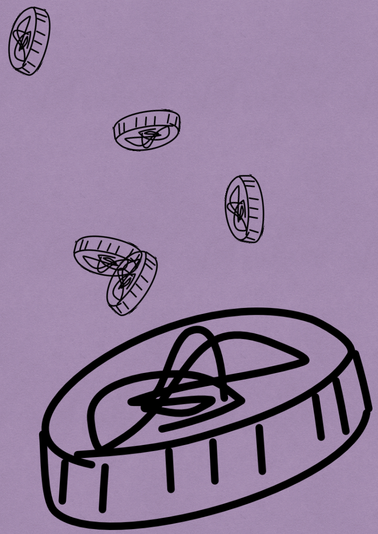
Disabled Costs

The Arts Workers highlighted that there was often an additional personal cost, as well as a financial cost to their disability.

Topic 1: Personal Cost of Disability

Topic 2: Cost of Disability

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



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Topic 1: Personal Cost of Disability

1. I find so much of my experience ends up with me performing either overwhelmed or unwellness so that people don't think that the days that I’m able to manage better, that I’m cured and therefore they don't need to give me care. And then, on those days I find myself, my inner protector is putting on a monotone or putting like a cloud above my head, but I'm actually feeling better so it happens as a way of trying to make sure my needs keep getting met. And so actually, I end up maintaining this depression that I'm not always feeling as a mask because I get scared or tired of the days where I am really bright and people are asking ‘we can give you more things to do while you you’re not sick’ and I’m still in so much pain and really exhausted. So, um, yeah, I wish there was a normal understanding of how difficult it can be sometimes to just live. Just staying alive and the majority of my life.

2. I went a different way where I underachieved and I didn't try and didn't do anything because that was safe. And it gave me control over the symptoms of my neurodivergence that I didn't feel like I had otherwise cause when I chose not to do homework, or I chose… I felt like I was taking agency or something do you know what I mean? Not consciously. This is all a reflection obviously. But I think that's the only way I felt okay.

3. Yeah I think that I think that seeing like wheelchair using performers in general makes me feel seen, makes me feel safe, makes me feel happy because I had to stop MT training because of my disabilities. It wasn't made accessible for me to continue training so to see other people

now be able to come up through the training that I couldn't have, and do it successfully, and end up on a stage makes me really happy. I mean it makes me sad as well but it makes me really happy because like I just I love seeing that like you know they didn't have to go through what I went through and like you know change is happening and stuff… So I guess it’s, it’s harder because aside from the fact that a lot of my disabilities are invisible, I've not necessarily seen like characters that specifically have the same disability as me. But I think like wheelchair using actors and mobility aid using actors and characters yeah that makes me really happy and also seeing disabled actors playing disabled characters.

4. I could train up there if the National Theatre want to. But like we are capable of doing those things, but also sometimes that becomes a barrier for us playing our own roles, Like, when you have that specific need to fulfil… what, what is it… what what does it add to your performance other than like, prestige at this point? I've gone a little bit off topic there, but like the idea that like… We have to train to, to meet the expectations of the industry in order to be able to have our own voice and usually that voice isn't written by us, which you can tell by the design of the show.

5. I didn't think I… I didn't have any belief that I was going to live to even to now really, but to like 40s or 50s or to old age. It’'s only in the very recent years, the last year or two I've had some breakthroughs with my suicidal crises and ideation, that I can see a future. And that, in and of itself (laugh) has got it’s own fears, and anxiety and despair and depression. Like okay, I'm here, but I, I never, I spent the majority of my life living like I wouldn't be. So I've got no plan for this with how to imagine that there’s going to be an elder (participant’s name). And how much grief there is in feeling behind, like working for so long in my life and never contributing

to a pension or anything because I kept planning to die. And so, then now I'm scared to be alive. And um.. Or destitute as an old person, and sick (laughs).

6. And I think it would have been nicer like when I was a kid/having more children aimed representation would be really nice so that kids grow up not having to for example quit their dreams because the world isn't made for them.

