging frameworks and are looking instead to use our understanding of radical mental health practices which center harm reduction and the voices of people in need, to create opportunities for queers to have fun in alcohol-free spaces.

**MISERY** is for friends actively struggling with mental health and/or substance use issues, for people who are curious about their relationship to intoxication and wellness, and for folks who want to have a good time.

There is pressure on everyone, but particularly people of colour, queer people, marginalised people, to be "happy" and "strong" and "fierce" and "hot" and "inspirational". Too often, we only hear accounts from people who have been miserable once they have found their way out the other side, as though sadness can only be tolerated in hindsight. No-one wants to be sad all the time, but **MISERY** is an invitation to come as you are, to talk and heal collectively, to be sad or quiet in public, to celebrate, and to give gratitude for those before us and around us who have not had that option.





# Brain- foggy thoughts on disability and gender

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By Lian

I was going to write a well researched and coherent text for the zine but have been failing to do so for a while because I'm in pain and I can't focus. So I'll just write what randomly comes to my head and accept failure. That's something I have to do all the time anyway. Accept I can't leave the house, accept there is no cure right now, accept I have to lie in bed, accept I can't do the things I loved doing anymore, accept I lost concentration again and don't remember where this sentence was headed. Yes I forget what I want to say half way. Sometimes

I just stop in the middle and don't even remember what I said. My friend has gotten used to it and sometimes asks and tries to help me remember what it was that I wanted to say.

Sometimes thinking hurts me so badly, it feels like physical pain, like the thoughts need to path their way through my head with a hammer. It's hard work and hurts and leaves me totally exhausted. Sometimes it's better but it's never like it used to be. So folks who read this who are not sick: be happy and appreciate it while you have it! There is so much you can lose. I recently heard that a lot of ableism is based on the fact that people push away the thought they could become disabled anytime and that their ableism is really their fear of becoming disabled themselves. I think there might be truth in it. Some people who are now suffering from long-haul covid certainly said 'oh don't worry corona is only bad for the old and chronically ill...' And how that sentence has hurt the disabled community! It's not exactly nice to hear that no precautions need to be taken because it only affects the weak. That all feels too painful and complicated to get into, lots of people have tweeted about the ableism in the pandemic. I'll have to stop now.

Sorry.

Originally I wanted to write something about how gender and chronic illness intercept. I'm hungry and I have the choice: eat and have bad cramps or not eat. Not sure what is better cause if i don't eat i also feel even weaker. See, I'm not writing this to whine oh I'm doing so bad, I just want to write what comes to my head because oftentimes I feel people don't understand what it's like to be sick. And I somehow don't want to hide

that part of me, it's such a big part of me now. Most of the time I hide it and say whatever but not really how I am because often I either get advice or but even if people react nicely the rare occasions I have to meet friends I also like to hear cheery stories. And I'm afraid people think I whine or exaggerate because I don't have a diagnosis where people think: oh that is very bad, and my illness is invisible. That said it is invisible if you are not very sensitive, like people who know me know how different I am when healthy. It's just also been so long that I am sick. And another thing people in mainstream" society (sorry to call it like that, I am also ) often don't understand that I am sick now, to them I am lazy now, and I was lazy then when I was still leading an activist life because huh I wasn't making money or having a career then and now either so it's kinda the same. Yet for me it's my life turned over. When I was still healthy or more healthy I was fulfilled fighting to make things better, my life was adventure, outside and full of sense. Now it's surviving, loneliness and trying to find some happy moments in small things. I'm not completely lonely. I have my partner and my dog and some friends living far away. I'm dependent on my partner to survive. I can't pay them for the help, because I lack the power to fight for that and my diagnosis doesn't help me much. So my illness also has quite a strong effect on their lives and sometimes I feel guilty about that. And the best thing, my condition could still get much worse. When I first got on Hartz IV<sup>1</sup> I thought great that's so much more money than I've had in the past, but I also cannot live the same life anymore, I don't have a community here anymore (had to move to another city), I can't live as cheaply (no hitchhiking, no biking, no walking, no squat, can't eat skipped food...) and being sick is expensive because there is always a part you have to pay yourself, treatments the

insurance doesn't cover, and I can only eat a special expensive diet...)

