‘The Right to Invisibility’

- Emotionally Regulating Others

Disabled workers presented a wish that others in the sector had a better understanding of access and disability, so that their needs become centred in the process and are not singled out as unusual when raised.

Please note all documents have been written for screen reading software.

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Examples of The Right to Invisibility - Emotionally Regulating Others:

1. Yeah, which I guess there's a magic wand fix. There's just like… I want to be invisible sometimes. Yeah.

2. I wish people knew that can be quite isolating for people with like my experiences to be kind of singled out in that way and asked questions about the thing you're doing to feel more comfortable.

3. There are some things that I feel like someone shouldn't have to ask for that they should just be the norm.

4. You know there's a kind of insidious pressure to minimise your symptoms in that kind of situation which then means that when you get home you're wrecked. So you know what is it about the situation that makes you think you can't own your disability in a way that is acceptable to other people? And that kind of troubles me.

5. The magic wand fix could just be like understanding of like when my brain does things that the people in the room get it.

6. So sometimes I'll be struggling to keep up or understand things sometimes like, I mean… especially in like a rehearsal process or something where maybe they're flying through things, maybe sometimes I'm internally I'm panicking, but I don't always say anything about it or let anyone know because I don't want to be… I want to be a problem, so to speak.

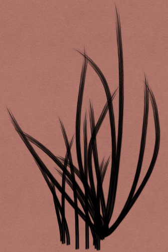
7. But it goes back to like, oh, hoping people have more empathy for your kind of like peculiar sort of needs.

Three main topics arose from participants responses that connected to the theme of 'A Right to Invisibility':

Topic 1: Normalising Access Requests and Measures

Topic 2: Understanding Communication/Cognition Differences

Topic 3: Acknowledging the Impact of Disabled Workers Extra Emotional Workload



Topic 1: Normalising Access Requests and Measures

1. Like asking for those things is reasonable like I understand that. But it’s just hard and it's hard to expect people to keep up with it or remember, or which I wouldn't expect them to necessarily, but I think constantly having to be like, hey, you know, I need this thing. I need this thing. I need this… saying that that comes a bit difficult I think.

2. I have acquired some ear plugs recently which are quite good and sort of filter out background noise a bit and it’s really been a game changer for me, to be able to put those in. But you know it’s not always an option. And also I don’t always want to, depending on the situation and how willing I am to be kind of open about my disability, I don’t always want to be visibly putting in ear plugs because I don’t want people to invite the question of like what am I doing? So yeah… all these little work arounds you have but then you have to like judge when is the right time to do them.

3. One of the biggest things I wish would change would be roads being flat and a better surface and all that jazz, you know to make it like actually physically accessible. Every building in the world being step free. But like that’s never going to happen.

4. I think I wish it were kind of woven into everything like most aspects, do you know what I mean. I wish there was a broader consciousness about it because I only tend to find it in very like enlightened kind of socially conscious individuals, which are oftentimes are quite like I think quite hardcore like sort of sort of like social justice warriors, you know what I mean and I wish it were more…

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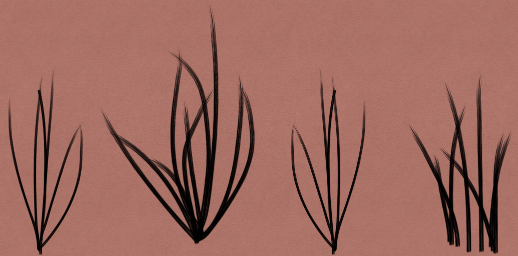
I wish everyone felt that way because I think a lot of people think it's bullshit and a lot of people don't bother. So, I wish it were more pervasive I think.

5. I guess just specifically the space holding, because it always felt very important when they… Because sometimes it will be written down in like a document or something that’s sent through to like tick the box but when they sincerely take a moment and take the time, I think it means a lot and it makes a big difference and it speaks to their empathy and their concern for you as an individual rather than like a box ticky technical thing.



Topic 2: Understanding Communication/Cognition Differences

1. Or like, If I'm in a room and I think something in my head and I know I want to say it out loud, but, I know that I shouldn't. I will make an audible gasp trying to hold back what I want to say. And sometimes that is the moment the director turns to me and goes okay [name of participant] what do you want to say? And I’m like, no, it's cool, please don't make me say it out loud because this is me stopping myself from saying it’. It's, you know, there’s obviously parts of that might be my anxiety not wanting to say, or sometimes it's like, no no in this situation, I know this is the wrong thing to say at this moment. So let me just gasp and move on.

