Who Jumps First?

Disability rights activist and performance artist Liz Crow on a political awakening that happened in about 20 seconds flat, and why she took her wheelchair to the fourth plinth on Trafalgar Square.

Interview by Angharad Penrhyn Jones

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You don't talk about your impairment in very specific terms in public. Why is that?

The disabled people's movement is premised on the concept of the social model and it's an incredibly liberating thing. Essentially the social model makes a split between impairment or the body, and social structures or the things that actually keep disabled people out of social life. For me, and I know this is the case for hundreds of thousands of others, that has been transformative, and in many instances even life saving, because it shows our exclusion from society is fundamentally not about the way our bodies function, but the structures that surround us.

My impairment is relevant, because I am ill and that has an impact on my life, but the primary focus of my work is the world out there because that can be changed. The primary focus of my campaigning work is the world out there because that can be changed. It’s the social structures around us we can change, and it's much more relevant as an activist to put the focus on that.

What story is the government trying to tell about disabled people at the moment, and how do we counter that story, those myths?

Currently the story of anyone needing social support is one of the scrounger, the shirker, that they're too lazy to contribute to society and need punishing back to work. Disabled people are seen as being right at the core of that. Once upon a time we were the ‘deserving poor’, which was hugely problematic, but now we've joined the even lower rank of the undeserving poor. [Laughs] And there is no room in that story for the contributions we make.

You’d think the Paralympics would have counteracted this, but actually it heightened it, because we ended up with these really strong contrasting images in the press and in government briefings: the sporting ‘superhumans’, lauded wherever they went, and the benefit scroungers, the two set side by side, each exaggerating the other. Things were difficult before the Paralympics but got a lot worse during it and in the immediate aftermath.

With massive benefits changes and austerity coming in, I’ve see a lot of things happening. There’s been a turn in the press and the way that we’ve been portrayed, so whilst we’ve been routinely misrepresented in the past, suddenly the scrounger rhetoric is huge, with a really strong effect on myself and the people around me.

When the changes came in, I saw a lot of things happening. There was a turn in the press and the way that we were portrayed, so whilst we had been routinely misrepresented in the past, suddenly the scrounger rhetoric was massive, with a really strong effect on myself and the people around me. Hate crime against disabled people has doubled since the coalition government came in. Like a lot of people, I'm aware of holding myself differently when I'm in the street, of trying to ease social contact with strangers - look them in the eye, smile excessively, and just ease that process. I know so many people who have experienced increased hostility; being confronted, receiving hostile comments, being spat on or subject to physical violence.

I'd been an activist for a long time but I shifted to this area in direct response to current events. The government's claim was that austerity was a necessary response to the economic crisis, but it was quickly clear not only that austerity has a bad record as a financial solution, but also that it was an ideological move to dismantle the state, with a primary focus on the social security system.

In the thick of this, I knew that I would be assessed for the newly introduced Employment and Support Allowance. Like a lot of people I have an impairment that's very poorly defined and changeable day on day. The new system is even more problematic than the old one. Not only does it ignore the impact of social barriers, but it's also constructed for people with very quantifiable, fixed, recognisable, visible impairments. Anyone not falling into that category – generally the people who need the support most of all - fails the eligibility test and falls through the gaps because the system is incapable of recognising them. Initially, I decided I wanted to focus on the misinformed concepts built into the test, and implicit in deeply biased government briefings and press reporting. I decided to explore how what you see of me in public is not how I am behind closed doors. So where I edit myself to perform as this apparently well person in public, articulate and active, what you will never see is the preparation for that to be possible or the recovery needed afterwards. Without that full picture, you can't make a judgement about who I am or the support I need, but because that private side meets with such social disapproval, it's something I kept under wraps for the best part of 30 years. In common with a lot of disabled people, basing any judgement about what I might be able to do, or whether I need a particular aspect of support, only on what is visible will be flawed and potentially dangerous.

You're faced with social disapproval because you're lying in bed?

Yes. Because I'm not productive in socially approved ways, because the aftermath of activity is not attractive, it doesn't communicate well, it isn't lively, it isn't all the things that get celebrated in society. If you imagine their opposite, that's how I am in private much of the time. And whilst I've hidden all of that for years, the dangers of the scrounger/fraudster rhetoric and its translation into hate crime and claimant deaths means I needed to start playing with those two stark contrasts and bringing them into a public space to trigger a deeper, more informed conversation.

