

Labels, identity and presentation

The public/private divide – and its consequences

@OTalk_Occhat @RGPLizCrow My first question is what inspired you to take this route in your performance?

@RGPLizCrow My own experience of a divided public/ private self, which kind of worked for 30 years until the benefits onslaught came along. I'm used to performing publicly and hiding the ill me, but benefits demand a reversal. I wanted to explore what others see as contradiction (or fraud), which is really only the complexity of real life. The division worked quite well for me, but also with compromise. Now the acceptable public face is used as evidence that we don't need support.

@hippiedream: "I wear a public self that is energetic, dynamic and happening, I am also ill. I conceal it carefully." <http://www.roaring-girl.com>

@RGPLizCrow My private self is neither beautiful nor grownup, it does not win friends or accolades and I conceal it carefully. <http://www.roaring-girl.com/>

@RGPLizCrow In effect I have been lying for 30 years, for good reason: the truth feels dangerous but I think we are in a time where not telling the truth places us in danger, and we need to get past the reluctance to talk.

@wildcandytuft Sometimes I wake up exhausted and want to stay in bed. Do you feel obliged to get up to appease others who may not understand?

@RGPLizCrow For 30 years I have been pretending to be well. As soon as I am in public I know I am watched and I've noticed that people like me better if I behave as though I am well.

@ticgran People that like you better if you pretend to be well are not worth your energy. Concentrate on you!!

@criquaer I no longer have energy or stamina to be a people-pleaser. Take me as I am or not at all!

@RGPLizCrow When I project my public self it seems that I don't need support.

@access2arts "It's a trade. If I parade my private self, there's a chance I get the help I need."

@shudisability It's not a decision for disabled people to open up their private selves. It's a requirement of the system.

@DADAAorgau How do you articulate that you are deserving of benefits?

@RGPLizCrow I don't. I articulate entitlement! I try hard to present the facts and in public at least try hard not to justify for fear it feeds others' demands that we constantly justify our existence.

@shudisability The disability benefits system takes your dignity in exchange for money <http://www.newstatesman.com/2013/04/disability-benefits-system-takes-your-dignity-exchange-money>

@McnabbTeddy Yes, it's the indoor, the stuff we're dealing with behind the public face... How do we get WCA [Work Capability Assessment] to get that?

@VoiceofT_Reason It's about constant self-surveillance as well as wearing masks for others.

@tippyscarecrow Hard to get a balance: wear a mask and have a life versus knock-on effects on impairment. Many people only see me in my mask. I think your idea is fab!

@Alexandarshippo I have to be open in order to gather feedback about seizures, to constantly monitor, to give to doctor at annual review.

@OTalk_Occhat Yes, I (@claireOT) look very different when I'm "at work" versus when I'm #beddingout

@McnabbTeddy And no one would know if they only come across you online. Are people different online and offline in respect to your disability?

@TanteRos I don't have the energy to 'wear an expression.' It is exhausting trying to interact in a 'normal' way with others.

@tottwriter As someone with epilepsy, there is a vast difference between the healthy and disabled halves of me. Very behind #beddingout.

@anygirlfriday My life, every day! Brave face, expendable energy, don't let people down, collapse at home.
<https://twitter.com/anygirlfriday/status/322005162963124224/photo/1>

@wilde On good days, my brain works and I appear "normal" – which limits understanding because like many of us I 'disappear' on bad days.

@Onlyfluffyone You get good at hiding the real true self... Well, for a short time... But payback is massive 😞

@missdennisqueen Re 'butyou don't looksick': lots of people are only seen when well enough to be out of bed. But their absence often goes unnoticed.

@ambir In my experience people try to look and act as if they are less sick than they actually feel.

@missdennisqueen I agree most of us try to act less sick. Periods of being less sick are a massive relief to take advantage of. The world at large seems to have no idea that for many people, activity makes us more ill. Sigh! I have often said the majority of my work has been done from bed. Not armchair activist, but bedding activist!

