Disabled Time

Disabled arts workers highlighted issues relating to their experience of, relationship to, and use of, time.

Topic 1: They experienced time differently due to their Disability/Long-Term Illness/Neurodiversity.

Topic 2: That it took a period of additional time to manage the administration of their Disability/Long-Term Illness/Neurodiversity.

Topic 3: That they required time to manage the symptoms of their Disability/Long-Term Illness/Neurodiversity.

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

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Topic 1: They experienced time differently due to their Disability/Long-Term Illness/Neurodiversity.

1. I have no concept of the passage of time in a sane way. Sorry that’s probably not the right term to use but like (laughs)… My sense of time is very influx and everything feels like it’s taking forever or like it’s happening really quickly.

2. My mind kind of freezes and then my partner tends to be reactive so he'll get, he can get mad sometimes and then it becomes the whole thing and I just found it really unhelpful or people tend to think I’m being disrespectful or… attitude. And sometimes I feel like I'm being a bit dense do you know what I mean, like, sometimes I feel stupid. And I know I'm not stupid but like it's just everything feels very clunky, a lot of the time, you know what I mean.

3. Oh, my god, my fucking memory as well, Jesus. I can't remember anything because it's just chaos up there. Pretending to focus, pretending I’m paying attention when I'm not. So I know my mind is like off somewhere because I have to, I have to drift, do you know what I mean it has to go somewhere.

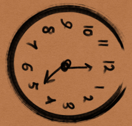
4. What the biggest issues are for me at the moment. Its’s sort of like executive functioning/productivity/motivation/like actually getting shit at done, is at a fairly low level at the moment. And I suppose that links to what I wish other people knew which is that like I'm not being lazy like I literally can't do it if my brain says no then it's no. And it's not as easy as just like ‘oh you

need to set up a better work environment ’, ‘you need to get off your phone’, ‘you need to…’, like it's not as easy as what people think the simple fixes are.

5. And so, all of that [personal admin] is happening and then that'll go on sometimes for, I don't know, two hours, an hour and a half, who knows? And as it goes on, then my anxiety builds as well. And I feel my day slipping away from me.

6. Like I, I know what the deal is like, I, you know, sometimes when I feel depressed and I feel anxious, it's because of this… because I didn't always know that it was associated with anxiety and depression, do you know what I mean? And I just thought, like scattered thoughts or like, you know, maybe diminished ability to like, function, whatever.

7. And yeah that changes on a day-to-day. My disability needs are often very dynamic and there are some days or periods of time where I’m unable to leave my house or I’m unable to leave my bed, or unable to even lift my head up or open my eyes or to, it's... And then there are days or hours or seasons where I’m able to be really active and can dance, really (pause)... the word I’m wanting to use is, athletically and I can think in lots of different realms or time travel and it’s also this experience of my disability where I can also have extra sensory experiences which can feel like a gift. But also be very distracting and can lead to me feeling simultaneously closer to other beings but also like I'm behind a glass wall.



Topic 2: That it took a period of additional time to manage the administration of their Disability/ Long-Term Illness/Neurodiversity.

1. And you know for the people and I'm including myself in this because I did get PIP in the end but it took me 6 years, for the people who get to the end of the process with… successfully. It is worth it but it's only worth it in hindsight because you go through… most people, like 95% of people go through all of that and don't even get anything at the end of it. And it's (pause) gruelling and it's traumatic and it is *really* hard. And you know there's a lot of people that think that being on disability benefits means that you sit on a couch and eat biscuits all day, and it couldn't be further from the truth like it's such hard work even just to get it.

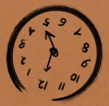
2. How hard it is to make plans as a disabled person. It's not just a case of finding a date that we're all free and booking the thing and doing the thing. I have to do all the research in advance to figure out if I can get in or if I can't get in then how am I going to mitigate that. I have to literally calculate my spoons backwards to work out if I'm gonna have enough energy to do all the things and if I'm not going to be able to use my chair then am I going to have enough energy to do the things without my chair. I have to like contact people in advance and let them know what my needs are in and what to do if I pass out and all of this you know medical stuff. I have to think about what I'm gonna pack like I can't just grab my handbag and leave. I have to work out what supplies I'm gonna need have I bought enough ice packs in case

I faint. Have I got enough snacks, have I got enough salt, have I… I don't know how I got all the supports that I might need in case something dislocates. Like it's hard bloody work no wonder I have no energy (laughs).

3. I’m like extremely capable of sorting myself out if I need to I shouldn’t have to, but if I have to I just I can and I’ll be exhausted and I’ll have to crash out for a month after I finish the job, but if that's what it takes, that’s what it takes.