So, here, I draw a picture (bear with me I'm not good at drawing) Most doctors I meet don't care to investigate what's wrong, they only see my beard and think they've found the cure. Don't know anything about inter and nonbinary, for them if someone they see as a woman has a beard it's sick and the reason for all ailments.





So, back to the interception with gender and ableism.

Another personal example: The illness I have is a multisystemic illness and an autoimmune illness. Women<sup>2</sup> get more autoimmunity illnesses and there is less research than about illnesses that hit men. (there is clearly also a race bias, basically most research is done for white men, and also often with the focus on those who can pay a lot). With my disease there simply isn't much research into it, because at some point a misogynist dude came along and published a paper that was not based on research or interviews with patients or doctors, he basically just reasoned if it's 80% women who get it, it must be hysteria, made up, all in the head. So he proposed the treatment should be psychotherapy (mind you not supportive psychotherapy but psychotherapy to talk patients out of false illness beliefs as if not believing you are sick would cure you!) and exercise when exercise is actually really harmful. So it obviously did not help anyone, and even their own research showed it, so they simply changed the definitions of it and kept the results hidden from the public! Only after years of legal fights have people won the right to look into the research and exposed it as fundamentally flawed, so that now in 2021 finally they admit officially that those treatments were harmful and that actually there is no treatment right now and more research is needed. (And it's not that other researchers didn't want to investigate it, there was simply no funding for it because this misogynist with his psychologies had so much power).

So, yeah, not surprisingly the medical system is misogynist, transphobic, classist and racist as fuck.

So what do we learn from that? Getting a diagnosis can be

very hard, the medical system is often traumatising especially for people who are not white rich males, so please if someone fights through their fear of being denied and feeling like a burden, to ask for accomodations, please don't question their needs! A lot of illnesses are invisible. Everything in the medical and social system is a fight, getting benefits, getting assistive devices, anything, so please make it easy to ask for accomodations, ask people if they need anything, take some focus and energy away from what you are doing to make things accessible. And yes sometimes it's work and it needs money, often there can be creative ways of finding solutions but not doing it is hurtful to people who get excluded and who have to often fight for access all the time anyway. So really it is a value for our movements to include people, so then let's also make the effort! The movements I used to be part of have become mostly inaccessible to me. In part because my illness takes up so much of my time and anyway limits my energy but also because the movements are made for people who are very able, and I hardly get any support back from them. Like in those groups the couple gets criticized a lot, calling more for a collective approach to things. And I share a certain critique of the individualistic, separate approach of the nuclear family without wider community, I agree with it and I felt I was part of a collective before I got sick, it just seems to be a common experience of people who get sick that the collective or political group does not support them but often the partner, the family, other disabled people and the state. And why is that? Often because we replicate the ableist and virilism ways of valuing and prioritising things. Like direct action often is the top priority, looking after people and supporting each other is not. And the care work is often done by FLINTA<sup>3</sup>...

And my illness should not be my private issue! The private is

political, we support people who are in prison, why don't we support people who get sick? Who gets traumatised... I would like to be in the movements or groups like I am, that we really share how we are and support each other, do political work if we can, but don't put it over everything. I find it really hurtful when I am in a flare to be asked: oh why didn't you do this task, why are you leaving us all alone with this?! I feel like, wow I've just told you I am very sick and instead of saying "sorry, can I help you?" I get scolded and criticised for not functioning. It's such a capitalist way of behaving!

What I envision for a good life is groups working together, where everyone can take part, and everyone supports each other, everyone is welcome and appreciated for who they are and not what they can or cannot do. (I can see you hippie phobics roll your eyes, but i find it useful to envision where I want to be, to actually move towards it) We still have a way to go, so let's move there!

<sup>1</sup> Hartz IV: is a type of financial assistance in Germany.

<sup>2</sup> Women: I don't agree with that binary way of thinking gender, I'm non-binary myself, but that's the categories that research uses.

<sup>3</sup> FLINTA: Abbreviation for Women, Lesbian, Inter, Non-binary, Trans & Agender, in German.