That's what led me then to develop, *Bedding Out*, a performance piece in which I took to my bed for 48 hours in an art gallery, live streamed and with a Twitter feed alongside, in order to convey that complexity and create a platform for discussion. Disabled people responded with visceral recognition of the public / private divide, that editing of self. And it created a platform for an incredible range of issues relating to benefits changes and their impact, representation, hate crime, protest, you name it.

Discussing this in public conversations held around the bed and in the Twitter feed, it became clear that the kind of questions we were looking at, the debates we were having, were not in the end about disability, but about much broader and deeper questions: what, as a society, are the values that are important to us, what kind of society we want to live in, and what do we do to bring that about?

So to critics who might say that performance art is a marginal, self-indulgent, middle-class pursuit…

[Laughs]

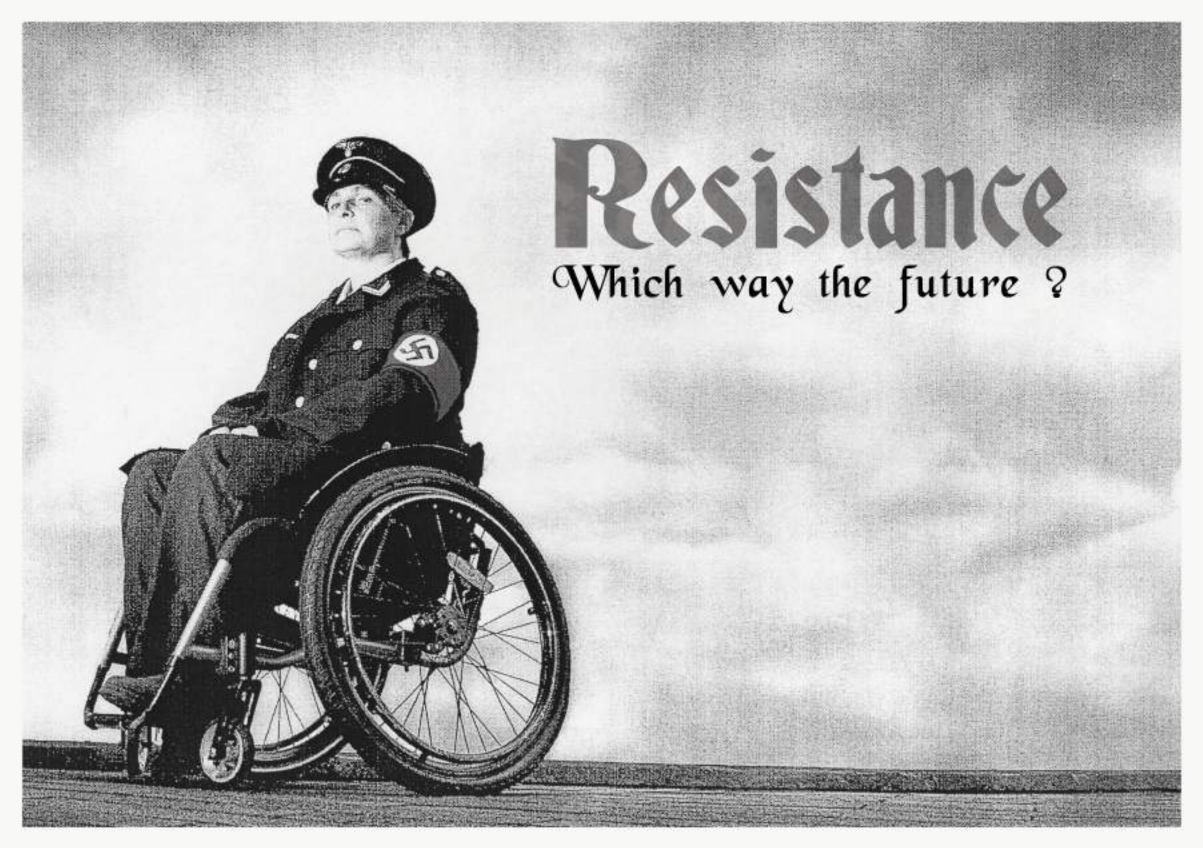
What would you say to them?

