

Not all surfaces catch the light at the same time

A curated selection of blog posts by Sonia Boué, written during the Arts Council England funded Neither Use Nor Ornament (NUNO project).

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A Delicate Dance **August 29, 2018**

This post is a series of reflections on autistic 'unmasking' at work on my Arts Council England funded project, *Neither Use Nor Ornament* (NUNO).

'Unmasking' has become a hot topic for some autistics recently. In reality it is, and always has been, a daily negotiation.

What I want to say in this post is that, while it must always be acknowledged that some of us don't have the luxury of choice about 'masking', others are dancing a daily, if not hourly, delicate dance with their 'masks'.

Some have, quite rightly I think, questioned the term 'masking' – here meaning a survival strategy adopted by autistic people. The 'social carapace', 'role playing', 'performing neurotypicality', and 'faking it' are all terms which can be used to describe what we do at any given time, mainly (in my case) unconsciously (until diagnosis that is).

And, before we go any further, 'faking it' here goes beyond 'normal' usage.

One fascinating consequence of my identification as an autistic person is that I can now tell when I'm launching into social adaptations that go beyond the 'me' I'm more comfortable with. There must be shades of 'masking', gradations if you will. Some late-diagnosed autistic writers I've encountered via blogging write about the difficulty in knowing where the line is between the adaptations they've learned and the 'authentic self'. As articulate and deeply intelligent beings, they often conclude that there is no such line.

The 'authentic self' as a concept is flawed. Perhaps what we can best say is that we are deeply influenced, as all other humans are, by our nurture – except that in the case of autistics the nurture has so often been the wrong fit. We want - in important ways - to return to nature, to our natural selves. The problem is locating the self in an alien milieu. This search is compounded by the 'loss of self' implied by 'masking' in my view.

My own experience is that second guessing what others want from you as a blanket survival strategy leads to immense confusion in the area of identity. I'm glad to leave this aspect of 'masking' behind me.

That is not to say that I don't 'mask' – of course I do – my professional life depends on it (despite my also being 'out' as a professional), and in reconstructing my personal life post diagnosis I am often immensely grateful for the many 'masks' in my repertoire. I am infinitely more comfortable and honest as I move through my days, and as I observe myself slip on a 'mask', but this doesn't mean I have it made. I don't.

I still get caught out. I still find certain situations overwhelming. I am still humiliated.

All I mean to do here really is observe some changes, and reflect the difficulties inherent in the actions both of 'masking' and 'unmasking'.

This is pertinent to my professional life too.

Central to my work as an artist and creative project lead is the idea of being 'out' as an autistic. My own creative work as such is not about autism, but I am committed to championing autistic arts professionalism (as I see it) within my sector (freelance visual arts practice). The autistic artists who currently work alongside me form part of an experimental project in which we seek to challenge preconceived notions about autistic artists. We are not savants, we are not outsiders, we are professional people doing a great job. Unfortunately this will be news to many!

This would seem, on the surface, to be a wholly professional matter. Except that of course it isn't because it involves our 'unmasking' – that delicate and infinitely unstable (because it is constantly shifting) negotiation of the self. This is so utterly personal!

Imagine the 'masks' we use as a cache of theatre props and costumes or a child's dressing-up box. Imagine having to constantly judge each new situation in your day and rummage through the box for the right thing to wear. Imagine tuning in to the voices to find the right voice to use. Imagine studying the gestures to match them perfectly. Blend in, blend in – don't show yourself as you truly are, because you won't be accepted! And all without consciously understanding what is happening or why (before diagnosis).

For some of us this process will have become entangled in our creative work, performers especially, I imagine.

For the artists I mentor, I usually suggest tuning in to the inner voice. This is to avoid a tendency to fragment and 'mask' in the face of outside influences. Locating a calm and loving inner voice can be a real challenge, however.

This is why I'm currently loving the idea of quiet reflection – the practice of creating spaces in the day for the chatter to die down. Observe the 'masks', observe the self, practice with and strengthen these muscles of observation (if you can).

Recently I've had cause to think about this key element of the incredibly powerful and exciting *Neither Use Nor Ornament* project. I can't assume anything about where we will all be with our 'masking' at any given moment, and that's a wonderful dynamic to work with when you think about it. What better example of nuance in presenting autism could I dream of than the 'now you see us, now you don't' reality of our lives?