7. And that's been a whole dream, you know, even like [participants age] now and I think really only started doing like serious, like, emotional work, like two and a half years ago, probably on.
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And I'm grateful for, like, how far I've come in everything but.. yes, not easy. With things, things… just your internalised stuff. Don't you ever just.. And I think like everything, like in life, maybe like all my relationships and all my hopes and dreams and all my trajectory and everything sometimes at all feels like it's like balancing on the single point and all that pressure is just on top of me and kind of greatly digging and digging into me and just kind of taking into that sense.
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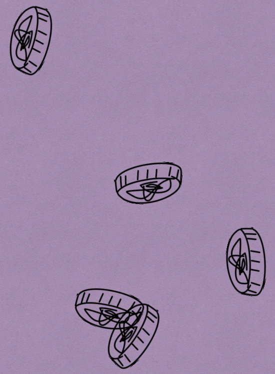
That you're not good enough, you're not, you know, you can just function, most of the time and like bigger things out, but… Yeah, they know it's not that bad really, but it's just sometimes that's what it feels like, but you know, good days and bad days, I guess.

Topic 2: Cost of Disability

Factors highlighted were:

Theme 1: Overall Cost of Disability

Theme 2: Disability Benefit



Theme 1: Overall Cost of Disability

1. Being disabled is so expensive! People don't understand how expensive it is and how much more expensive it is then like other people's lives.

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My wheelchair is absolutely useless and the reason I don't have one that is suited to my specifications is because the one that is suited to my specifications is upwards of £15,000 pounds. I don't have £15,000 so… like I got approved for a service dog last year. I couldn't go ahead with it because they wanted £15,000. I don't have £15000, and I can’t… I would love to get a puppy and train my own but I don't have the time, the ability or the energy to do that, so I need someone else to do it for me but someone else doing it for me costs £15000. But then there are also the things that people don't think about I like to call it the ADHD tax when you forget to return something so you just have to eat the costs even though you're not going to use the thing, when you buy food that sits in the fridge and then it goes off because you don't use it, when… I mean all of the impulse buys obviously.

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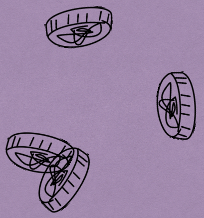
And then there's all of the things that should be free but aren’t and therefore we have to pay out for those as well. There's a lot of places where it's still not free for a carer or personal assistant or it's like half price or whatever and usually.. and I can't go to places on my own so if I want to drag a friend and they don't want to go I can't expect them to cover their ticket if they don't want to go.



2. I don’t like to generalise because everyones access needs are very different but percentage wise the most accessible seats are going to be the ones that are also the most expensive. Because it's going to be the centre aisle seats and it's going to be the front row of the dress circle and they are the most expensive places to sit and that’s not fair.

3. When I go to the theatre as an audience member, my access requirements would be an aisle seat, an essential companion, or possibly two.
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I’ll choose my seats based on my knowledge of the building so like if I know that there's seats that have extra leg room, it will always lead to a better experience if I go for that. It doesn't necessarily mean that I can't attend if I don't get extra leg room I will, there will be consequences that I then pay for late after not doing that if that makes sense.

4. Whatever you put your needs are the seats that you go for will then offer you options so you will be able to pay the like selling price of the seat if you want to because some people do and I think there's a lot of people especially older people who find the concept of being offered a discount insulting because like it's like you know you don't think I can pay full price just because I have needs. Which I think is just as important to acknowledge as what other generations might think. So they have you got the option to pay full price and then you've also got 2 or 3 other price band options including the cheapest seats in the theatre so they'll let you basically they'll offer you any price band you want to pay but they should at least be offering the cheapest seat in the theatre to assume that that's what you would go for if you could sit there which is great but a lot of other theatres don’t do that. There’s usually only about 4 seats in any given theatre that she can actually fit in.