When you start doing a piece of work like this, there's always a risk it will be dismissed. It *can* be completely self indulgent, but equally if you don't do it, you can't know where it might lead, and this piece led to places I couldn't have imagined, got people discussing things and considering things at a depth that amazed me. Some of the journalists doing the more thoughtful reporting about benefits seized on *Bedding Out* because it gave them another way in to the issues. Disabled people who'd felt so poorly and dangerously portrayed, said they felt represented, and a lot of people new to the issues said they were presented with a story they simply hadn't heard. There's a risk involved with any of this kind of work, a risk that it'll be misinterpreted, a risk that you'll look foolish, and of course there's always the next project that doesn't work, but the power is in that risk, because it's only through risk that extraordinary and unpredictable things can happen.

When you're cutting through wire fences or blockading buses, there's risk. I don't draw a firm divide between that performance and the performances I have done in blockading buses. I think it's all connected because they're all about creating a compelling image, a symbol to encapsulate stories that are rarely told, and all of the time – whether you call it art or activism - you need to be making judgements about message and presentation and how to respond to events as they unfold. All of it requires a sense of occasion and spectacle and symbol and how you make that work for the thing that you care so deeply about. I come from an arts background and so I call it performance quite comfortably and people who don't maybe call it something else, but I think they're entwined.

Could you talk about your performance piece in Trafalgar Square?

The artist Anthony Gormley's work *One and Other* was appearing on Trafalgar Square's Fourth Plinth. Over a period of 100 days, 2,400 people were selected by draw and given one hour each on the plinth. I realised it was an opportunity to get disabled people represented, so I spread the word and threw my own name into the lottery, then forgot about it. But then my name was drawn out of the hat [laughs] and it was a non-transferable place, so if I didn't take it up it would be a lost opportunity. It coincided with the launch of my *Resistance* project, a film-based installation that looked at the Nazi campaign of mass murder that targeted disabled people and at how the values underpinning those horrific events remain absolutely contemporary. This was a hidden history, and even though it was the 70th anniversary year, the press did not report it. It was obvious this was the subject I needed to take onto the plinth and I needed an image either to convey the issues I was dealing with or to stop people in their tracks and cause them to ask questions - so not give all the answers, but to make people think, ask questions, in ways they hadn't done before.



The poster for Liz Crow's Resistance Project

I was talking it through with a friend, chucking ideas around, and suddenly the idea came up that I should go up there in Nazi uniform. It was such an appalling thought that we burst out laughing, then took a breath and realised that the image, that uniform, with its swastika armband, combined with my wheelchair, made the piece.

It's the incongruity of it.

Yes. It creates an unresolvable image. There's this symbol of hate and this symbol of apparent vulnerability and dependence in the same image and you can't square the two. I'd seen an image on the web that had played with something of those ideas, of a young Asian man wearing a red t-shirt with the Nazi swastika on it, looking to the camera and grinning. My response was visceral, like the rug being pulled out from me. I couldn't explain the mismatch between his expression, the image, the fact that he'd have been a target. I couldn't resolve it in any way and the image stayed with me, keeping me thinking, and I thought, if I could create a reaction like that in other people… I didn't finally decide to go ahead until four hours before my time slot because the prospect was so terrifying. I had no way of knowing if people would get what I was trying to do or whether they would throw bottles, and it could have been anything between the extremes really. And certainly I had a really good discussion about security with the organisers. [Laughs] There were people looking out for me on the ground but for the hour on the plinth there wasn't a lot anybody could do to protect me, so it felt… it's probably the most risky thing I've ever done. It took a week for my heart rate to return to its usual level. I did think, I can't do anything like that again, because it was *too* dangerous and yet I'm glad I did it too.

At the same time, a group of about 40 people from Direct Action Network grouped loosely around the plinth, handing out leaflets. People were coming up and going, 'What the fuck?'. The first tweet was 'WTF' [laughs] which was the same response that I had to that image on the internet. But the DANners knew the issues and at one point one of the women called up to me and said, 'It's okay, Liz, they get it'. They ran out of the leaflets in the first 10 minutes, but then strangers began passing leaflets on to each other and in the Square and on Twitter, which was relatively new back then, there emerged these incredible conversations between people who, collaboratively, were able to make links between the historical and contemporary and fill in the gaps that the image deliberately left open.

One thing I'd like to bring up: we might think of disability as being something fixed, that you're either disabled or you're not, but that anybody can become disabled. It's a very obvious point but it's something that physically-able people forget, that it can happen to any of us.

Yes. If impairment doesn't happen to us it will surely happen to a family member or friend or colleague. It's the most ordinary of things. Bodies change over time, and when bodies change, what we discover is that we have created the social world in a very narrow way. It's very, very easy for people not to fit. A tiny shift in how your body functions means you no longer fit, because of social structures.

