

Bedside Conversation 5 of 5 with Liz Crow as part of the *Bedding Out* performance

Friday 12 April 2013 10.15am

Liz Crow: So, welcome everybody around bed and welcome to everybody watching this on the Internet and joining in in the parallel conversation on Twitter.

This is the fifth and final bedside conversation of the *Bedding Out* performance. We're live streaming from Salisbury Arts Centre. *Bedding Out* has now been underway for 44 hours. So, there are four more hours to go so we're reaching the final stages.

This bedside conversation is going to be slightly different from the others in that it will have overlaps but it is also a kind of summing up in the sense of, "Where do we go from here?" as the end of the performance comes closer.

What I wanted to do was begin by giving the participants in this group something of the background to the performance and why I've come to be here.

I was looking at the idea of working with the hidden life that I have as a disabled person. I'm playing with all kinds of ideas.

But then there was a specific story in the newspaper that made me finally decide that I had to go ahead. And that was a story in the Sun. But at the time it could have been in any one of the newspapers because they were all handling similar stories at the time.

It was about a woman who was photographed with her children at a theme park on a rollercoaster. She was a claimant of Employment Support Allowance, which is the benefit you can claim if you're not well enough to go into work. She claimed because she had a very painful back.

This photograph appeared in the paper, and she was accused of fraud and she was taken to court over fraud. She was there for a day out with her children, but she was found guilty of fraud.

Now, I looked at that picture and I don't know anything about that woman's

circumstances. I have no idea whether she was committing fraud or whether she was somebody who absolutely needed that support and was wrongly accused. But as I looked at the photograph and I read the article, I realised that it could just as easily be me. Because if I look at last summer as a single example, I went on the first horse ride of my life last summer with my daughter, because she was desperate to see what it was like to go on a horse. And more than anything she wanted to do it with me. And that's the kind of thing that we try and do with our kids. So I went for it.

But like the woman on the rollercoaster, all the people saw was the me on horseback. What they didn't see was the preparation time that I'd had to put into doing that or the recovery side of it. All of which was out of the public realm.

And I just realised how incredibly dangerous that reporting can be. That if that whole picture of who we are is not taken into account, then incredibly dangerous judgments can be made. And since we're in a climate of extensive changes to benefits and a major overhaul of that system, a parallel reporting in much of the press of the scrounger rhetoric, and the work-shy and fraudulent rhetoric, that has actually been linked to a doubling in hate crime, the idea of actually looking at those stories and countering them has always been important but now it's more urgent than ever.

Really that's why I decided to go ahead with this. Partly to make visible a community that is simply not in people's imagination because it is so hidden. But actually much more than that. To try and reveal the complexity of our lives. That there is this negotiation between public and private that goes on constantly. And that until you find a way of integrating those in the public imagination of what it is to be us, then you cannot build safe systems and make safe judgments about the people you come into contact with.

Of course the last thing I want to really put across with the work is that in the current climate that very real sense of danger of not taking that into account.

So that's how I've come to be here and I just wonder if that strikes a chord really with anybody here.

Speaker 1: There's a lot to do with perception. Public perception. The media will always polarise a situation so they can make it more, I suppose, user-friendly. So people can say, "These are the goodies and these are the baddies and he's got to do right, and that's wrong." And I suppose judgments are made by journalists and editors who say, "Right, we're going to put this out so that we can get everybody making discussions, however, falling on one side or the other in an argument. So that just fuels more debate. I suppose in a way, it's good to fuel debate because you're actually making it equal to everybody to see what the debate's about.

Liz Crow: I think you've hit on something really important. That the drama in the oversimplification of the 'good guys' and the 'bad guys' is a great way to sell newspapers and to really lead people into a situation where maybe they don't think too hard. They grab the headline because it's an easy thing to latch on to.

I mean my real concern about the way the press has gone is that, if anything, it's stifled debate. Because it's really shocking the kind of misinformation that's being put out there and how it doesn't bare relation to reality.

Places like the Guardian now have shifted in their reporting. But two years ago that was the reporting that was going on. Different levels of kind of histrionic headlines. But the predominant rhetoric was the scrounger/shirker. The Guardian is now adding some incredibly strong investigative reporting and revealing some of the true stories and the true facts behind it.

But to give an example, a couple of years ago there was one particular headline, and there have been many, many versions of this since, that said that – this was in the Daily Mail, could have been in lots of places – it said 75% of disabled people are faking it.