5. There’s also another thing that people don't realise but I guess there's also a lot of access measures that I use myself, so it's not even necessarily something that I have to ask for or that I would say my access needs are, but it's things like all of the extras that I carry in my bag in case I need them and like choosing to like doing the research in advance and telling people in advance about certain things are kind of like access measures that I take for myself. Taking a mobility aid with me…

6. One of the biggest issues just everywhere in the world is this whole needing to provide proof of disability. It’s really insulting it's also a lot harder than one thinks it might be and most of the things that they ask for are mostly impossible to obtain and/or something you have to pay for which isn't okay and I don't think people realise that. Like you can't just waltz into your Doctor and get a letter like any medical note you have to pay for. Often they use, they allow, blue badge as proof now I do have a blue badge but the point is you still have to pay for that.
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But for people who don’t drive for example, imagine telling them they need to get a blue badge, and pay for one, and they aren’t even gonna use it. Obviously they love PIP which is a nightmare, even the nimbus access cards cost money.
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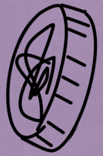
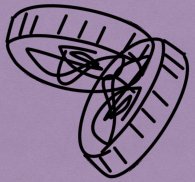
And also a lot of people getting a diagnosis is a privilege, a lot of people don't have a diagnosis and you can't prove a condition that you're not diagnosed with but that doesn't make their experience any less valid. I’m a massive massive advocate for self-diagnosis because I have had to self diagnose all of my conditions except for one which I didn't know I had before being able to actually fight for any form of anyone to listen to me. So I had to figure out for myself

that first and that takes a lot of hard work in and of itself. But for people to then tell you that it doesn't count because you haven't been diagnosed.

7. *On Wheelchairs:* I could come up with a thousand reasons and I did come up with a thousand reasons as to why me needing a new wheelchair is integral to my job, it's not to my job it's integral to my life, but I want them to pay for it so.





Theme 2: Disability Benefit

1. I used to do a lot of work with disability benefits and a lot of people would say they wanted it to be simpler because it's a really complicated system and actually I think it needs to be complicated and I think it's the same with access.

2. To get access to work you have to be earning like, whatever, there’s a minimum… there's a minimum you have to be earning, and it is, when you do the math, the minimum that you have to be earning is basically minimum wage on a full-time job. And the whole point of access to work and this is the argument that I've had over and over again, is that I can't do the hours that she's asking of me and earn the amount that she's asking of me until I have the support in place that I’m asking for and if I can't get the support until I do the hours then we're stuck in a loop aren’t we? Because she's the one who you know, they’re the people who want you off of their like government benefits and working and I'm like well give me the support and I will! I'm not trying to get all of this to then not work you know I love my job.

3. And I think finding a way to to make the system more responsive to, to folks needs. You know cause like I remember like years ago having… was really really depressed, and there was a lot of paranoia and then you would get a letter from the benefits agency saying, right this is what you've been entitled to, but if you've told any lies or whatever then we’re gonna come and find you and we're gonna take your money off you, and you know, you're left kind of **thinking** shit they’re after me. You know, and it's like there's no, there's no understanding of mental health conditions in particular with how these communications are affecting people and impacting

them. And there's always… the whole thing is rooted in suspicion that you're defrauding this, you know, the system.

4. I can't yeah I can't think of anything intended to support.. well I suppose my answer to that would be like the benefit system and the access work system because it does more harm than it does good.

5. I don't think we know how to fund equal access so our words are way way ahead of actions and words aren't anywhere near adequate to where they need to be but actions are way behind. So if you're serious about it then things like PIP would acknowledge not just the support you need to do any work, but the support you need to do the work that you want to do.

6. I mean it's never going to be like a wonderful affirming experience but the basic dichotomy is that you have a health condition that you spend your life trying to manage and trying to find positives in and trying to engage with constructively and a system that asks you to be as negative as possible about what you're not able to do in order to get money to support you and do the things that you want to be able to do. And it it feels like it's… they're like, two worlds that are not communicating with each other at all.

7. I think it's really complex and it's about negotiation and it's about discovering what you can and can't do and how that works in situations and how you enable everyone to rub alongside you as well.

8. *On access to work:* And I still have, like… I suppose freelance you can't really describe as a full-time job but I still work pretty much full-time alongside it because … But yeah I still work like pretty much full-time alongside it and to get access to work you have to be earning.