@Kirstystrain The struggle to seem well versus the struggle of explaining (defending) illness. In a way, it's damned if you do and damned if you don't reveal illness.

@opinion8ed_dyke But *if* you behave like you are well, people (even so called friends) then think you are a fraudster.

@RedRubyGem As a parent of an ME sufferer, I see my daughter at her worst but no one else does.

@MichelleBull4 I totally understand how that feels with son with ME. The worst can be very bad.

@RGPLizCrow Anon says: "My Secret" I spend almost all non-working hours in bed. At first friends and family found it odd. Now my bedside visitors mostly accept that my bedroom is also my kitchen, living room and exercise yard. I hate pity more than pain, which I hate with a passion right now. I don't want pity, just acceptance. So when I say I can't do something I'm not lazy and it's not a choice, even though I could do it yesterday. When I look clumsy or awkward, I'm not being brave; just getting on with some of the £&@@tier bits of my reality.

@opinion8ed_dyke Many sick/disabled people spend life (like me now) in bed pacing for later activity.

@harriet3241 When Stephen Fry first 'came out' as bipolar it created waves but being 'ok' in public is different to the reality.

@allbigideas Coming out as mentally ill... Like that notion

@Quinonostante There's been a shift to destigmatise mental health over the last three years. We've been successful but now people think we don't need support.

@allbigideas Currently #beddingout after a rather public display of my impairment. Want to hide away

@cusp My disability is invisible. Only apparent when indoors/in bed.

@dembones3 Some wheelchair users may also walk at times. Doesn't mean they're faking. We work with how our bodies function best.

@RGPLizCrow There's a constant negotiation between a public and private life.

@cusp Fluctuations of some conditions make things so difficult re coping and benefits. Not everything is black and white

@lisapeacefrench My PTSD means I have achieved great things publicly, but they are not without personal cost privately.

@RGPLizCrow What is seen as a contradiction (fraud) is just real life.

@JuJuMarlow Yes. I (and many) have good days, bad days, great days and really horrible days. Why is that so hard for some to get?

@AnnabelFenn Hi! Did presenting your private self in a public space change your self-perception? How did the public react?

@RGPLizCrow I am working on it: hoping the public and private become more integrated. It's a slow process but there is some shift and I'm hoping it gives permission to others to do the same?

@RGPLizCrow #beddingout is not a work of tragedy, but of in/visibility and complication <http://www.roaring-girl.com/>

@DADAAorgau When we think about institutions we always think about the bed and its associations. Are you trying to free the bed?

@RGPLizCrow Wasn't consciously. It's more about the person than the bed. Plus the bed is a symbol: literal for some of us, but also a reflection of how many of us have to edit ourselves in public. But our survey shows that for many with bed-life, bed **is** still haven and retreat .

@Abilty_PTR I hope the bed can also be metaphor-ed to enable any disabled person to recognise how we edit and divide ourselves to meet other expectations. And beginning to reintegrate our selves.

@Helen_otuk Was this a difficult decision to make?

@RGPLizCrow Yes and no. It's very exposing but also liberating. I'm sick of hiding away waiting for reassessment and fear of "fraud" – much better for me to be answering back and trying to change things.

@RGPLizCrow Through this piece I want to present a counter story of the collective picture currently held.

@BADHofbauer Disabled people need to be more prominent in society so people realise we're for life, not just the Paralympics.

@heySMM And have us not be a plot point or special guest.

@RGPLizCrow What I am doing most of all is presenting true stories to counter the propaganda of disabled people as scroungers, always essential to get these stories out there but currently more urgent than ever.

@RGPLizCrow I decided I wanted to make the invisible visible. I hope #beddingout is starting to tell a different story. I want to show that what many people see as contradiction, what they call 'fraud' is only the complexity of real life ,<http://www.roaring-girl.com/>

@RGPLizCrow The public/private divide is something most people recognise. The difference is in how extreme and how conscious it's required to be.