But this is something that we can change, and desperately need to change, because we lose so much by sidelining people. You can apply this to any equality issue, where people are losing opportunities to fulfil their potential and even losing their lives because of external structures. But society, too, is losing out. It seems extraordinary to have a society that needs every one of its resources, knowingly ignoring masses of those resources. There's no sense in it.

I'm interested in how you became a disability rights campaigner in the first place. You said you've been doing it for many years – so was there a sudden political awakening or did it coincide with you having problems with your health? What was the trajectory for you?

It was a sudden political awakening that happened in about 20 seconds flat.

Really?

There's the before and the after, it's as simple as that. [Laughs] I had an impairment from the age of 10 but it was a very undefined, undiagnosed impairment which I was under pressure to pretend wasn't there. I didn't knowingly come across any other disabled people, so I was very isolated, and there was nobody to act as any kind of role model to advise or support me or tell me I was okay as I was. My family were brilliant, but my parents were so young, with no experience of battling bureaucracies or anything like that, so we were very much on our own. I was in mainstream education. I had a lot of difficulty writing because of pain. The school had no idea how to work with uncertainty or complexity in a system that required clarity and rubber stamping and they were unbelievably hostile. They asked me to leave rather than take exams, because it was a hassle for them. I had no learning support, so I would gather all my day's work and take it home in the evening and dictate it to my mum who gave up her job to support me during my O level years. I took exams but it was all down to my family fighting for it.

I got out of school as quickly as I could and managed to get into medical school. I was really excited. They knew I needed to dictate my exams and I got through the first term, but clearly the right person hadn't clocked it so they withdrew the exam provision and threw me out. I'd had a comfortable, secure upbringing and maybe that’s the burden of a middle-class upbringing! You're taught to think that ‘with determination’ anything's possible, and there’s a long way to fall when you discover it's not so simple. I was struggling to get back into the med school and get the provision I needed, but was meeting a brick wall, seeing all these men who were my dad's age create walls where they weren't prepared to listen, reason, hear, and when I had to leave it wasn't simply that I'd lost my degree in medicine, it was bigger than that. I'd lost my compass if you like. I didn't understand any of the things I'd based my life on.

It was a time of being incredibly confused. I became a volunteer at the students' union for a while and happened to go on a weekend community action training. There was a brief session on disability equality training in which these two disabled women explained the social model.

And suddenly I had an explanation for all the years, suddenly there was a language that made sense. I'd got a word for what was happening, it was discrimination. That I'd got an impairment was a given, but there was all this other stuff, this discrimination, that didn't need to happen, and actually my primary distress and loss of opportunity wasn’t from impairment but disability. Being able to name it changed everything. Shortly after, I became a disability equality trainer; that became my work, how I earned a living. I moved to London, got involved with the burgeoning disabled people's movement, the very beginning of the disability arts movement, and my life changed absolutely radically and much for the better.

Did you feel that you were more equipped to face the bullying and the walls and the barriers?

Yes, but I think it's more than that. I think I found my community. I found a second family really. And that instant recognition, where if you had a conversation with another disabled person there was so much that didn't have to be stated, that always had to be stated in the world outside, and that was an incredible release. I found a common explanation for what was happening and a common focus for what needed to change. And the late 80s was an exhilarating time. It really was a kind of born-again feeling, like we could take on the world. And to some extent we did. We were the first, I suppose. There had been disability campaigners in the past but suddenly what we had was this mass movement, an international movement, and it felt that anything was possible. And some of the time I think it really was. We changed things with a rapidity never been seen before.

Can you give an example of something you changed?

A really early protest was against ITV Telethon. Telethon was a television fundraiser that demeaned disabled people in order to raise money, often to fund essential services, such as education or community facilities, that most non-disabled people took as given. It was charity based and celebrity-driven, and portrayed people as objects of pity in order to release the purse strings. There was something so fundamentally wrong about that victimising process, yet people were not seeing the mismatch, just getting caught up in the razzmatazz of the event.

