Diagnosis

Arts Workers indicated a strong relationship to receiving diagnosis and revealing it in a working environment. Topics covered by participants were:

Topic 1: Masking Symptoms

Topic 2: Receiving Diagnoses

Topic 3: Revealing a Diagnosis

Topic 4: Discussing Diagnoses in a Public Space

Topic 5: Awareness of Other Diagnoses in Arts Work

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

Funded by UK Government

Supported using public funding by ARTS COUNCIL ENGLAND

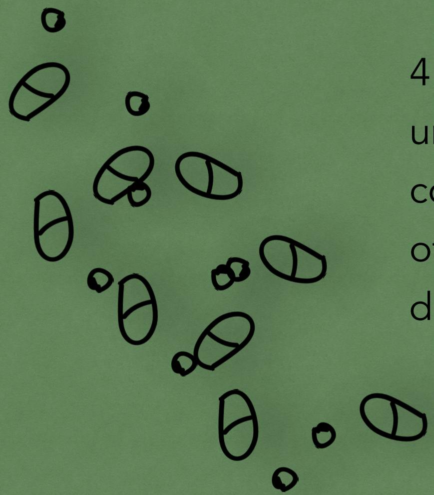
Topic 1: Masking Symptoms

1. I think this is a really hard one because I don't really know who I am without masking. That's not something that I've really worked out yet.

2. The reason that I know I'm masking is how I feel afterwards. So if it's been a good day and I've just felt like that and then afterwards I've still got energy and enthusiasm, and passion, but if I leave and I'm like, ‘I am wrecked’, then it’s like an indicator of how much you've had to pretend in that situation and therefore how much energy you’ve got left for the rest of the day.

3. Sometimes, I don't feel, I don't know, like I am playing a character but sometimes I don't feel like I’m pretending necessarily, and it's like, taking the parts of myself I’m not comfortable with and kind of like elevating them and then pushing out all the good stuff and all the evidence of like when I am competent, when I am capable and all that kind of like gets put in the background a little bit.

4. God it is just kind of lying a lot of the time isn't it? I think it's really pretending I've understood, pretending I'm more organised than I am pretending… I’ll pretend to be competent and not to say I'm not competent but like I’ll pretend to feel competent. I think a lot of times especially in, like, new work environments or sometimes we'll have a wave of like no, I don't like how I feel, I don't like this. You are going to treat me differently - la la la.



5. I think if I’m masking I try and stand still, I try and like really… but all I’m doing is like focus, focus, focus, focus, look, look, look, look, don’t move, don’t look weird, don’t look weird. I'm not even listening to what's going on. I don't know what's going on but I just know I’m self policing so much. That's where all my mental energy is going and I think the thing is when I get comfortable which is lovely. And you know, the work can get done.

6. Okay so for me the term masking is about performing social signals that don’t come to me naturally. Because everybody learns social signals but for a lot of people I think they become unconscious. And for me I do have to think about it. I'm quite aware of what my face is doing, and quite aware of what my voice is doing when I talk. And for me not masking just means I stop thinking about it, and I’ve done it in front of people and seen them be very like: ‘That’s weird!’ Even if they’re cool people who are nice and like I warned them.

7. So yeah, that's kind of what I mean about masking is losing the energy and choosing actively to stop trying… because I don't, I don't choose to mask at this point. It's so ingrained in me that I only choose to not.

8. I think one of the things I'm learning at the moment is, how much masking I do of how I'm really doing. So, I will make it through a meeting and then fall-over rather than fall-over halfway through the meeting so. And that's not other people's fault, you know, it's me trying to manage

in the situation but realising that because you're not communicating what it’s costing you people don't appreciate that that's not… maybe not a good thing to be asking or expecting and then because you did it last time they expect you can do it next time. And again the thing with the variable condition is that means nothing.

9. Masking is something that I meditate on often. And to me it is something physical, emotional and metaphysical. It is the real… the mask is real and we’re all wearing masks, all the time.