@Helen_otuk Yes also the effort required to plan and keep things 'separate'. How much energy does that take up?

@DADAAorgau Liz, do you feel like you are performing another self – a third self maybe – crossing the line between public and private?

@RGPLizCrow On the nail! Sometimes feels like a real conflict, like I'm not sure who I am in this space. Usually I transition between public and private. Here I flip between the two in this public/private space. Very strange experience.

@RGPLizCrow I've seen the sharp end of what cuts are doing to disabled people.

@RGPLizCrow What made me take the plunge is at least 32 people dying a week found 'fit for work'. Now it's life and death.

@RGPLizCrow @SoniaPoulton says: "I have reported on people who have committed suicide over these reforms."

@k_runswick_cole Welfare reform is about life and death.

@RGPLizCrow Floor: "Not totally surprised by the 32 deaths, cutting of services for people unable to always articulate their needs."

@RGPLizCrow Floor: "I'm happy you are doing this due to the fact people say to me 'you don't look disabled', and I don't want to look weak."

@allbigideas I understand completely. It is a constant process of deciding what/how to reveal/fight, according to ever shifting circumstances/resources.

@tiggerbumble: Yes it's the preparation that goes into maintaining a life, a persona out there. It's exhausting. And goes unseen.

@AnneDean10 Agree. An ongoing struggle, or do I not bother? Then people think I'm fine but just can't be bothered. Or that I'm anti-social!

@maryqmcgowan We waste so much precious energy caught in this

dilemma!

@twowolves In a mental health context being seen as 'looking ok' is very important to the individual, but damning in terms of claiming a benefit.

@sharpsecret Yup: he looks okay so he can't need any help, even though it's taken two hours and help from others to get you dressed!

@lydiafleure93 Independence isn't just about being able to do things on your own.

@harriet3241 'Independence' becomes a rod to beat us with.

@CC_Me_AND_ME "I'm terrified that if I speak up, for example at meetings, then people will think I don't need benefits".

@MyalgicEncephal No assessment should be based on looks. That is a subjective tool and has no scientific basis.

@lisapeacefrench: #beddingout is really making me think about how I resolve my public strong self with my PTSD which I don't let other people see.

@RGPLizCrow It's not just a performance: I **am** ill, and I have to square the consequences.

@opinion8ed_dyke: I did *normal* stuff on Saturday. Looked *normal*. Today, Monday, I need to be mostly bedbound to recover.

@wilde On good days my brain works and I appear 'normal', which limits understanding because like many of us I 'disappear' on the bad days.

@theredissee It's eight steps to my sofa. "Not far," I hear you say. But when I'm feeling poorly it's a continent away.

@redfoxcountry When did resting become a crime?

@twowolves There's horrid physical and mental pain from bed life. You have to be very strong and work hard to keep well as possible...

@twowolves "You talked of a bubble and a knife edge and I recognised that".

@RGPLizCrow Floor "Do you think it will be a double edged sword? If only the disabled were not so coy?"

@RGPLizCrow One of the real tragedies of keeping complexities hidden is people I've known for years don't even know I'm ill.

@lisapeacefrench I think this is very true of many people with a disability and a 'public self.' I certainly feel the same.

@bluehook So what is it about bed-life that is taboo? People reporting they don't let on about how it is. Has it changed recently?

@jeshyr Not sure. I tell anybody who'll listen about my #beddingout life, but most don't want to know. Too depressing??

@jeshyr My feeling is that bedridden-ness is so confronting that people recoil somehow emotionally from the reality?

@RGPLizCrow Instead of "I'm OK" when asked "How are you," what if we told the truth?

@RGPLizCrow "I told you your life wasn't worth living" is a risk.

@Freewheeling4 One of the things about disability is anyone of us could experience this in our lives.

@RGPLizCrow We have complicated lives, non disabled people are allowed complicated lives.