In writing this, I realise that so much of the anxiety of 'unmasking' is in the reception we receive – that's the bit we fear most because it can be dangerous (and/or humiliating) for us, and that is unpredictable. So privileged am I in my 'unmasking' today, that I often forget the deep, deep root of my social conditioning, in the playgrounds and playing fields of school. I forget that, for many autistics, especially where other minority statuses intersect, 'unmaking' is unsafe and not an option. I plan to work much harder to remember, and to coordinate the project with this at the forefront of my mind.

If we wobble in our resolve it won't be through cowardice – if we choose to 'mask' in specific situations, there will be no judgement at all.

I emerge from blogging today with a new image for the project – that of a beautiful, sparkly, multifaceted gem. Not all surfaces catch the light at the same time. Let this be our motto.

I am an artist. I am also an autistic person. I live in sensory peril.
October 28, 2018

I am an artist. I am also an autistic person.

The other day someone rudely crashed into my Twitter timeline, expecting me to embrace a sudden urge to include me in a conversation about their work on embodied experience and the sensory world in a wholly unrelated context. I won't say more as I'm not into identifying people, but the stall set out in just one Tweet was honestly not in my area. Not even close.

It's a good example of a growing phenomenon of people wanting some of the good stuff, i.e. the benefits of authentic autistic insight, but chasing like puppies at the first ball in sight. Perhaps predictably (and with equal speed) they crashed out again when I made clear my inability to speak to their area of interest. Better to be honest. It's okay – social mistakes emanate from both sides, though it's time to admit to this true fact.

However, what crashed into my timeline that day was privilege and false equivalence. The sensory world and our survival in it is not a drill for autistic people, so please don't come to me with your teaching tools and professional insights. This is mere hobbyism in comparison.

I'm deeply interested in sensory survival, because sensory stress disables and ultimately kills autistic people. I'm not being sniffy if I don't want to play with you, but please understand that I'm just not your go-to generic autistic; I'm a professional artist trying to survive and improve conditions for late-diagnosed autistics, and for future generations too.

I am an artist. I am also an autistic person.

I like to say that I'm an autistic professional, not a 'professional autistic' – and I say this with no disrespect to those autistics who do consider themselves professionals in the area of autism first and foremost. I'm incredibly grateful to them for their work – but this isn't my identity.

I am an artist. I am also an autistic person.

The sensory torture of a hospital environment became my reality a couple of weeks ago, and I've been forced to reflect how much activity must be sacrificed to manage sensory stress in my life.

It's been a tough lesson, and I've been made aware of my unusual level of privilege with regard to sensory stress at work. In fact – without my realising it consciously – my working life is organised around sensory stress. I've compensated for it without even knowing it. I work freelance, and increasingly I work from the comfort of home.

Hospital was only a series of day visits to support my nonagenarian mother, *but*, as I imagined my own hospital stay, or working in such conditions, I felt the scales rapidly fall from my eyes. Here is a flavour of my long visiting hours, and the level of challenge such conditions can imply.

Another layer of the autistic onion peeled away as I clung desperately to my composure under the cruel lighting of a small shared hospital ward.

Myriad whirrs and bleeps monitored patients, during endless hours of uncertainty – in a vacuum of information – as staff in varying shades of uniform darted like fishes, eyes down. I was in foreign waters.

Hierarchies of need, codes of conduct, signs and symbols – all had to be absorbed – and so the decoding began. I knew I must measure each interaction carefully. Life and death hung in the air – I am busy, I am busy, the staff blared silently. How to signal that I posed no threat?

How to soothe and inch my way towards the person inside the uniform? I know, I know, I wanted to say. I will only take a second of your time!

It was a long game of observation over many hours. Snatches of information – disjointed – because it takes many parts to care on such a scale not all of which connect. Time, so much time...

Sudden changes. My mother was moved at dawn, a wash bag and reading glasses left behind. A new scene – entire geographies to absorb on my arrival the next day. A ward of four women in varying states of peril. The layout is key – architecture and uniform colour signals who's in charge, and who I must woo. Judgements are quickly made, but I am slow.

And now I am in it once more. Reliving it.