+

I meditate on the fact that the word person comes from persona as in like a character in a play. And so, even pretending that we're always even people is a joke, you know? Because I often don't feel like a person. And so a mask is actually for me, the outline or form that I cling to, to pretend, that I am a rigid fixed structure of a being so that I can communicate that this is what this unit of being is to another being. And so they feel safe that I am something that they can conceive of and see.

10. But the mask is always changing and I'm always changing, but in that moment that is the picture that they need to feel that we can interact. And it's also something that I also need to project. To feel that it’s acceptable to interact.

11. The times where I feel that I am not masking, I don’t look like…. that's what I'm doing now. I probably wouldn't do this as often as I need to do it and I forget that often I need to close my

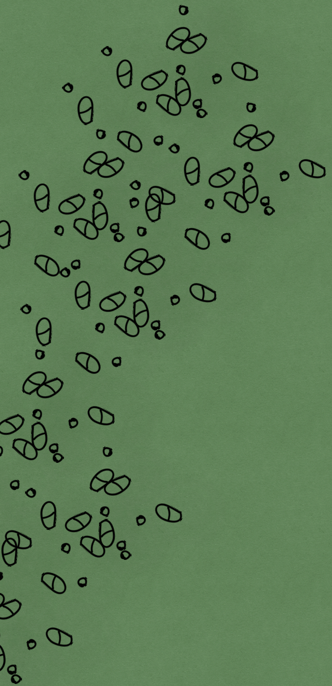
eyes and use my hands like a conductor in order to be able to think. And most spaces, they don't do this.
+
And then I actually shut down. Because I'm shutting my own thought process. That feels natural to me in that moment.

13. When I have a mask when it feels like something that is imposed. And I feel that It's harder to breathe underneath it.

14. Masking can be useful. Masquerade in lots of cultures including Igbo is a way of channelling, you know, spirits and energies that can support you to do things that you otherwise would not be able to do. And, and so sometimes it can be a protective software, sometimes it can be hardware, sometimes it can be a disguise, and sometimes it can enable you to become… access a part of yourself, or or something other, beyond yourself that enables you to do things that in your current form you can't do.

15. So I think that’s important to say because in so much of the process of masking and unmasking I’ve been really focused on the feeling of being suffocated, which is true, but I also have been thinking about how I connect masking with drag and and how when I transform and create these other characters that I'm definitely able to access parts of my selves and beings actually that exists that are beyond me, but then within me that I as (name) would find difficult to access otherwise. It can be a curse but also a type of magic.

Topic 2: Receiving and Experiencing Diagnoses

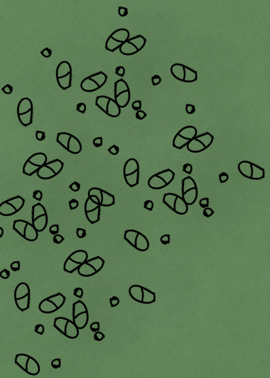


1. Another thing I wish people knew, how hard it is getting I mean how hard it is getting anything but how like…. you can tell people to the ends of the earth but they will never truly understand how hard it is to get medical help, how hard it is to get diagnoses, how hard it is to get benefits, any of the above.

2. I have disclosed to you that my diagnosis is Borderline Personality Disorder but I don’t actually identify with that diagnosis. I did at first, at first it was really useful to me because I could access information, I could access therapy which has evidence behind it that it helps, and it did help.
+
It has become more and more [clear], in my opinion, that Borderline Personality Disorder/EUPD is what we call autism in women who have been socialised or traumatised into presenting differently.

3. Yeah, cause I'm coming kind of late to the party in terms of I only got diagnosed 4 years ago, but it kind of made sense of the 20 years previous. So it's been a… it's been a slow one.

4. Yeah, yeah. I had a lot of medical issues. I'm pretty sure you know that when I was younger and it's like an ongoing, chronic condition. But there were times when like my body even when I was older wouldn't work for me because of it. Where I couldn't function properly, and I

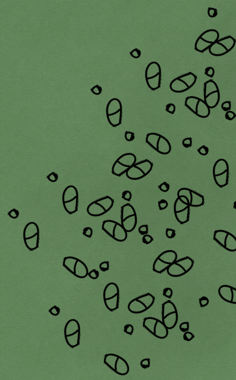


became quite ill or didn't even have the stamina to get through my day and it just compounded the mental complications as well, because they would interact.