You turn to the Department of Worker Pensions own statistics on fraud, on Incapacity Benefit – what's being replaced with ESA – it's not 75%. It's 0.3%.

So the figure given in the press is 200 times reality. Yet, when you look at where the power of the press is, the newspapers who are pedaling those headlines reach something like five times the population of the ones that are telling the actual factual statistics.

And many, many more see them because they're headlines that you can grab as you go past them in the supermarket and of course you can access on the Internet.

So those kind of very dramatic, propagandist ways of reporting are just having actually a devastating impact on how we, as disabled people, are perceived, and how we're claimed to be perceived.

But also, maybe even more dangerously, on how we perceive ourselves. There is a point where you risk buying that as a description of yourself.

Speaker 2: Yes. If everybody looks that way and sees that way then I can't be right, kind of thing. You know it's almost that strong. It's an exaggeration. It's like it's not about the stories of the people that are going through it, what they have to get through, why they are not at work. And they might want to be at work.

Liz Crow Yes.

There's something about the way that we're reported, the way the benefits and claimants are reported, and the social security system as a whole, that is done in a sense of great isolation.

As though, first of all, the claimant doesn't exist in any social setting. There are no factors like the level of education that you've had, the discrimination you might experience, the availability of work. All these different factors that impact on someone's ability to move in and out of work and impact on somebody's health.

But there's also no account made of relationships. So I was talking to somebody the other day who was saying – she's now in her 20s – as a child her mum had an impairment. She was ill for a very long time and she was on benefits. The woman I was talking to was one of three children. She was telling me how guilty her mum felt about that.

We were talking about the work that her mum had done, unpaid but absolutely work, raising three children, who have now gone on to become taxpayers and so are contributing both economically and socially, given the jobs that they are

doing.

But no account's made of that. No account is taken of the fact that, for example, I sometimes look after my friend's children if they're off school sick. So my friend goes out to work and carries on paying taxes. Or the fact that I've employed personal assistants for 20 years, and in some cases counseled, careers (sic) counseled, employed people off benefits. There are all kinds of ways that people contribute, and much more subtle ways, in the kind of ways they relate to people.

Very often the levels of compassion and empathy that come out of experiences that don't have a monetary value and are therefore quite hard to credit, but absolutely exist.

The other area of relationships, of connectedness, that I think is terribly important, is that social security doesn't exist in isolation of other systems. So, for example, why people claim is very related to how the education system works. It's related to health. Health is related to Health Services and whether it's able to respond to our needs. It's related to social services and whether our needs are met and therefore whether we can get out in the world. None of those can be looked at in isolation.

Yet at the moment the way it is put across is these individual shirkers and scroungers don't exist in that social world at all. But of course the reality is that we absolutely do.

The only way you can address the picture of why so many people might be claiming, what's brought people to that situation, is by looking at that bigger picture. Including looking at wage levels and why we're subsidizing so many employers who are not paying enough.

Speaker 2: You know, I used to be a social worker and our son is on the autistic spectrum. But because we are perceived to cope, we don't have a case worker or anybody really.

So I do all the reports and make sure they're right and chase people up. And that's fine. I'm okay doing that. But if I look at how many meetings I'm in one

week, or hospital appointments or whatever, and there's nobody else to take over, then I can't find an employer who will employ me between 10:00 and 2:00 in the afternoon, you know.

And if I could find one, we would lose all our benefits and we would be ten times worse off than we are now. We are just only scraping getting by. Not by choice, because I mean we both volunteer. We both have jobs to help other people because we have ways to give back, and I think that's very important.

But I do – we do get upset about being portrayed as... Sorry. (Crying)

Liz Crow That's alright.

Speaker 1 (Crying) I think it's just really important that people like you give people like us a voice.

I'm obviously not where you are but I had my handrails fitted yesterday for when I'm coming up the stairs. But I'm not disabled because I can still walk. Some days I can't and that won't get any better and I know that.

But, you know, I don't want to be painted off as a scrounger of the system because I'm not. I'm keeping my kids from staying out of trouble and I'm teaching them what we have to teach.

Life is hard for everybody you know, so we try to do the best we can and I'm really, really – Jenny told me about this and I'm – I'm glad that she did. Because you start hiding too quickly I think. Because you don't want to come out. Because you don't know what to talk about. Or I don't, anyway.

Because when we go to the job center, we obviously have degrees, we shouldn't be on the dole.

