

Transcript: The Social Model of Disability + 'Unmasking' poem

Presentation by Tom Juniper at The Open Road Carnival Conference (North), 12th March 2022. Hosted by Callaloo Carnival Arts

[Clare]

It gives me incredible pleasure to introduce Tom Juniper to talk about the Social Model of Disability and its impacts and particularly around autism and the impact of that so thank you again for joining us today.

[Tom]

Thank you so much for having me it's a real honour to be here, it's also quite a surprise! I was at work yesterday and the wonderful Marina Poppa messaged me and asked if I would like to come speak to you about the Social Model of Disability about my experience as an autistic person and a performer - oh and if I could link in my experience as a blue devil that would be great, oh and by the way it's tomorrow morning!

So here I am and I don't know how much you've heard about autistic people but that might sound like the last thing someone like me would want to do because autistic people, apparently, need order and routine and we can't cope with loud noises or chaotic environments and we hate changes of plans because of our 'tragic condition'.

We could never enjoy something like Carnival much less give an impromptu talk to a bunch of strangers and friends and that's basically the Medical Model (of Disability) at work.

The medical model is the idea that disabled people can't do certain things because they're 'too disabled' and 'it's a shame, but what can be done?' and I don't really like the medical model.

Being autistic doesn't actually disable me at all, being forced to do things in a way that doesn't work for me or else not do them at all that's what disables me so the idea that we don't have to do things the way we've always done them just because we've always done them that way, we can disrupt those old habits, we can find better fairer more inclusive ways of functioning as a society and that's why we call it the social model of disability that speaks to me a lot more than the medical model and that applies to lots of different things.

It's how we design our buildings, how we structure our work days and it's how we celebrate Carnival as well so do we do it the way it's always been done and blame those who can't access our events for being 'too disabled to cope'? Or do we find new things do we do things in sorry, do we do new things in new ways that are more inclusive for everyone but before I go any further I should probably explain the blue devil thing that Marina asked me to include.

So many years ago I was part of a community chorus for a show by the theatre company 'Told by an Idiot' and the dance company 'Nitro' and it was called 'The Evocation of Papa Mas' and it was a very surreal play based on Trinidadian Carnival tradition so as the community chorus we got to work with carnival performers and choreographers and designers and they transformed us into skeletons, pitchy patchy birds, policemen and blue devils and because I'd said on the form I quite like wearing body paint I immediately qualified as a blue devil.

Theatre and performance have always been magical to me being allowed to clown around in a dedicated space for clowning around and make people laugh on purpose instead of by accident - that's hugely liberating and doing this project I discovered a secret about Carnival that I hadn't known before - the blue devils the jab jabs rules don't apply to them, the jab jabs make their own rules.

And I was a shy awkward person who hadn't really come into my own I didn't know then that I was autistic, I didn't know that I was trans, I was stifled by trying very hard and not very successfully to be a neurotypical cis woman. That was the hardest role I ever played in my life so being a genderless, mischievous demon covered in blue paint instead that was a holiday, that was amazing!

And I can't speak for all autistic people but for me loud music and busy streets or a busy stage don't bother me as long as you're not expecting me to make small talk and be 'polite' at the same time.

If it does get too loud that's what earplugs are for, if I do get overwhelmed that's when I take a break - I can adapt and a truly inclusive space can adapt around me. Leaving behind the scriptures of concept 'polite conversation' and unwritten rules that I can't really decipher and instead entering an environment where for a while all rules are laid aside and everyone can be their own true, outrageous selves as far as I'm concerned that sounds like autistic heaven.

One thing autistic people are really, really good at is what we call masking. In carnival terms I'd describe that as the most boring, frustrating version possible of playing mas we put on our costumes - uncomfortable work clothes that scratch our skin.

Instead of dancing we stop our hands from flapping our feet from tapping, we hold our faces in 'normal' expressions we make small talk, we try to fit in - we may get quite good at it but it's not fun.