5. Obviously, on a page my access rider is something I'm still working out - how to translate myself to the working world and the way that it is now. I was far more able to do this before I realised… I got diagnosed that I was autistic and ADHD, I found masking or translating or code switching, all of the above, far easier than I do now, and actually, some of the codes that I had learned that took me through my work life up until now, I seem to have lost my language books in and… so things that I do that, I'm like ‘this makes sense to me, this is the way that my mind speaks’.   Has taken me a while to understand how that has been received by neurotypical or allistic people.

6. And actually like, DBT, Dialectical Behavioural Therapy is offered to autistic people now because miraculously this thing which was developed specifically for BPD also works for autism, it’s almost as if there’s a spectrum for neurodivergence and we’ve just said, okay well difficult women are this and clever boys are that.

7. *On ME and Fibromyalgia:* The way they present in my body are so different and they are distinct voices.



Topic 3: Revealing a Diagnosis

1. It really depends on the context. It really depends on… I mean, in terms of my access rider, I have disclosed my conditions on that and I'm changing it all the time based on my experiences of discrimination. And I'm deciding now to also consider whether… when I share it and if I share it at all.

2. *On revealing a Borderline Personality Disorder to another person with Borderline Personality Disorder:* And usually yeah it goes around to like 'yeah I don't really agree with it though'. Pretty much everyone says that (laughing).

3. I think more and more I will start discerning when I feel comfortable to share it and for it to be used as a mutual reference document, and when I feel like, I just need to pick something from it, and share, because I don't feel comfortable disclosing my disability at work. I often don't have a choice because so often I am just stimming like a motherfucker or I'm wearing my Irlen Glasses or I've got my stick and I may need them. But actually a lot more recently, as I have had a very unusual couple of years for me of big gaps where I haven't been working. It's just shifted my relationship with myself, my self-esteem, my sense of security, and my relationship to work, such that I now find… the other day I saw myself going to an audition and I left my stick at home and I needed it and I and I knew it was because I didn't want to be discriminated against (laughs). And actually, then I just had a really hard time walking up the

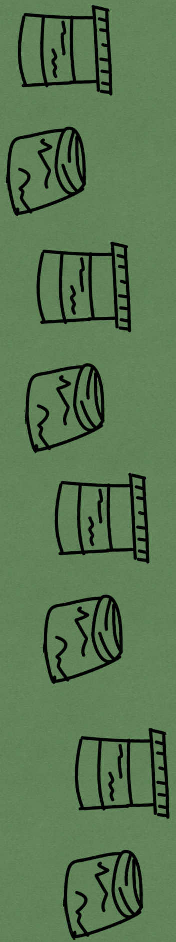
stairs. And it was a conscious choice. So yeah, I think I do hide, sometimes subconsciously, but more consciously now than I did before.

4. There’s a reason that I told my psychiatrist to never put my diagnosis in any letters because that means my GP doesn’t know I have it, and doesn’t have it on their records. Because I didn’t want the GP to see Borderline Personality Disorder any time I come in with an illness for the rest of my life and discount my experiences. The stigma is so out of control against BPD specifically in the medical community, it’s awful.

5. We all have a right to medical privacy. I’m pretty happy to disclose to people the fact that I’m neurodivergent, the fact that I have disabilities. And I’m quite happy to say things which are relevant information that might be useful. But that’s on my terms.

6. It depends who I’m working with. Yes if I'm surrounded by other disabled artists, if I'm working with an inclusive theatre company or you know other disabled artists but if I'm working with like an entirely non-disabled group, very much less so. Also depends on the stakes so like when I'm working with a tiny company on a little fringe show then I don't mind necessarily saying, especially if they're kind of around my age, and kind of you know seem to be trustworthy. But the closer I get to more high-stakes you know West End and stuff like that, I'm very very wary of what I say because I don't trust that I won't lose out on opportunities and I think that although it is technically illegal to discriminate to not give someone a job based on disability, it's also far too easy to find excuses or give reasons or find the reasons even if that's not what they mean. And are there have been times in the past where I haven't gotten a job

and they've given me whatever reason they've given me and I just, I don’t believe that this are the actual reasons but I don't have any proof and therefore there's nothing you can do about it, cause you can't prove that their discriminating. So yeah I think the answer is it depends on who I'm around.