# "Our heroes in the trees protecting the forest"

by Raupe

## Our Heroes in the trees protecting the forest



me before I got a chronic disease

me today:

I was laying in bed, trying to stand my back-pain. Then I went to physiotherapy, after I had to rest. But I also had to prepare the special diet for my disease...

don't want to talk about it.

I feel so stupid for showing of with climbing before

I built a tree house - 30m high!

Wow! Nice!

And what did you do in the last week?

We organized the skill-share, it was so much work. We did not have time to eat. And who needs to sleep.

This winter, it was -15°C on the tree house. Drinking-water was freezing.

Oh! What did you do?

We kept the water in our sleeping bags.

Wow! You are so cool!

So strong!

I wish I was able to do that...



And when the cops came to evict us - they were a lot - but I climbed away very fast, they did not get me. Only 2 days later.

Wow, you are so cool.

Ohhh!





# "Me and My Car Going to a Sustainable Mobility-Camp"

by Raupe



# Coping With Disability Is Hard Work

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## *Women With Disabilities Work Unwaged*

*by WinVisible*

- In an inaccessible world, all people with disabilities have to work hard just to survive, but women with disabilities work even harder.
- Many of us look after children, friends, families and others in our communities (who may have disabilities themselves), on top of coping with our own disability or ill-health. As women, we have less resources than men, and have to deal with worse discrimination.
- Dismissed as a “drain on society”, we want recognition for our work

and contribution – we are carers and workers too, for ourselves and other people, even when we don't have a waged job. And mostly, the jobs we can get have very low wages and bad conditions, making us even poorer than we were on benefits.

- So much of the disability work we have to do is not necessary – it shouldn't take so much effort just to move around, communicate, or get things done.
- Billions are spent to kill and disable people in wars – on landmines across Africa, cancer-causing depleted uranium-tipped bombs and other weapons in Afghanistan and Iraq, Agent Orange and other poisons in Vietnam and Colombia, nuclear bomb testing in the Pacific, bulldozing and shootings in Palestine... Little is spent to meet people's needs, including those of us with disabilities, even war veterans, or to clean up pollution – those funds are limited, rationed and regularly cut. Since billions went to the banks, no one believes that there is not enough money to meet community needs.









# What Disability Pride Month Means To The Triple Cripples

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By The Triple Cripples

July is 'Disability Pride Month'. For most, disabled or otherwise, this is the first time that they are learning about such a celebration.

## Disability Pride Month

A quick Google search shows that disability pride has been celebrated on and off in the US since the 1990s. Parades and events dedicated to celebrating disability in all its forms. And acknowledging and paying homage to those within this often ignored and meticulously

marginalised group. From Boston to Los Angeles, these events sought to change the frequently negative thoughts and perceptions about disability and those that had them. Disability is very much a part of human nature and a sizeable thread in the fabric of human experience.

## **An Accepted Identity**

I am still learning about the histories, legacies and lives of global disabled ancestors. A month dedicated to disability pride is not something I can claim to be familiar with, at all. For much of my earlier years, I spent a lot of time, brain space and creativity minimising my disability. Something that is rather difficult to do when you use a leg brace and two crutches. My disability was always a fact. I was, and always would be, disabled. For a long time, I was not okay with that. I resented that fact and used humour to distract from that fact.

I have become okay and accepting of this aspect of myself. This has certainly become an easier journey since the inception of the Triple Cripples. Having a partner in crime that just gets it has helped me come a very long way. And through the creation of this platform, it has lead me to learning more and researching more about disabled people. Something that I would have never imagined doing as a young disabled girl in school. It would have been counterproductive to find out more about a part of myself that I wished wasn't there.

However, even with this acceptance, I still didn't know that

this identity was one in which one could feel pride. I am okay with being disabled. With each passing day, I have fewer and fewer issues with having a disability. I couldn't say that I was particularly proud of it within myself. I feel an immense pride in being Black, in being Yoruba. But this never translated to disability, perhaps one day it might.

## **Finding Pride In The Disabled**

I feel the greatest pride in the amazing disabled people that have done so much for me and mine. The truly astounding and incomparable Harriet Tubman, the most well known conductor of the Underground Railroad. Through much of what is written about her, so often her disability is left out. A giant of an ancestor, who did the impossible, over, and over, and over again with a disability. How could I possibly not feel pride in that?