The vertigo sets in. Tinnitus too. The lighting drills into me and I fight hard to deflect it – I have a long day ahead. A pitiful curtain shields a terminally ill woman as she retches up the awful hospital Friday fish lunch in the bed next to my mother's. She is two hours at her labour, and her family rush back and forth with cardboard bowls. Can no-one do anything? She needs a private room.

My mother is quite deaf and I encourage her to take her hearing aids off. Television now costs a bomb in hospitals and so the distraction of daytime TV is lost as no-one bothers. Ghost TVs perch on brackets above every bed. Heartlessly we do the crosswords my mother loves. She is losing heart and fearful that she will never leave this place. I'm desperate to keep her spirits up.

Later I encounter the woman's son at the nursing station.

Your poor mother, I'm so sorry we did the crossword while she was so unwell. It had felt callous and uncaring, but what to do? You were right to distract your mother, he said kindly. We exchanged stories, which somehow led to a shared history of watching the 1970s TV series *Crossroads*, famed for its turgid scripts and wobbly sets. It was equally adored and ridiculed in its time. We managed a laugh, but his mother was dying.

This was beautiful and terrible. I felt intensely connected.

Hospital time is not the same as in the outside world. To enter is to surrender your agency to both the care and will of others, and to a system. That system is housed in the kind of environment that I'm sure no-one likes, but has people like me scratching at the walls to get out.

There were screamers in that long corridor of rooms and wards. Generally the screamers got their own room. I'd be a screamer for sure.

On my third day of visiting I checked out at 9pm, drove to my mother's house in a complete daze, and resolutely

left the lights off. I didn't want any food. I couldn't swallow. I couldn't speak. I ignored my dear sibling and their family and went to bed in the spare room fully clothed, jabbering to myself, it's just a meat factory.... When my husband rang me all I could do was bark like an angry dog. It's often the person you trust the most who feels the brunt of your sensory distress.

I am an artist. I am also an autistic person. I live in sensory peril.

This is my admission to myself and to the world. Mainly, I manage my life, I am happy and I am loved. But it is very hard indeed when I am out of my bubble.

I have had many accidents in my life: falling off my bike on a major roundabout is the only one I feel comfortable sharing. Having witnessed several cyclist fatalities in Oxford city I now don't cycle because I know my physical limitations. Accidents of this kind are due either to a sudden onset of vertigo or sensory overload.

This is something I wish all hobbyists to understand: I'm not hostile and I'm not angry. I'm just busy trying to survive.

What does inclusion look like?

November 22, 2018

In my day job, I am a visual artist with my own practice, but I'm also a community artist, mentor, trainer, and consultant. I work on various community arts projects as a freelancer, and I also lead my own projects.

I'm writing to share some of my findings after three months of working towards an inclusive Arts Council England funded project, where autistic and non-autistic artists will exhibit their work together (in February/March 2019 in Oxford, so there's still a way to go). Our project title is *Neither Use Nor Ornament* (NUNO).

It began with the grand idea to bring together two distinct networks, one predating the other. The longer standing group of non-autistic artists were to show their work in an exhibition that had already been planned. The newer group of autistic artists would create an events programme to run concurrently, thereby creating a distinct but equal platform while allowing for a cross-pollination of ideas and influences.

In my mind's eye, the group show appeared as a fixed point at the core of the project, and the events programme whizzed around it like a Catherine wheel! I liked thinking about the dynamic interdependence of each element as a metaphor. Could this be a new model in the making?

Audiences would certainly gain a sense of contrast, and when we began the project, the two networks were

indeed quite separate, their only real point of intersection being me. But would it make any sense beyond my own imagination, and would this represent genuine inclusion? As a visual artist especially, I need to ask myself: what does inclusion look like?

The project (in a nutshell) is really about one person's professional journey towards congruence after a late diagnosis of autism, and their (my) greater commitment to journeying in company for the benefit of a wider group. My project is about making change happen for some of the artists involved. It also seeks to inform arts organisations. Challenging audience perception is important to us, though our spirit is not confrontational.

Our first model was what you might call high on visibility. At this point, I didn't know any better. High-vis (or 'Day-Glo diversity!') could meet with approval from a body like Arts Council England, who we know need to be seen to be doing better on this score.