7. Interviewer: Do you feel comfortable to speak about or disclose your disability in performance spaces either during work and social discussions or with other people as say, for example, in an arts venue.
+
Yeah. (Laughs) There you go.
Interviewer: And disabled spaces as well?
Yeah. Yeah. No. I've just made a choice that I want to talk about it because I think folk don’t and yeah, it helps.

8. Interviewer: Do you feel comfortable to speak about or disclose your disability in performance spaces…
+
No.
I don't I actually don’t, no.
I don't know, I can mention it like casually in conversation and stuff with other like peers. But no I don't. I don't like it. I don't I don't like how it feels. I think it feels a bit… It feels a bit too vulnerable for me to say in front of a crowd and I think it goes back to like managing the

attention that I received.

+

Yeah yeah, I think I… I think I feel… I think I feel shame. I think feel shame sort of. Yeah I do and even that's kind of hard to say to you and I could say anything to you really.
I'd feel shame about it, I wouldn't like… and because I like to think that, like, I don't care what people think, but I do, I do.

+

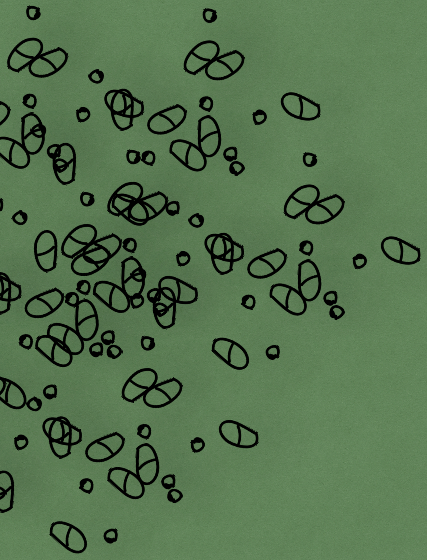
And maybe not all the time and maybe not forever and maybe not every day to whatever like it varies, you know what I mean?

+

Sometimes, maybe I feel like I'm faking it or not very good at, or I'm just trying to be (pause) myself. Like I'm trying to be a version of myself I guess, and that is acceptable. Which implicitly kind of means there's parts of myself that I don't find acceptable and you know not wanting to talk about disability.

+

Yeah, I think inherently there's something I find unacceptable about it and therefore I feel shame.

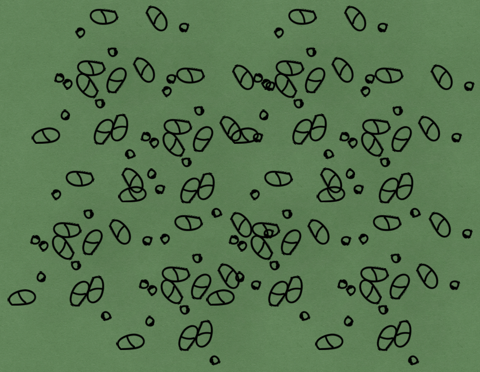


9. I don't hide it because, it has become part of the brand I market myself on, which (pause) I don't know if I think is a good or bad thing. It’s just what gets me the work I need. Because I do fulfil, a requirement that theatres are looking for in terms of both neurodivergency and gender

fun. And, I think, because they're quite invisible until you actually work with me and then it becomes like blindingly obvious… those labels are real or really important for me to keep ramming into people's heads that like, this is what I've got before you choose to work with me. Or, you know, not that, that should change their decision, but it should impact how they think about that process and how they think about engaging with me? You know, I think they should always engage with people in the best way. But in this industry, that is not kind of the standard. It's very hard like it's very tough and very competitive. And I think that those labels sometimes we'll just let them go 'okay, normal tactics might not be the best here'.