@RGPLizCrow I want to be in control of what information I make public about my impairment, and when I say something about my impairment or access needs, I want that to be trusted, including by the benefits system.

@IsabelleClement When the private becomes public it helps to illustrate the existential panic disabled people can end up feeling in the brave new world of Tory welfare reform. www.roaring-girl.com/productions/bedding-in-bedding-out/watch

@RGPLizCrow Anon says "I am in tears hearing and seeing someone articulating what is my living condition, my hidden disability. I am so proud and happy about this art taking place. It speaks the truth to you who choose to listen."

The victim label

@RGPLizCrow To avoid the 'scrounger' label, many have turned to a 'victim' role, neither is accurate.

@RGPLizCrow Some people have resorted to the victim role to secure the support they need, yet people fought for years to move away from that.

@criquaer In some ways the DLA/ESA/PIP/DWP/Atos/Capita pathways force one to be a victim!

@MYHeardRadio So we've moved away from the fragile dignity afforded by the care/welfare system, towards justifying existence?

@twowolves You are right but we are forced to, even unconsciously, and it is very important to debate this, to expose how we are being funnelled.

@MYHeardRadio How has it happened that in the UK folks think it's actually okay for sick and disabled people to need to justify and 'defend' their needs?

@RGPLizCrow Is there increasing pressure on disabled people to portray themselves as victim?

@MeganDudziak Disabled people have to present themselves in a negative way in order to receive benefits really needed.

@dembones3 It's a myth that disabled portray ourselves as victims to get benefits, but we are forced to reiterate our disability to counteract the scrounger myth.

@RGPLizCrow Floor: "The one word they are trying to take away from me is 'dignity'."

@Kitschmonkey Identity becomes eroded through illness, and further by how we are viewed by public. I am not a victim. I am a whole person.

@VoiceofT_Reason But if we attempt to deny we are victims of our disabilities, we are told we are frauds and don't need any help!

@harriet3241 We need to avoid the 'victim' role and present the truth about complex stories.

@allbigideas Bridging the gap of private and public lives but not using victim.

@allbigideas Presenting ourselves to different agencies means assuming different identities. How to integrate them?

@RGPLizCrow Different impairments have different stereotypes attached to them and used against them, eg if we are go-getters we have brought it on ourselves, but not strong enough and we're at fault. We've had a series of videos showing bedlives and what has come across strongly is that we people dealing with very difficult situations but who are deeply humane and compassionate. We must not apologise for who we are.

@Kewryta We shouldn't have to pretend. I'm not a victim, I'm not a hero, I'm a human being with a disabling illness.

@lisapeacefrench It concerns me the Atos [company assessing ESA claimants] process revictimises those with PTSD – the worst thing you can do.

@RGPLizCrow Do you find that you are thinking differently about how you present to DWP [Department of Work and Pensions] etc since welfare reform?

@lisapeacefrench Having to justify your disability, victimises you – yet @number10gov does not want people with PTSD to stay victims. #catch22

@jeshyr Spot on! People misinterpret descriptions of disability as 'inspirational' or 'terrifying' with nothing in between.

@bluehook And yet the reality is we are everything in between. So much more to it than one extreme or the other.

@access2arts We have to be superhuman or work-shy fraudsters but not ordinary people.

@RGPLizCrow Even the Paralympians are shifting from superhuman to scrounger. Great athletes, but no more superhuman than anyone else.

@RGPLizCrow Participant comments that there are two images of disabled people: either dependent or Paralympian hero.

@Peckitt As opposed to just regular joe/josephine trying to get on with life.

@BADHofbauer People's view of illness and disability is too brightly coloured by mainstream media and political rhetoric.

@harriet3241 Nobody is superhuman and stereotype can be damaging because Paralympians are affected by the change to PIP from DLA

@allbigideas Voices of paralympic speaking out about benefit cuts are important.

@RGPLizCrow C4 Dispatches: DLA/PIP with Paralympians challenging public/private image [NB 200m rule has now been reduced to 20m]
<http://www.channel4.com/programmes/dispatches/episode-guide/series-123/episode-1>

@shudisability Labels and identity: a double edged sword?