However, as my project progresses, I'm increasingly wary of the Day-Glo approach, which you see quite a lot in the arts right now. Genuine work is taking place in some cases, but I'm disquieted by this trend in diversity signalling.

Inclusion should be an everyday thing, rather than exceptional.

A hegemonic insistence on 'normality' conditions us to believe that signalling 'difference' in highly visible ways challenges perceptions, and therefore creates an instance of inclusion. There are times when this works precisely because our assumptions about who can be a player in society are so rigid.

This strategy of 'watching' difference and 'noticing' it (often as 'inspirational') implies a norm from which 'difference' is discernible. This is hidden 'centring' and we must tear off the fetid blinkers of 'normality' conditioning to see it.

Losing that fixed point, ditching that norm, and embracing diversity within humanity as the default setting would have us up in arms at the inequities of our (very biased) everyday assumptions.

At this point I refer back to the wisdom of an autistic child I knew, whose logical insistence that if we're all different (as we are), then nobody is special when it comes to educational need (or anything else for that matter).

Ghettoisation in the name of inclusion within mainstream education can definitely be a thing, and it has marked this young person; as a teenager, their instinct for survival prompted them to ditch all visible support. Not wanting to appear 'different' because it so stigmatised them tells you everything you need to know about being

singled out for 'special' attention in 'mainstream' education.

Obviously, school pupils turn into adults. Some will go on to wield power and be the decision makers of the future. What will inclusion mean to them? What does inclusion look like?

Some of them will also buy lottery tickets – an important source of Arts Council England funding streams. Therefore, if current systems remain, some of these pupils will go on to fund projects like mine. Their adult counterparts of today have indeed funded my project, and ideally they could be among our audiences too.

My project is an attempt to reach out across these invisible fault lines, but the scales have fallen from my eyes. My Catherine wheel was never going to take off, I was in thrall to a 'neurotypical' hegemony called 'normality'.

As our work has gone on, I've listened to the artists on my project and absorbed the effects of high visibility on each one of them – and not all of them want it. Creative practice may seem like a 'safe zone' for the kind of self expression which extends to autistic 'unmasking' – but how safe is it really?

The problem with gaining a professional platform is precisely that you can be seen. Irony!

Where invisible disability (such as autism) is concerned, some of us have been conditioned to 'mask' our difference in order to survive, as stigma and discrimination threaten if we show ourselves. Art practices do not exist in a vacuum and art alone cannot dissolve ableism – we need to get real about this. We don't choose to use 'masking' strategies, they occur as an adaptation. I know that it's a relative privilege to 'mask'. Not all of us can do this, but for those who can, it is a right.

Increasingly, privacy is being eroded – we are encouraged to share professional profiles on the very social media that friends, families and colleagues use. It is now almost impossible to control personal information which forms any part of a public persona. This happened to me very recently; the funny look at the non-autism related exhibition opening.

Oh, you're Sonia Boué. My 'fame' in this instance was an autistic person not an artist. A google-eyed stare is not the end of the world but it's not a great look. I've learned to brush it off, but that's not the point. Invisible disability can demand a calculation at each and every turn. It's exhausting and sometimes the cause of great anxiety.

How much of myself do I show? Where are my safe zones? How often must I pretend and wait for my 'unmasking'?

Mainly, we must ask ourselves: what will it cost me? Will it cost me my job, if I have one? Will it affect my mental health? Will I be bullied or abused?

Here, of course, my heart bleeds for the autistics who cannot hide. The point is that no one should have to face this.

For me, this is one reason why an ideal model of inclusive practice comes without a whizz and a bang. Some of us need to 'mask' our identities while gaining in rightful professional development.

In any case, I wonder if great inclusive practice is something you can't necessarily see!

Increasingly, I think this could be a truth to live by. Not only is inclusive practice potentially a quieter, more careful and considered game than I'd imagined, but the ultimate goal is that we genuinely don't see 'difference' because we're all included equally.

It isn't so much what you see that counts. What matters is the activity that goes on behind the scenes to make a piece of work happen in a manner that's ethical and beneficial to all.

As I move forward with my project I find that my ideas are shifting.

Our new model is still forming, and the much-longed-for cross-pollination of ideas and influences is taking place. I'm pretty sure I haven't always got this right, but the learning curve gives a spectacular view. I have a brilliant team and the most wonderful artists on board. The biggest change for me is that I no longer see my project as being one of two parts. Probably, that's what inclusion looks like.