For me, I am proud of disabled people. I am proud of all that they have done and continue to do. Their sacrifices made it possible for Kym and I to be bold and daring in creating the Triple Cripples. That is disability pride to me. We are, because they were.

There are so many disabled trailblazers that we are so fortunate to still have with us. We have Marsha de Cordova MP, a Labour MP, and Julie Jaye Charles, Equalities National Council founder and CEO. I am proud that these phenomenal women are ensuring the future is brighter for those who come after them. I find disability pride in us.

## **“Let’s be frank, Martha” Martha Thought She Would Much Rather Be Herself...**

I have never felt part of any particular community, other than the global Black Community. So being classified as being part of any community always feels uncomfortable. Historically and presently, Black People have been overlooked for and excluded from all sorts of groups. From unions, to country clubs, to women’s circles, to political parties, to “at risk” intervention groups; there have been closed doors, and/or the entry qualifications required of us, exceeded what was reasonable or indeed humane. This was not accidental, but by design.

## **Blackness Is Expansive – Except When You Are Racialised As Black**

Growing up with that knowledge and feeling the sharp sting of exclusion, otherness, by virtue of my racialised identity, meant that I could only identify with one common group: Black. Of course, as I grew older and began to understand myself and society more, the world became more nuanced. The broad category of “Black”, became coloured with layers. Sex, Gender, Sexuality, Religion, Ethnicity, Nationality, Education, Language, Accent, Locality, Career, Class, Colour, Phenotype and Ability. But the lines of difference were all woven together with the ever constricting rope of ‘Blackness as a polar opposite to Whiteness’. Blackness in the context of White Supremacy joined all of us together; as at every axis of difference was the



pervasive stench of racism, whether or not we were conscious of its functioning.

## **“Go Back To Africa” And Other Classic Tales...**

When The Triple Cripples first emerged a few years ago, it was interesting to hear people from the Disabled ‘Community’ comment about the lack of necessity for a space, narrative or voice like ours. The rejection of our experiences, sometimes of our conditions, and of our Blackness in a European landscape, was stated explicitly “If it is so bad over here, eff off back home to Africa”. As if somehow, racism experienced by Black People would be solved by leaving white majority nations – forgetting that racism is a function of white supremacy, a global system.

## **White Solutions To Racism Are Almost Always Bad...**

Obviously the argument itself is full of cavernous holes. But what’s more interesting about this stance, is the idea that if you don’t like being bullied, abused, murdered, raped, erased, oppressed, tortured, cockblocked – you should ‘just’ move house. As if, that is a simpler solution, than the entity inflicting said behaviour ceasing. If we all moved back to our home nations after every breach of boundary, or affront – there would be nobody left in the UK. Think of the football hooligan exodus onto the shores of Spain, after every match! ...But I digress.

## **Black + Disabled = Still Black**

The point is, after 500+ years of being forced into one group and exclusion from all others, it is hard for me to feel safe or comfortable within any other group (as problematic as my group may sometimes be). So, though I acknowledge that being Disabled marginalises me in a unique way. I also recognise that I, and others like me, aren't regarded as having the right to the narrative of Disability. As with all things, Disability is racialized.

From the late diagnosis for some things and over diagnosis for others. To the gatekeeping of certain social funds/resources reserved for the vulnerable. To forcibly being made disabled through the brutal savagery that was enslavement (yet being refused consideration or adjustments). To the complete denial of our existence through media erasure and more. Black disabled people are forever on the outside of the general Disability Community, looking in. Our survival has heavily relied on forming our own support networks, our own community of recognition, information sharing, and validation.

## **Black Women Had My Back Before I Was Even Born...**

“The Three Queens of the Virgin Islands”, Mary Thomas (Queen Mary), Axeline Elizabeth Salomon (Queen Agnes), and Mathilda McBean (Queen Mathilda) organised the people and led the rebellion known famously as ‘Fireburn’

In modern Britain, Black Femmes like Julie Jaye Charles, Caroline Nelson and Michelle Daley have been at the forefront of curating these organisations, spaces and structures, for Black People with Disabilities. Of course, the groundwork was laid for them by our powerful ancestors who fought for freedom, justice & equity.