2. I wish they knew how it affects my cognition because like I said sometimes when I'm interacting with people it seems… sometimes they can seem like I'm ignoring them like, when we’re in conversation, because I have to think extra hard about something or sometimes very simple tasks are just a little more complicated. And I wish they knew that and had a little more empathy because I think people are quick to be critical or lacking and understanding and that kind of hurts me sometimes because it's just compounds this messaging. I've internalised about not being good enough or not being smarter or what have you.

3. And sometimes that takes the form of me trying to contain myself in the room. And sometimes I'd like just to be left to be contained myself. Like, keep doing your thing I'll speak up if I really think that something's wrong.

4. It’s also like a way that I do signal that I've got things to say which, which I want to say, but it's like… it’s those ticks or those moments of restraint, where I don't know if that's being

particularly, like, well handled in the room where… And sometimes I'm just the worst that like if a director has like, said something and gone… if I said something to a director and they've gone ‘no', my I won't, I won't get rid of the note. I'll go back the next day with the same note and the director will go [name of participant] we've already said no to this.’ Okay, fine. I just thought I'd check it twice just in case. And that's just like the intricacies of my mind and the way that I have a relationship with text and the work we're making is that like I'm constantly analysing, constantly trying to find the best version of it.

5. Daily experience of my disabilities is (long pause) … a feeling of chaos. And (pause) that there is more happening inside me than my flesh is able to contain. And that those events and changing states often feel that they're in a confrontation with my ideas, ideals, dreams, desires, what I imagine, or plan/what my consciousness is trying to envision itself to be/how I identify myself and what I intend for my day… is often something that ends up becoming secondary to this embodied, um, conflict experience, conflicting experiences, and my disabilities often feel like different characters in Inside Out. That they're all the different conditions and they all have these different voices and traits and needs that are sometimes in languages that I understand, and sometimes I can’t translate what my body is really getting at.

Topic 3: Acknowledging the Impact of Disabled Workers Extra Emotional Workload

1. Yeah I do often feel like I’m managing other people’s emotions as well as my own and it’s actually like a really big source of stress for me at times. If there's like the energy of a room feels off because someone's in a bad mood and then I feel responsible for managing that and making them feel better and I think it's like you say it's because so much of the way it's addressed is about like, you’re affecting people.

2. There definitely been times where I've not asked something I need because I was too afraid, there were too many other people around, or I didn't want to be a problem or whatever the issue was. And then I've suffered the consequences of not getting what I need because I was like too scared to say something or I felt like I was gonna be a problem or a burden or whatever. So it can be really hard and it's also… there's a lot of frustration and fatigue I have associated with having to fight my own needs because it's something that I have to do a lot and have… and 9 times out of 10 going into a conversation about my needs it's gonna be a fight or an argument or at the very least I have to defend myself or explain myself and there are times where I’m just like ‘I’m so sick of doing this’, and then it passes because you know like I do my job for a reason and if I'm not gonna do it for myself and other people then who it is and I have that fight so that other people don't have to.
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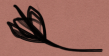
But having to defend it and prove it and you know it should just be accepted that like some people just need someone with them and that's just it. Or I need the radar key to your accessible bathroom please and that's just it you know.

3. What it's like to not be able to regulate your own emotions and how hard rejection sensitivity is because people don't realise what it's like to feel like literally the whole world hates you.

4. *On Access Riders/Access Notes* But yeah I still don’t always just send that by default because I have been met with again, often well meaning but actually kind of isolating responses when I’ve disclosed things. People again like asking lots of questions about it or kind of in the room sort of turning and being like [Name of Participant] ‘this’ in front of everyone and it’s like ‘cool’. Now everyone’s like: ‘why, why do they keep saying to [Name of Participant] specifically this information?’ It’s like okay I didn’t need you to single me out.



5. So yeah, how difficult day to day living is and how vulnerable it is to ask for care, to need care, to need a lot of care, to receive care and then, to also be infantilised, or fetishised or to be, treated like you then are in a position where you are not able to contribute or offer things. How restrictive it can be. And how lonely (pause) the experience of disability can be, and how confusing it can be to build a life with the competing demands of your inner and outer world.