I'm grateful for ongoing conversations with the Arts at the Old Fire Station & Crisis Skylight partnership in Oxford, my mentor Miranda Millward, and Thomas Procter-Legg, Headteacher of Iffley Academy in Oxford, in informing aspects of my thinking about inclusive practice.

I'm also grateful to Alastair Somerville of Acuity Design for his thinking on 'normality', in particular his latest writing on *Building a normal world* (https://medium.com/@acuity_design/building-a-normal-world-52f7d960)

Sharing practice as an 'autistic artist' – some personal observations on ableism.
December 5, 2018

I'm still processing.

This is a phrase commonly heard among a particular cohort. The group in question is a network of autistic women I've come to know who've been diagnosed late in life.

What I'm processing (to get back to that) is a first-ever experience of sharing my practice as an 'autistic artist'. Previously, I have only ever had cause to share my practice as an artist, period. Let me tell you, there can be a huge difference!

For the first time, I understand the fear attached to being labelled.

Perhaps to no surprise, it turns out that 'outing' yourself (to people who neither know you well enough nor have an evolved understanding of autism) closes down the shutters of perception. It can even dictate (it seems) what is considered fair comment – the like of which I don't think would be tolerated for any other minority group in the room. We probably occupy what is currently the last frontier in minority rights. Others will emerge, I'm sure.

When I share as the usual 'art me' – Sonia Boué specialising in postmemory work relating to the Spanish Civil War – I feel understood. I never fail to be met with respect and often even a gratifying interest in the many layers of my practice. Hurrah!

It is also understood that I have a track record: I'm a professional person who has worked hard and gained significant experience in many areas of practice. So far, so brilliant!

I have always felt included, and certainly never 'othered'. This, I now know, is a privilege. I wish I could say that I was afforded the same respect when presenting my work as an autistic person more recently. Ableism klaxon!

With hindsight I can see that it was my fault. Doh!

I had tried to broker any misunderstanding of my practice head on. My work is implicitly autistic (because I am) but autism is not my subject. 'Keep it simple' is a motto I try to live by.

But I had opened a crack in the door for ableist comment and aggression to pile in (unwittingly, it has to be said).

Do I exaggerate? No, not really.

Autistic people are subject to aggression and disrespect all the time, it's just that I'm masking and passing usually.

A code of practice?

For me this has highlighted a particular need for a code of practice when sharing our work as 'autistic artists', which I feel moved to think about more deeply – and process a little more.

It shouldn't be needed and perhaps won't be in all contexts, but until we make more progress on autism I'm for being 'share ready' or indeed not ready to share. I think this is about having more boundaries as individuals, but also about pooling knowledge on how to highlight and protect the needs of a community of creatives that is now coming forwards.

A great deal of what I encounter in my mentoring and consultancy practice is a gaping hole around 'mindfulness' where diverse neurologies intersect. I'm not talking about a buzzword version of 'mindfulness'. I'm referring to slowing down to a speed at which we can *all* process more effectively. I'm talking about controlling the parameters of our engagement (where we can). This is my ambition for my cohort.

It is an absolute myth that good work happens at speed, or that those who are quick are also more effective.

In my mind's eye, I see a giant hand. The palm is out-turned, signalling stop. It is gentle but firm – not a deity but rather a traffic signal.

I am secretly enamoured of the road sign and street paraphernalia that controls the flow of traffic. I long for tee-shirts with 'stop' and 'go' symbols! No entry! One way! Dead end! All beautifully simple and clear as means of communication.

You can't get a license to drive until you've learnt the Highway Code for a very good reason – you'd kill or get killed pretty quickly without it.

I like the idea of a nice laid out set of rules for engagement. I like rules.

My ideal beginning for sharing my practice as an autistic person would be: *Stop. Look. Listen* (responses on a post-it note *only*).

Now where have I heard that before?

Alternative Networking ***December 23, 2018***

I love it when nice offers come into my inbox through my artist website, so I was delighted when New York Foundation for the Arts (NYFA) invited me to take part in a Twitter Q&A on 'Alternative Networking' recently.