For me at least what makes my daily life more difficult is having to mask, to have to fit myself into 'the way things have always been done', to not disrupt, to 'behave appropriately', to be the opposite of a blue devil.

In environments where difference and diversity are celebrated, like Carnival, ironically we don't need our masks, well, we might need the Covid ones!

Carnival I think is very like the Social Model of Disability - I believe Carnival is about challenging the way things are supposed to be done so that everyone can show each other who we really are and I'm going to try and do some technological stuff now - if you would like to know what an inclusive Carnival might look like I have a picture from 2006 of me as a blue devil taking a break in a quiet space before returning to a party so I'll just see if I can share that so that there that's me having a little quiet time break in between carnival activities as a blue devil.

Let's see if I can stop sharing that... And I've messed it up now! I've come back - and

the other thing I'd like to do is share a poem with you, it's not about Carnival but it's about masks. I'd like to assure everybody it's not an anti-Covid mask poem but it is an anti-mask poem and if you'd like to check out more neurodiverse poetry there's an anthology called 'Neurodiverse' that loads of different neurodiverse poets have contributed to and you can get that from 'Flapjack Press' for 10 quid and if you google 'Flapjack Press' and 'Neurodiverse' it will come up so I'll finish with this poem.

'Unmasking' I should say I wrote this in the first lockdown for time purposes.

I don't want to wear my mask today
And yes, I know what you are going to say
It's for my own safety
And it's my social responsibility

I'm a threat to myself
And the rest of the world
if I choose comfort and visibility
Over keeping my contagion in, but, see,
This is a mask I've been wearing for years
I was maybe four or five when the idea
That I was different, broken, weird
Got hooked behind my ears.

And after that I tried to hide who I was
Knowing I'd otherwise fear and be feared.
And this I never questioned, never knew that I could call it out
Never quite knew what to call it back when autism wasn't talked about.

Well not for the likes of me, because I wasn't Rain Man, was I?
Not I, no, I was just awkward and shy
Always knowing I didn't know how to fit in
But always trying to. Never quite knowing why
I felt a bit like I was lying to
Everyone, everywhere I went.

Fast forward. 2020.
Now at least I know why I'm like this
I have my diagnosis, finally,
And I have plenty
Of experience in hiding it.
So much you'd hardly guess that I'm wearing a mask.
I know when to smile
Know when not to ask
What the hell is going on because
To everybody else it's apparently obvious.
I'm good, you'd hardly ever look at me and think "not one of us"
That is, until quite recently I was,
But then Covid-19 snuck up on us
Lockdown happened.
My mask became superfluous.

And for the last three months
I've just been... me.
Unfettered, unmasked, with no-one to see

But my nearest and dearest
And suddenly those hooks behind my ears, it's
The queerest thing,
They've become unfastened.
My mask has come off.
Peeled away from my skin
And you wouldn't believe
What a massive relief,
It is,
No longer holding myself in.

Now, when I'm feeling happy, I flap my hands
And randomly (ah!) vocalise
I don't have to make sure
The smile that I used to paste on my face
Fully reaches my eyes.
I don't have to talk for talking's sake
Let alone choose the appropriate lies
To ensure that people know that I accept my place.
And because I can take all the time that I require
To wake up.
And there's no socially acceptable personality to make up
And maintain all day without a mistake,
I'm not constantly tired.

And yes, Covid-19 is terrifying.
And yes, I'm heartbroken that so many people are dying
But Lockdown?
I would be lying
If I told you that taking my mask off
For months at a time
Isn't utterly sublime.

So, no.
I don't want to put my mask on today.
Please don't make me go back to the way
Things were before.
I've discovered something I can't ignore.
Yes, of course I will cover my face if I really have to go outside.
But I'm not going to put on my mask any more.

Lockdown has taught me one thing.
There's not one thing about who I am
That I want to hide.

Thank you very much.