About 150 of us gathered at the television studios on London's South Bank. We had our own singer-songwriters there and we had a sound system so there was a great backdrop of songs, really inspiring, energising stuff, placards, chants, and we were visible en masse, which was a thing that just hadn't been seen back then. At a certain point all the celebrities started arriving. Some of them were quite unpleasant and derogatory towards us but then went into the studios, giving these cheesy grins to raise money for people like us. [Laughs] So this whole mismatch carried on, and a couple of activists got into the audience and were flung out. Then at a certain point security put up all these high, six, seven foot tall interlocking fences and we just went up to them, dozens of us, and started rocking them. And if you think of the image of disabled people as being dependent and weak and pitiful and all the stuff that they were putting on the TV screen and, with that number of us just rocking… The barricades went down. At which point they called the riot police, and all of this was just unheard of. If you think back to the earliest days of Greenham where male police officers didn't know what to do with women, physically didn't know how to manage female bodies. And then later they got over that and started -

Started pulling them, pulling them by their hair…

Absolutely. [Laughs] They got over it quite quickly. But we were at that stage where they were scared of our bodies. And there were little tricks, like a woman with an artificial leg who loosened her leg when she was about to be carried off and that would cause a lot of fluster. [Laughs] And just the pleasure that we took. I think that was what was so wonderful, some of what we were campaigning for was life and death stuff and yet the joy and the sense of liberation in what we were doing was just life defining, life changing. Just to be in that moment. And it was a moment really. It was a few years, around the early nineties, where I think incredible changes happened. And some of those changes were in ourselves, which was probably just as important as the measurable structural ones, because, where some people say 'I'm not an activist anymore', I think just being in the world as a politically conscious disabled person you are having an impact. I think anyone with any kind of politicisation can't help but be an activist, simply by doing the ordinary stuff they do. So by changing that, I suppose it's what they call consciousness raising, isn't it? By making those changes the ripples were going out from us into the wider world. But it was the most dramatic thing and Telethon ended soon after. It was a defining point for disabled activists, realising we could have an impact, that our time had really come.

When you talk about this, you seem really joyful and light - and isn't that part of what campaigning should be about? There should be joy in it and playfulness and fun and humour. I think there's this image of activism of being a bit miserable and ascetic and self- sacrificing and punishing, and it can be very tough but it can also be playful.

Yes. I think much of the joy has gone from current campaigning. There was a simplicity back then. People say things are better now, and in certain respects they are, but mostly they are more complicated. And when they're complicated it's hard to campaign, because what you need is simplicity of message. I mean, at rock bottom, the stuff that we've always dealt with is incredibly simple - what is the value of a human life? Is one human life more valuable than another? Because that's embedded in our structures at the moment. The issues now are the same issues as then and the same issues as 150 years ago, but they've got a lot muddier in the way they're enacted.

If I think back to then I can remember, just as an example, being in East London, coming out of college, needing to get a taxi back home to South London at a time when there was no such thing as accessible public transport, so a taxi was the only way I could travel. For three hours taxis drove past me and refused to take me, and that was standard. That stuff still happens now but a little less. Theoretically, there's legislation we can call on now, but then it was completely legal and defended as reasonable. The level of behaviour and the attitude toward disabled people was so extreme that the college also managed to remove my place on the basis that I was a fire hazard. I have lost more college places than most people have had cooked dinners, and it's all been discrimination based, but back then it was all allowed to happen so easily, it was *normal*. And what many people felt towards me, simply for existing, was a profound sense of pity, unmitigated pity, that my life must be so awful it was amazing I was choosing to be alive.

Attitudes like this still exist, they still get expressed to me sometimes by complete strangers, but then it was wall-to-wall. But actually when it’s that blatant, it’s easy to confront, whereas now, most people know that stating that stuff isn't really acceptable or appropriate. It doesn't necessarily mean they don't think it, but they don't express it in the same clear way and therefore it isn't exposed for you to tackle with the same clarity.

And where we’ve made significant progress on some of the more visible and practical issues, I realise now that, relatively, they were the easy ones. You know, there are more disabled people now who are in employment, maybe have families, can get around on transport, relative to 30 years or so ago. But those are the very public and visible things to fight. The things that are much harder, nebulous and hidden, are about our value in society: do we deserve to live? Do we deserve to continue our lives? Do we even deserve to have lives in the first place? We need to find ways to confront these most fundamental questions, to demand the right to life, from conception to natural death, because they are absolutely out of sight, out of mind. There’s more need than ever for activist momentum, not to feel that, phew, well it's better than it used to be, because although these issues are much harder to organise on, they are the ones that everything else traces back to: whether we are of sufficient value even to be here.