Since my autism diagnosis in 2016, I created WEBworks, a peer support and mentoring group for autistic and neurodivergent creatives, and have written about networking and social disability. I've been able to gain

Arts Council England funding for my work, and am leading an ambitious inclusive project called *Neither Use Nor Ornament* (NUNO), to be delivered in Spring 2019.

It was this work which brought NYFA to my door.

It's been a joyful experience to collaborate with NYFA's Mirielle Clifford and Amy Aronoff (who produced the Q&A and worked with me to accommodate my needs), so much so that a blog was created as a permanent post, so that those (like me) who find processing fast moving conversations a challenge can read the Q&A at leisure.

I'm immensely grateful for the welcome given to neurodivergence at NYFA on this occasion. To reach out to an artist like me, to really listen and go the extra mile by incorporating their learning from me into the fabric of the Q&A feels like a dream. It has been a marvellous end to a truly remarkable year for me.

If you would like to read the full the full Q&A you can! (<http://current.nyfa.org/post/181228133203/business-of-art-neurodivergent-artists-build>)

Angel Hair and New Year Resolutions ***December 31, 2018***

Reflections on autistic project design and leadership at the half way mark #NUNO

A random memory. *Cabello de angel* – sugary threads tucked inside the belly of an *ensaimada*. Angel hair wrapped in the lightest sweet doughy spiral of my childhood.

I shower and reflect on the year about to pass. I think of angel hair. I feel its curious texture between my teeth once more as the white marble staircase to my grandmother's flat flashes before my mind's eye.

Under the influence of steam, I've visited the bewigged cake shop owner on the street below and am racing up the stairs with my treat. I'm probably seven years old. In my memory of her, this kindly woman resembled a mature Betty Davis, but underneath her wig (I was told) she was completely hairless. In my imagination, I saw her wig-less at her counter once, but this is surely fantasy.

Cabello de angel means that I'm both nostalgic and happy. Angel hair is all about rewards.

The family have been enjoying a peaceful Christmas, and in the gaps between viewing ancient Kodak slides on the viewfinder I gave my mother, and seeing off the remains of the Christmas pud, I've been evaluating my Arts Council England project.

A non-sequitur, I know.

The evaluation had landed in the online portal 10 days beforehand, and I'd only happened on it by accident, as there had been no notification. Not a good look to miss this particular deadline. The second part of our funding depends on it.

My boxing day was interesting. I spent the day in a blur playing catch up.

Managing a complex project can feel like a big ask sometimes, due to the combined challenges of autism, dyslexia and dyscalculia. It can be scary, for example, when your brain goes walkabout and you know meanwhile that the pesky checklist of vital project tasks won't tick itself. I like the phrase 'buffering', which I've come to trust as a necessary period of processing. It describes perfectly those periods of time when I simply can't focus on the 'right' details. In such a state it's honestly better to watch an entire series on Netflix than try, but when the stars align there is nothing to match what can be achieved by the converse state of hyper-focus.

It seems there must be other states too. States in which we try and fumble. Ones in which we 'do our best'. I often find it hard to remember these in-between places as being anywhere near useful, and yet they must be because I don't think that I've oscillated between the super functional and resting states in a constant loop from July to December. My main impression has been of grafting and trying – without the luxury of time and space to either buffer or hyper-focus in my preferred manner.

It's surprising to me that we've achieved so much, as I write about it for the Arts Council. My project is about making a difference, and it is doing just that, in pleasingly measurable and incremental ways. The 'angel hair' for the artists on this project is not for me to share in any great detail, but for some of us it has been transformational. The opportunity to work autistically has allowed for important developments to occur, the most obvious being our (potentially) day after Brexit exhibition opening!

Other effects will be longer lasting, and relate to vital relationships and networks forming (and consolidating), and further opportunities of work alongside present employment – which will lead to profiles being raised and reputations made. This is the stuff of working lives, but the stuff some autistic artists have been long denied, due to specific challenges in the area of social semantics among others.

So despite the sweat at times – or more likely because of it – we have some really important half-time outcomes to feel good about. I want to be very un-British and blow our project trumpets loudly!

I want to be clear that this is what happens when you begin to work in autistic ways. This is what happens when we are free to design our own projects. This is what happens when we lead.

My New Year resolution is very different this year. For 2019 I promise not to change a thing.



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