4. I'm really really lucky that I have my mom to support me because after arguing with this woman over email for like 2 weeks I just copied my mom in and I was like I can't deal with this anymore and I let my mom argue with her because… anyway. And you know for the people and I’m including myself in this because I did get PIP in the end but it took me 6 years, for the people who get to the end of the process with… successfully. It is worth it but it's only worth it in hindsight because you go through… most people, like 95% of people go through all of that and don't even get anything at the end of it.

5. *On being a carer:* And I think, I think also having dealt with my mother and her like emotional disregulation or inability to like self-soothe and things like that. You end up going into a parenting role early, just to manage the chaos and manage them. And you do so much of that that you don’t have to think about yourself so much and your problems kind of get pushed to the side or pushed to the back burner.



6. So then you’re kind of monitoring yourself, you're monitoring the situation, you're monitoring other people, and then you're expected to be the interface between all those things as well. I'm just moaning now aren’t I? (Laughs).

Topic 3: That they required time to manage the symptoms of their Disability/Long-Term Illness/ Neurodiversity.

1. One of my conditions makes me really dizzy and I have episodes of fainting, but I suppose I wouldn't like I wouldn't faint every (day) well there are periods in my life where I have fainted every single day and then I go chunks of time where I don't faint at all but I'll still experience like the other symptoms of that condition it just depends really. The weather is the massive impact, if it's cold then I'm in pain more and if it's hot then I faint more (laughs) so I can't really win.

2. Chronic Fatigue is another big one, so again it'll be, energy levels will fluctuate. At the moment I'm going through quite a big flare of chronic fatigue, so having the energy to do, like. even, leave the house would constitute like a good day. You can't rely on how you're going to be tomorrow. Just because you're feeling something at the moment doesn't mean you're… so it's very difficult planning is really difficult and anything that involves a change in routine or going somewhere else.

3. I think for me it's like the key thing is that it's different every day and I don't know how it's going to affect me at any moment.

4. So I've then had a long period of not working. And when you tot it up, I think I've had like 7 years off work in total over the last twenty years. So basically 1 in 3 years I've not been at work and therefore I haven't experienced any discrimination (laughs) from the workplace because I've not been able to be in it.

5. The big one is yes it is different every day, so most of my conditions are fluctuating., […] most of my conditions revolve around chronic pain so it really just depends on how much my body hates me that day as to how much pain I'm going to be in.'

6. One of the things I often wish people knew, and this is not like a you know woe is me feel sorry for me, it's just a fact, it's not a 'either I'm not in pain or I am in pain', I'm always in pain… permanently and it's just, I don't have like good days and bad days, I have like bad days and worse days. So like the normal level is what I have learnt to cope with and that's just how it is most days, and I then I've got days where it just gets worse.

7. So it really just depends on how much my body hates me that day as to how much pain I'm going to be in.

8. Any emotional response is very very heightened and can be very time consuming because then I have to kind of.. notice what I'm doing, and then get myself to a state of you know

responding in a more sensible way and that can take time. So yeah little things can really like set back my day and make everything take longer.

9. There’s lots of coping mechanisms that I have to the way that my brain functions. I guess like if, if there was something I wanted people to understand about my disability that they don’t maybe is that sometimes I'm already making a load of provisions for everyone else. So when it seems like I'm being unreasonable or not having done enough work it's because I’m already putting a lot of work in and this is the result you get.

10. And just the monitoring itself is really tedious, and your energy levels are kind of linked to that.

11. It takes me a long time to get going in the mornings. If I have to get up for work earlier than I’m used to… it’s a struggle… if you want me to start work at 7am and it’s an hour commute I’m not getting up at 5:30 I’m getting up at.