But I think there was a joyfulness in those early days because it was this whole new discovery of community, of the power and potential we had, and that simplicity ran through it. All through the 90s we were doing big bus blockades and, again, that was exhilarating. The idea that one wheelchair user can wheel into the road, put up their hand and hold up a double-decker bus and all the traffic behind it for a reason that's absolutely clear and compelling, and in the process of that, yes, annoy some people, but really change the minds of some others, is just extraordinary. I mean, everybody should have that experience of what life can be! [Laughs] It's absolutely brilliant. But, I think for a time, as a movement, we've lost our way. A lot of our organisations have floundered through loss of funding. The political context shifted so that, where in the 80s and 90s there was a ‘wall’ of opposition to hit against, a clarity of opposition, it became more nebulous, harder to focus. When Labour came in, instead of that wall, it was like dealing with blancmange. There wasn't that same thing to hit against. You could recognise things that were fundamentally wrong, policies going through that were damaging, but the crystal clarity that had been there before was gone. And the current government, instead of announcing one clear policy change at a time, introduced a scattergun approach which has been very effective in dissipating a united and focused opposition. That's some of what we're struggling with now.

In the bus blockades our tactic was really obvious: the transport system is inaccessible, you go and you block the transport system. But if you decide to move on to something like institutional living, why so many people are forced from their own homes into institutions, do you carry on stopping buses? It's the most visible, public tactic we had but I think we have gone past the point where blockading a road gives the return that's needed, it's not direct enough to communicate on broader issues, but we still haven't found a replacement. I still don't know what that replacement is, for that particular issue or for others, the non-transport issues if you like. There was a beautiful clarity to it. It was a gift. The very first bus blockade people held up a banner saying: 'At last, disabled people are catching buses', and it hit the front page of national newspapers.

Liz taking part in a bus blockade.

Were you there?

I wasn't at that one, no. I was going through an extremely ill phase. But it fed me, knowing it was happening. It was a powerful thing to experience direct action as a spectator, knowing that next time I'm out there, I might be sustaining other people in the same way. Over the years, I have had to move in and out of that kind of direct action and, these days, much of that way of action isn't practical for me. But I also think we need to keep inventing new and imaginative approaches, and part of that comes back to making sure the artists are present. It's not that they're the only ones that can provide imagination but sometimes they bring in a spark or a new perspective and just release some new and striking way of doing it.

I think one of the things we need to do is get back to the absolute basics of why we're activists, what it is we're trying to do. I guess at the core, it's about communication, whether we're communicating hidden or invisible lives or communicating an injustice or a solution to it. When I'm in front of the bus, it's about communicating to the people on the bus and the driver of the bus and the other people stuck in traffic or passing by and, ideally, with the media, getting it out to more people, communicating that public transport that excludes a community is not public, until ultimately we build pressure on the policy and law makers to effect change. And whether it's direct action or a work of art or a piece of writing, it's always about communicating.

Isn't the difficulty partly that we're all so much more scattered now than we used to be with the rise of the internet, so that it's harder to get a message across? It's a complicated thing, because the internet itself can be a powerful political tool, but the public is so much more scattered.

I might have given you a different answer two days ago. I've just started reading a book about how we've become used to talking more than listening, and I think the internet feeds that. I don't know that it's entirely responsible but there's a pattern of parallel voices just shouting into the dark: one voice shouting that austerity is necessary, that there's great injustice that not everyone is working and the taxpayer is subsidising idleness and fraud, and then us, the opposition, going, 'Well, actually, here’s why people are out of work, here’s why most of the population is a benefit claimant, here’s the true fraud rate and the truth about tax avoidance, but the risk is that you've got all this voices yelling in parallel and no one at all is hearing what the other is saying.

So there's a lot more noise.

There's much more noise, and if we're all busy making the noise then who hears it? Not just who can filter their way through it, but if everyone is making noise then they're not even trying to hear.

On the other hand, I think social media at its best gets beyond the shouting and can allow conversations between people who might never actually meet. This is what I saw in *Bedding Out*, where extraordinarily deep and thoughtful and deeply supportive conversations took place between friends and strangers, both around the bed and through a range of social media. When it works, it can be transformative.