10. I am happy to say I'm disabled. Leave it at that. I have on occasion said I'm neurodivergent. But less so I usually keep it very vague I'll say like I'm a disabled performer. Or I'll say I have an invisible disability and I usually won't go, that's about as far as I would ever go in kind of a room sort of people.

11. It was more of a supportive presence than a full on facilitation, so I just sent a paragraph of things that I thought would be supportive and used it, the access rider, for me as a reference document, rather than send the whole thing.



Topic 4: Discussing Diagnoses in a Public Space

1. I do not generally voice it to a room… if I’m going to say it it will be in a conversation with a certain person who I have decided to speak to it about, or in an email or something in a written format ahead of time. I wouldn’t ever in a group sort of rehearsal or in an interview or something just kind of bring it up.

2. Interviewer: Do you feel comfortable speaking about it in disabled spaces, so that could be like an art space, or it could be like a medical setting?
+
No. Also no.
I don't think mine is… as bad as other peoples, I think I've had a pretty easy go of it. Relatively. And I can function. So I feel a bit, I feel that silly, if I'm being honest, because I think I encounter people that have like much more severe situations.
+
And yeah again, if it's casual, then yeah, I'm fine. But I think sometimes when people are like oh well it's you know, it's disrupted my whole life and I'm on this medication and that medication lalala. I mean it's been disruptive to my life but like I've made adaptations and I make it work, you know what I mean?
+

So yeah, I think, I think it’s… I feel uncomfortable trying to be a part of it or be a part of something when it's worse for others. And I know the logic behind that is flawed completely but… (pause) I don't think I don't think I've accepted it, I don't think I’ve accepted it. I think I’ve struggled against it forever even… And yeah, it's funny because you don't know what's going on like even as a child like, especially as a child. You don't know what's going on.

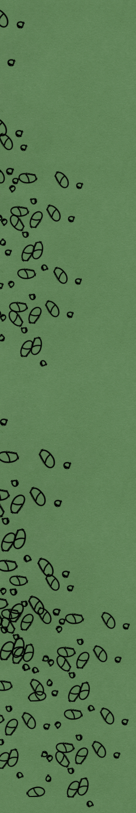
3. Interviewer: Do you feel comfortable speaking about it (being a carer) in disabled spaces, so that could be like an arts space, or it could be like a medical setting?
+
Do I feel comfortable bringing it up? No.
I think a lot of it goes, it goes back to the attention thing and feeling a bit exposed, I think there's some things that feel way too vulnerable for me.
+
So, like, I can reference you know, having a difficult relationship with my mother sometimes, but I think the specifics of it, having to play caretaker, having to cope with addiction and the emotional issues… (pause)
+
It's a lot. And I think, I don't want to give people like a sob story. Do you know what I mean? Like close friends. Obviously, I can share that with, but I think, I think once it becomes a group… (pause)

4. No, no, it's too vulnerable. And because it was my mother, like it turns into, like, it stirs up all the feelings about her, and our relationship and stuff like that. That like, I've only kind of recently felt more peace about and like understanding with and it kind of stirs it up in a way that like okay fine, maybe they're not totally resolved, but like will they ever be, do you know what I mean? I think sometimes it's best for me just to like, make the peace that I can and carry on. And then I'm always thinking well, you know, people have like crackheads for parents and things like that and I didn't, you know, it wasn't that bad.

Topic 5: Awareness of other Diagnoses in Arts Work

1. I had never met another person who had POTTS until I went to my second drama school and it was a major coincidence that there were 4 of us in the same year group and it was so lovely. Because I had never met anyone who had it before.

3. I can not think of anyone who is public about a diagnosis of BPD. I can't think of anyone. The most public person I can think of it is me because I have actually put it online before. And I have since chosen not to. (Pause) Because I no longer associate myself with that diagnosis.



4. People with diagnoses of autism, I have met a lot more people who are public about that diagnosis.

5. I know one or two other people who have said to me oh yeah me too, but as far I can remember I really do mean one or two… as far as I can remember each of the people I can think of I said it first. So I felt comfortable enough with that person, and I think that I'm particularly quite… more willing, and I'm *not* very open about it. But I think even for somebody as un-open about it as me I'm probably more so than other people.