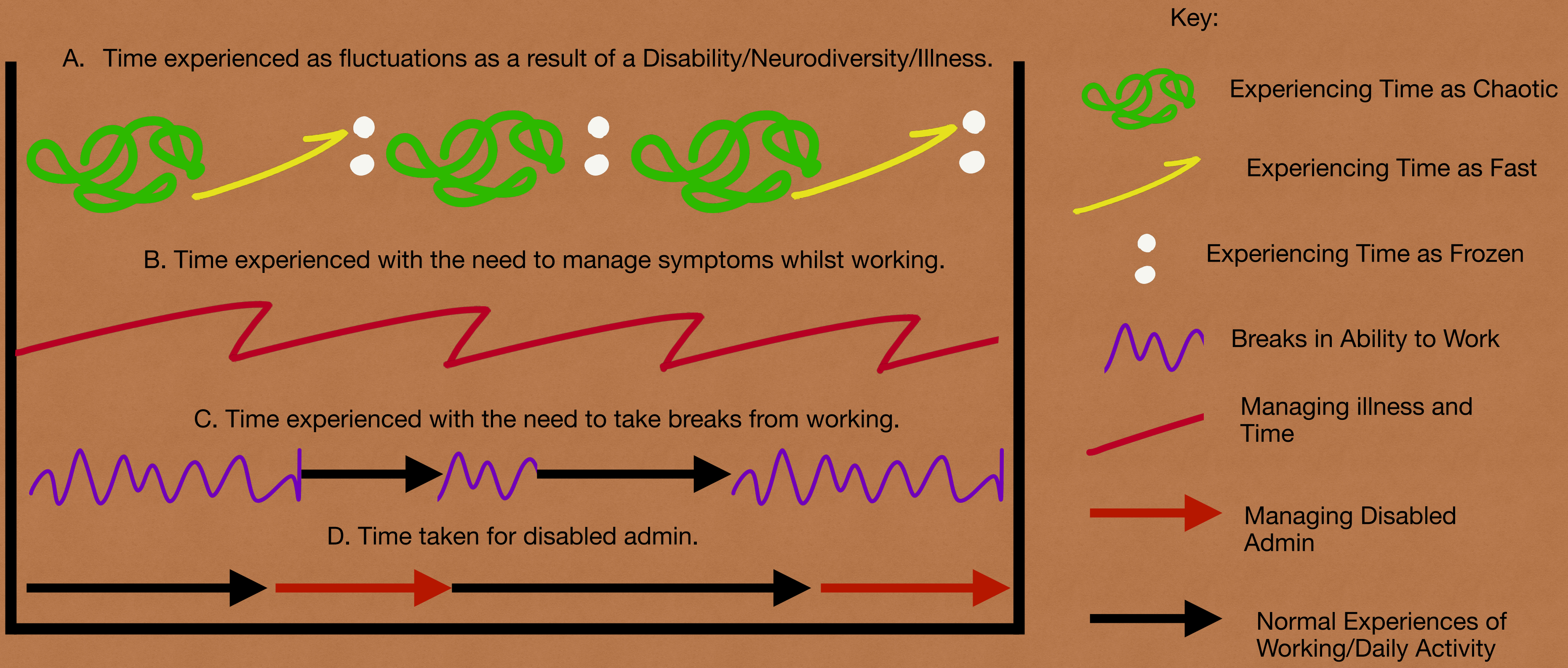
12. I think it bothers me because I think people tend to think sometimes I thought but like oh well, it's because you're lazy, you're just organised or you're just not good at anything. When sometimes it's just a struggle to figure out what what comes next.

13. I wish... I wish people knew how much pain I'm in all the time emotionally and physically.

(For Screen Readers: The two next pages contain images of arrows or lines indicated different experiences of time in relation to normal experiences of time. There are no other images in this document. Themes highlighted are: 1. Experiencing time as Chaotic Time. 2. Experiencing time as Fast. 3. Experiencing Time as Frozen. 4. Breaks in ability to work. 5. Managing illness and time. 5. Managing Disabled Admin)

DISABILITY TIME GRAPH

Whilst we all experience fluctuations in time, Disabled participants reported issues with handling greater fluctuations of work in relation to time. That the workplaces lack of recognition of fluctuations in time provided issues for them in artistic funding and artistic work.



A. Time experienced as fluctuations as a result of a Disability/Neurodiversity/Illness.

B. Time experienced with the need to manage symptoms whilst working.

C. Time experienced with the need to take breaks from working.

D. Time taken for disabled admin.

Key:

Experiencing Time as Chaotic

Experiencing Time as Fast

Experiencing Time as Frozen

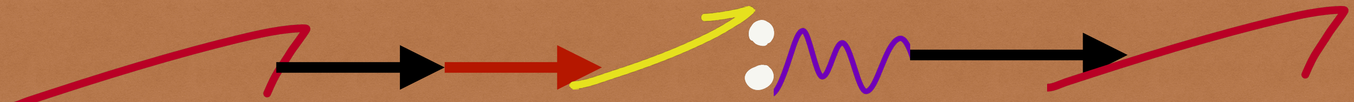
Breaks in Ability to Work

Managing illness and Time

Managing Disabled Admin

Normal Experiences of Working/Daily Activity

More ‘Normative’ Experiences of Time.



An example of a Disabled Experience of