The book is called *The Art of Listening*, by Les Back. I'm at the beginning of it, but his introduction has grabbed me. His thesis seems to be about the role of sociology in an age that wants certainty, and the need to embrace the fact that actually life is uncertain: your life will be different from mine, therefore we can't necessarily extrapolate from your life and know how mine will go, sometimes we have to accept not knowing. And I think we need to devise an activism or a way of expressing art or whatever that works with uncertainty instead of shying away from it. Maybe in some way that links with the issue of risk as well, that when I say risk, I mean uncertainty. I can't be sure how the onlooker will react to my work but actually if I leave the interpretation open they have to go more deeply into themselves in asking questions and finding a position than if I just say what they ought to be thinking. In *Bedding* Out, people seized the idea and kind of ran with it and made it work for them. And I think where projects such as that reach people and start to change their minds, preferably in the direction I'm hoping for, that change might well be far more profound.

And by telling people what to think, arguably they become further entrenched in their own positions - so it can become counterproductive.

Yes, that’s the risk. I keep referring to bus blockades, but you could substitute different actions in there. And when we were doing the blockades with that clear image, clear rationale and so on, there would of course have been some people we alienated, but it's about trying to weigh up the costs and the benefits. If you judge that you'll probably reach more people, shift things more than you will do damage, that's the point at which you might make the decision to go ahead. But you're highly unlikely to sweep everybody along with you. The risk is that you will entrench some people into a more polarised viewpoint. I think we need to acknowledge those risks, that they *do* exist, and then allow them to inform the decisions we make.

I wanted to ask you about the collective response to the coalition government's attack on the disabled. So the Spartacus campaign, DPAC [Disabled People Against the Cuts], Black

Triangle, and others. Tell me about the way people have banded together recently and your part in that groundswell of resistance.

I wouldn't say it's an entirely united front. There are different perspectives, different degrees of politicisation, and that has its tensions. There is an attempt at the moment to define a kind of core to which those different groups can subscribe, to define the values that can reliably inform everybody's work. This recent campaigning and activism has been really interesting in that a whole new swathe of disabled people have come out of the woodwork. Some of that links to the internet because there are people now able to be activists, to be present through the internet, in ways they can’t be physically present in the broader world, and that's really exciting. So you've got people with more extreme or complicated impairments, who spend most of their time at home, maybe in their beds, who have become incredible activists, creating far-reaching campaign work. We're getting those new perspectives coming in and shifting the way we work to become more inclusive. So if there is still a movement of disabled people, and that's a big debate that goes on, it's becoming more representative than in the past. I find that very exciting. If you look across the range of activism, it covers everything from the more traditional campaigners, the letter writers writing to newspapers, MPs, creating petitions and so on, through to the more radical wing of doing blockades and all of that stuff, and everything between. And there are crossovers between the work of some of those groups so that different approaches feed and reinforce each other.

I don’t know if this is typical of activism as a whole but I think there’s always been a divide in the disabled people’s movement between activists, artists, and academics. I don’t fully understand their resistance to each other since I kind of move between all three and think the cross-fertilisation of ideas and support the three communities can give each other are critically important. The night I performed on the plinth really underlined that for me, where the academic work underpinned what I did through historical and contemporary evidence… gave it gravitas. The artistic side communicated that to new audiences, and the activism came through the people on the Square reaching out to the public and the people who have since seized the image and used it to push forward debate and change.

That relates back to what you were saying about how we need to take different approaches to achieve political change.

Yes. If we think about the people that we're trying to reach, they range enormously in the lives they lead, in levels of education and literacy, in the kinds of thinking they do, whether they're very cognitive-based or creative/emotional. Such different ways of being mean we need lots of ways of communicating. If you pick blockades as your sole form of action, you’ll reach some people but fail to reach others, whereas if you go for multiple approaches, which might be creative writing or dense academic study or it might be poetry or theatre or whatever, you'll reach many more. If we're to be effective we need to call on everything we have at our disposal.

That's a very positive idea because it suggests that there's a role for everybody. It's actually really important to talk about all the different ways in which we can become active and make our own interventions.

Activism is more about how driven you are or what your starting point is or your clarity of purpose, rather than the tools that you use. Somebody recently wrote about my work, saying I'd recently turned to activism through the plinth and other performance. And I was thinking, no, actually, all the film work I did before was activism. It was more subtle activism, but it all has a role. Sometimes it's necessary to be confrontational and sometimes it's vital to be subtle and nuanced. Our task is to find effective tactics for different situations, different modes of communication.

People have said to me, 'Oh I could never be an activist', and what they mean by that is they could never blockade a bus.