@kirstymhall We need to combat the idea that all disabled people are a drain on the state. We are taxpayers too!

@bluehook Quite right Sonia, we're all taxpayers. It's used as a way to separate us out, but you can't avoid tax.

@RGPLizCrow No account is made of the contribution made by disabled people to the economy (eg though their working, spending, children etc).

@lisapeacefrench What frightens me is the government's stance and that welfare reforms are **causing** discrimination and stigma.

@lisapeacefrench Such a big concern for me too... I compare it with the pride at last years paralympics and I can't believe the change in attitude.

@bloomer71 Some Paralympic athletes rely on DLA [Disability Living Allowance]. Yet I was told "You should try harder like the Paralympians, then you wouldn't need DLA."

@RGPLizCrow How do we safely make public our personal selves? What are the implications of being honest?

@Kewryta This is my biggest worry. If I do nothing, I'm lazy. If I achieve, I'm a faker. All I can do is tell the truth.

@Kitschmonkey As an ME sufferer I am often viewed with suspicion. I refuse to apologise for being ill.

@tippyscarecrow There are things I wouldn't share as it would stop me getting some jobs.

@leni_lava My honesty will not help prevent Atos lies.

@lisapeacefrench If I risk repercussions, so be it! My illness / injury comes with both strengths and weaknesses and I will now share both!

@cusp Earlier stream really made me think about how to show my disabled side without looking like a victim Thank you x

@RGPLizCrow Floor: "I want to be appreciated as an entire person"

@lisapeacefrench People say to me "You are so strong." I am no stronger than anyone else. I have just been tested more.

<http://reallylisafrench.wordpress.com/2013/04/09/a-life-with-post-traumatic-stress-disorder/>

@lisapeacefrench I will not allow myself to be criticised for my achievements! My achievements are **because** of my illness and experience!

@lisapeacefrench My PTSD gave me greater empathy, it is a known symptom. I would never change that gift.

@TanteRos In society I am judged by all I can't do and somehow made to feel ashamed. Yet I am proud of who I am as a person.

@VoiceofT_Reason Do you believe demonisation of disability by welfare rhetoric encourages invisibility? It worsens that aspect for me.

@LonAitewalker I hid because I was tired of being accused of faking and made myself more feeble. Now I really don't care...

@jeshyrl think fear of disability is a more severe disability: people said to my face they'd commit suicide rather than live like I do.

@bluehook Yes, I get it, if they're not lost in admiration of your 'bravery', they're fearful of what they don't really understand.

@jeshyr Also many un-fun things about being bedridden – commodes, tubes, nausea, incontinence, confusion, etc. Nobody wants to dwell!

@DACymru And some of us do manage to do amazing things in between #beddingout or indeed, whilst in bed, on the sofa etc.

@jeshyr Spot on! People misinterpret descriptions of disability as 'inspirational' or 'terrifying' with nothing between.

@bluehook And yet the reality is we are everything in between, so much more to it than one extreme or the other.

Why I don't name my impairment

@RGPLizCrow A number of people have asked about my impairment, I have deliberately not answered, because I didn't want the performance to be about a certain impairment, but about the bigger benefits and cuts themes.

@RGPLizCrow I am keen to highlight that the name of the impairment is irrelevant to the work. If I say I have 'x' impairment then the work becomes about people with 'x', when it's about the impact of social and political decisions on all of us.

@twowolves Yes I totally agree and hope you stimulate people to think: I purposely left off names of my disabilities.

@BADHofbauer I hate the way people want to know. It's as if you are your illness or disability and they need 2 validate you.

@Peckitt it's about putting people in boxes. Liz can be either the disability activist or helpless cripple. Can't be both.

@RGPLizCrow The 'name' of an impairment is not important in #beddingout. The effect of welfare reform and perception truly is... Join us today.