Ancestors like Queen Mary of St Croix, La Virreina Juana of Cartagena, Queen Njingha of Angola. Nanny of the Maroons, Ohemaa Yaa Asantewa of Ghana, Breffru of St Jan and so many more, around the world. Exclusion even from truth itself, means that tales of Black Women & Femmes are often erased by a godawful, white supremacist, patriarchal lens (regardless of who has written it). We rarely get to be revered as part of the community of women of old, recognised for living breathtaking lives.

## **An Eternity of Spiritual Giants & Black Pride**

So my pride is not in being classified as disabled, in a purposefully ableist society. Nor is it from being classified as Black, in an intentionally white supremacist, anti-Black society. But it comes from being part of a phenomenal gene pool of indomitable spirits. Goddesses who continue to make room for me and those behind me, in a world that continues to deny and actively attempts to erase our existence. Black Women, Black Femmes, are **EVERYTHING**. This month and every month, I honour **US** in **ALL** our wonderful iterations.



# Our Tips for More Accessibility on Facebook, Instagram, Twitter, and Everywhere, Where There Are Hashtags

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By Barrierefrei Posten

## Image description

- Describe details especially if you are being responsive to them in your text or if, for example, a funny comment on the picture is only understandable if you know this detail.
- Describe as short as possible and as detailed as necessary! As a rule, describe only the most important.
- The length of your image description can vary. It always depends on what you want to convey with your photo. If you take a particularly detailed picture or want to say something specific, then this can also be



described more detailed.

- Mark your tweet with **!B**. This way, sighted users will also know: Your tweet has an image description.
- Don't get confused: The text of the image description is called "alternative text". On Instagram and Facebook you enter an *alternative text*, on Twitter an *image description*.
- Just briefly describe what you see. For example: 'Look, I have a great box of candy here' instead of 'Look what I have here!'

## GIFs

- GIFs *do not* have an automatic image description.
- Twitter: you can enter an image description just like you would for a picture. Yay!
- Facebook: You *can't* enter an image description :-/
- The only thing that helps: describe the **GIF** in the text.
- Instagram: **GIFs** are videos on Instagram. And unfortunately you can't enter an image description for videos.  
The only solution is to describe the **GIF** in the text.

## Hashtags

- Start each word in a hashtag with a capital letter. Capitalize every letter in an abbreviation.
- Explain the abbreviation in a tweet.

## Sign Language

- Sign language is the native language of many deaf people.
- It can be better understood by many deaf people than written language. It also shows respect for the deaf community.
- Hire a translator for your videos. In many cases, you can hire deaf

interpreters for your video. We recommend that you do so.

## Subtitles

- Subtitle your videos!
- *Open captions* are always displayed, they are hardcoded into your video.
- *Closed captions* can be switched on and off by the user. Facebook can do both. Instagram and Twitter can *only* do open captions.
- Subtitles are not only useful for deaf and hard of hearing people. This way, more people can understand your video, even without sound.
- In the best case, write 1:1 subtitles. If you have too much text, try to write the content in a meaningful way.
- Each subtitle should consist of no more than 2 lines and be visible for about 7 seconds.

## Wording

- Please respect people's wishes. If a person/group feels offended by a word or not named correctly, do not use it for that person/group. If you are unsure, ask.

## Language

- Write your texts simply.
- And write your texts easily.
- Write short sentences. A short sentence has 8–10 words.
- Explain difficult words.
  - Many rare words are difficult.
  - And many long words are difficult.
- Try to find another word.

# SPECIAL MASSIVE THANKS, ACKNOWLEDGMENTS & CO.

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## Our Vision

We'd like to move towards a world where accessibility is possible to everyone, however we also understand this isn't always possible. Not only because of limited awareness, but also because of conflicting wishes arising from different needs. The same goes for 'safe' spaces, and this has become all the more evident to us as we explored this subject, as we found that many of the tactics and expectations used in activist spaces to create safety for some people, can in fact be quite reductive and exclusionary for others.