6. Interviewer: Do you know other people working in the arts with the same disability or illness as you have, they disclosed it publicly and how many?

+

Yes. Oh my god. Oh my god. Yeah yeah. Several. Some of them yes and some of them, they're like, they know they have it, but they haven't been like, professionally diagnosed or they have been professionally diagnosed, but not medicated. And then some of them, I'm like, I've diagnosed you. So yeah, I know, I know a couple but oh yeah, but I don't think they have an awareness around it…

7. Uh, yes, I have come across lots of other neurodivergent or autistic creatives. Sometimes, I don't know who is actively labelled outside of the spaces I operate in. I do. It's like just part of my practise that I go here are my labels at the very start at the process. Like when I apply to something, or when I advertise myself. I use those as kind of like signifiers of who I am.

8. I think I know a lot of people who are now actively identifying more than they used to. Or people with not necessarily my condition but other conditions that I'm like… people who who've gotten into the industry through hard work, and, battling past their barriers without getting the support they need, starting to go: 'Actually, okay, now I'm here I feel safe to start saying, here are my conditions, I need these provisions'. Which isn't how I think the industry should work. But it is a pattern I've seen where some people just don't want to be a problem. And then get to a point where they feel that they have earned enough respect to get to ask for things. Which is not my experience because I'm just demanding. Or no, I just I like to stand up for what I've got and what I want and what I believe in. So I will do my best to make it known

what I require in order to do my best work because if they want my best work, these are the things I need and I would like to do my best work for those people.

+

Just how many of the top of your head is just If you can think people that I have interacted with and know our working, we know it's a rough number so it doesn't have to be perfect.
In Wales. Five. Yep. Maybe I'm going over the top. Yeah, I'll say five.

9. *On disclosing multiple diagnoses:* I know… I mean I definitely know of one person and as far as I know they haven't disclosed it publicly but they like to drop hints.

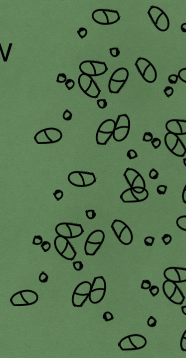
10. I do a lot of work with disabled and inclusive theatre companies because that is just where I'm at my happiest so I have met quite a lot of people that have like one of you know matching disabilities or whatever. Generally it's not publicly known. I think it's the same as me, it's not like publicly disclosed but it's not a secret, it's just that it's never like happened… I don't I don't feel the need to… I mean I suppose I never like shy away from telling anyone like it's not a secret at all I just don't need to like scream it all over my social media.

11. I think it's important to me that it's noted that because of the fact that I surround myself with other disabled artists my number is not going to reflect like you know people aren't… I don't want people to see that number and be like oh there's loads of disabled artists who are being involved like being brought into the arts because that's not true it's just because of the population of people I my surround myself with, but I suppose… my guess would be like 15/20.

12. I know more folk who are bisexual than bipolar and that's kind of weird when you look at the stats. I mean I know in terms of people that I actually know there's one other person I know is Bipolar and working in the arts.
+
But there's a bunch of more famous folk, who’ve come out and said they’re bipolar, and that's helpful because they're working in the arts, but I don't know them.

13. Interviewer: Have you ever seen someone play or write your disability who has your disability?
+
I don't know. (Long pause) Yeah, I don't I don't know that I have.
+
Interviewer: How many famous people?
I can think of six or seven, just the top of my head.

14. You’re the only person that I know that works for the arts that has fibromyalgia and has disclosed that to me? I know a few other people who are saying more that they either have autism or ADHD or think they have autism or ADHD as a kind of self-diagnosed thing. Very few of these people that are saying that are public about it. And then I would say… I know quite a few people who have CPTSD, Depression, Anxiety, Disordered Eating, Body Dysmorphia things… that I would put in the “Mental Health” bracket. That's the thing that is the least



disclosed publicly. Even when it’s such a core part of many of these people's works or even very clearly semi-autobiographical pieces, it's still something that is not really disclosed so much. It's still a… lots of shame around that.