It's just one strand. People have also said to me: 'Why do you do all this confrontational stuff, why don't you write letters?' But who says I don't? The confrontational stuff is just the most visible – I'm out of sight when I'm writing a letter or signing a petition, but I do that too where I think it's useful. I imagine most activists pull on different strands - it's simply that some are more visible than others, some are more headline grabbing. If you climb up the outside of a very tall office block you probably get a headline. If you write a letter to your local MP you probably won't. But they are both a form of activism since they both actively pursue change.

You've been politically active for thirty years. Are you able to identify anything that sustains you, motivates you, keeps you going? What stops you from stopping?

I think what stops me from stopping is that new stuff comes up. What I keep saying is that my next piece of work is going to be fun, it's going to make me laugh, it's going to be light and then something else comes up so I deal with Nazis. [Laughs] Or contemporary echoes of that. I get driven by the urgency of it. It's about lives on the line. People are dying in large numbers because of current policy, while others are finding they're hardly living. It's as simple as that, how can I not keep going?

There is incredible trauma amongst people because of current political decisions. There are people dying unnecessarily, whether it's because the support they need is withdrawn, whether they're being driven back to work in ways damaging to their health or whether the stresses they're being placed under are driving them to suicide. People are dying. It's known to the government and they're ploughing on anyway. And when you see that, how can you not keep protesting and looking for solutions?

I think it's important to recognise what activism does for *us*, as well, that in focusing on what's out there, we can feed ourselves. When I started doing disability equality training, I was able to take the horrible everyday things that were happening to me, these everyday insults, and turn them around. When something bad happened, instead of feeling it just as a personal attack, I was able to think, 'I can use that'. I can use it as an example in the next training so that people can understand that social process of discrimination and then understand their role in dismantling it. It was a really liberating experience for me to be able to make use of what was happening to me. I might be there in a room and people even think I was this dynamic trainer, but outside I was still getting all of the crap that all disabled people do. The difference between me and lots of others was that there was somewhere to go with it, to turn it around and use it.

And I think that was the case with *Resistance*. I was dealing with a really difficult history, with the fact that really difficult things were happening, currently, politically, to disabled people, and I was able to do something constructive with it. The idea of using a history that was so hopeless in a way that just might change things for the future was really significant. If I had looked purely at the history perhaps I couldn't have dealt with it, but that I might be able to turn aspects of it around, to apply it for some better purpose, changed everything.

Physically I need to look at how I'm an activist, because my illness is quite problematic if I'm trying to do the more physically demanding forms, and emotionally the relentlessness of it can take a toll. I suppose I'm asking myself questions about the different ways it's possible to be effective as an activist, whether there are ways that take less personal toll and are still effective. A more gentle way of being an activist. Rebecca Solnit's book *Hope in the Dark*, is wonderful. She talks about how, as activists, we need to live what we're working towards, that it's no good saying, for example, 'Well, I know we exclude lots of people from our campaigning but it's so urgent. Once we've sorted this issue then we'll look at including all these other people.' You can't do that because it's a fundamental contradiction of what you're working for. You can't create this utopian world having excluded people on the way there because it will be flawed.

And quite dystopian. [Laughs]

Yes, exactly! So what we need to do is start looking at how *we* function in the world and using that as a way to communicate the changes we want to see. And living better becomes a part of our activism, even if it's not the most direct and visible part of it. It gives an integrity to the work.

Also the collaborative nature of activism is critical. We hear about Gandhi and Martin Luther King – extraordinary leaders though they were, they didn't do it on their own, they were never a single person creating those changes. It's rare to be able to say 'I - or even 'we' - did that, I made that change' because what we create are ripples, where the work of many people combines to make change. That can be hard because, however long you work, it's not often you really know whether you've had an impact. In the end it's a leap of faith, a determination to keep on living what we're working towards,. And maybe that's something I need to look at: how do we create a bedrock of resilience in the population so that all of us learn how to recognise injustice and have what it takes to answer back. How do we support each other to take that leap of faith and not wait for others to do it first, not wait to see if it's effective but just do it anyway because it matters enough?

The thing that came out of *Resistance* for me was this question that people ask so often about the holocaust: what makes ordinary people commit such evil? But the question that came from the project for me was what makes ordinary people commit such *good*. It was ordinary people who turned those events around. Even in the desperation of the disabled people's holocaust, the beginning of ending those events came from disabled people. Even when they knew they couldn't save themselves, it was disabled people who alerted the wider population until they were compelled to protest. They didn't wait to resist until they saw someone else doing it first. It's a tangled web of who jumps first, and actually you just need to jump, and you'll bring other people with you.