The path to justice and responsible allyship starts within our communities. We need to hold each other accountable and to recognize the roots of problems in order to dismantle systems of oppression – the system that some benefit from is the same system many of us have to battle hard in order to survive. We would like this to be a wake-up call for greater empathy and care. Our intention is to reduce barriers and to reduce harm within our reach as much as we can in order to create spaces that are more accessible and safer for all.

## Call for action

We find it necessary to state that people's experiences are not up for consumption or debate. No one single individual can speak for a whole group of people, so let's broaden our horizons and listen to as many perspectives as possible, especially ones of those who live in the intersections of marginality. We are not entitled to the wisdom and knowledge of marginalized people and it's important to remember that people are dealing with systemic oppression, while trying to survive in a world that devalues the lives of disabled, financially unstable, neurodivergent, trans\*, migrant, Black, Indigenous and racialized persons. Therefore, reach out for education with the intention of paying for their labour. This is a crucial act of solidarity and support, as reparations, and as an action that is grounded in our material reality beyond our ideals and aspirations. If you lack the means, there are plenty of good resources online. We understand that, as grassroots organizations and small collectives, sometimes it is difficult to find the financial means to pay a fair fee, but if you are able to in any way, invest what you can in supporting the efforts and labour of those who are creating, sharing and providing such educational material to entire communities.

We also encourage self-organised learning, e.g. creating a group to learn together with friends, sharing & recommending content, crediting content creators & educators.

## What we learnt

This project served as a reminder that we can only be the experts of our own life, highlighting the importance of letting each person

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present their own experiences as well as their own topics.

We are in the constant process of asking ourselves who is taking part in our activities, who isn't and why? Who is giving the workshops? What topics are given priority and how do we talk about issues? How do we incorporate our shared politics into our daily lives?

As organisers, we still have a long way to go in terms of learning! This is an on-going process that we are committed to. We want and need to keep educating ourselves everyday, for the necessity of justice and liberation for all. Despite our best efforts, mistakes are inevitable. In the spirit of ongoing learning, we invite you all to get in touch with us and share your experiences, as well as any feedback, notes, or comments that you may have by sending us an email.

## **Special massive thanks**

In this process we are very grateful to the people we have learned so much from, since this wouldn't be possible without them.

We would like to send a super special and massive thanks to everyone who contributed towards this publication & who shared their work and experiences with us; to the contributors: Romily Alice Walden, for the 'Primer on how to work with disabled group members – for Feminist/Activist groups'; Lian and Delila for the zine "Caring Movements – Chronic Illness and Activism", Barrierefrei Posten, for the tips on how to make social media more accessible; Raupe for sharing with us your experiences through images; The Tripple Crip-les for always Increasing visibility and highlighting the narratives of Black and non-Black Women, Femmes and Non-Binary People of Colour, living with disabilities; to the groups we interviewed – Misery Party, Radical Resilience, WinVisible and the organisers of Mad and Disability Pride Berlin who were so kind and accommodating even in these times of uncertainty, and who really took the time to help us make this a reality with all the sincerity, vulnerability and passion that we will forever carry in our thoughts and actions.

This publication is by no means exhaustive or a complete guide, but it can be the starting point for many important conversations that we would like to see happening in our communities as we move forward, and perhaps to encourage people to be curious enough to seek out those representations so often missing on the discussion table.

We can only create a free society from within the constraints of our material conditions, so in the spirit of sharing resources with those in need, we are honoured to have the opportunity to share with you a bit of what we have learned so far.

Pass it forward, keep an open mind and a curious heart!

Autonomous Passage:  
Intentional access for / by mindful movements



EYFA - European Youth for Action

***Written:*** by eyfa network & team

***Editorial:*** eyfa network & team

***Layout by:*** Cila Yakecã cilayakeca.com

***Illustration by:*** Ciel Incarnadine alchemicum.com

***Font:*** Dyslexie Font

***Project Coordination by:*** EYFA - European Youth for Action

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## ADDITIONAL SOCIAL MEDIA RESOURCES

We have gathered a few accounts we already follow and from which we have been constantly learning. We are very thankful for all the creators sharing their content, experiences and knowledge. If you know of other accounts we should definitely be following, please contact us at [eyfa@eyfa.org](mailto:eyfa@eyfa.org) and let's shape that list together!