It's just not like that. It really isn't.

Liz Crow I think these are exactly the stories we need to be telling. That is just so absolutely different and more compelling and more complicated than any of those kind of splash headlines we see.

Speaker 1 Yes.

Liz Crow But those splash headlines aren't about human beings. And what you've just told, that's exactly what it's about.

I think one of the things that's really struck me in doing this project is there is something absolutely critical now about getting these counter stories out, these truthful stories of what our lives are.

And I think that's on two sides. And I'm sorry, I'm actually going to look at my notes because I just really, really want to get this across.

That I think that there is so much there are so many untruths out there. And they have got to a point where they have so much power that I talk to people who I know are really good, kind, compassionate people, and they still say to me, "But we are in a period of austerity and fraud is rampant."

And it's just like they are buying the stories they are given. And it becomes critical that what we do is counter those. That every time we hear something that we know is wrong, that we counter it. That we use whatever resources we have. You know it might be tweeting it, blogging it, speaking it, living it. Whatever we do that we find what's within our resources to do it.

For me that's on two fronts. We've got this new hash tag now that – which is the #truefacts. We are starting to put stuff out on the #beddingout Twitter feed for this where we look at the so-called facts that are given and the #truefacts.

So, to take the example I gave earlier, we're going to be putting something out such as, "Daily Mail says 75% of disabled people are faking it. DWP says 0.3%."

And what we want to do is get those facts out in really simple tweets that people can grab hold of and re-tweet. But also stash them in their memory so they can use them in conversations. Really succinct facts.

But the other thing is, and it may be that other people want to join in on the Twitter feed with information like that, if you can make them as simple and succinct as possible so that people can grab them, that becomes incredibly useful.

But the other thing is the counter stories. The true stories. The stories that counter the false stories that we're given.

And those may be stories of struggle. They might be stories of resilience, solutions. They might be banding together and fighting it in a united way. Because all of those different things are happening. Sometimes we don't know about those at all.

When I started this, it really felt as though I was the only person in the world that lives a lot of time in bed. I've realised through this that there are thousands and thousands of us living this way. In some ways that just feels overwhelming. In other ways it's incredibly empowering.

Because when you also plug into the conversations those people have started to have with each other, you realise actually, this is a group of people who are living really demanding, tough lives. And yet with a resilience they don't always recognise in themselves and an incredible sense of compassion.

They show characteristics that actually are what we need in this society. They model ways of living that actually we can really learn from.

So getting those stories out so that we end our isolation. But, just as important, so that we communicate those different stories out there, again every time.

You know, a family friend said to my mum recently, she did the line about, "But there is a lot of fraud," and that's the time to come back. One thing I think she said there was, "But you don't think Liz is committing fraud, do you?" Of course the answer then becomes, "Oh! No, no, no! Because I know Liz." But then it's trying to understand: but if she thinks that about the strangers, then actually the strangers think that about me.

Actually it becomes about protecting ourselves and protecting each other as well

and just getting those stories out as much as we can.

And sometimes, we don't have the health resources to do that. So we need to work within the limits that we have and recognise those. But one of the things I've seen in the last few years in groups such as Disabled People Against the Cuts) and Spartacus is there's been an incredible mobilisation of people campaigning and protesting. And the way that they have managed to work is that, when someone is well enough, they're out there and they're campaigning. And people who aren't are in the wings recovering enough. And when this person needs some time out, this person moves forward. It's like a dance going between people. It becomes a much more collaborative, much more powerful way of fighting and making a difference. It's remarkable watching that process.

Speaker 2: Is it about the platform? I mean, are you using the bed as a platform to put over your opinions? And in actual fact using art as the platform to put over your opinions, rather than journalism which has got a different audience?

But then it will have an audience of presumably creative-minded people that do go to art galleries and do want to understand other creative people.

So are you actually lowering the boundaries between creativity and journalism?

Liz Crow I am. And I want to just pick up on the first bit you said. Can you bring me back to that if I lose the thread?

I'll just get back to where I was, sorry.

Yes, I'm using the bed as a platform. And this is my real life in that I spend most of my time at home and a lot of it lying down and quite a lot in my bed. But I've also realised that this is a kind of metaphor as well, and that when I talk to other disabled people with different lives, there's a very strong recognition that so often we edit ourselves when we are in public. And then we recover from that in private. And we are all pretty much grappling with this split in how we present ourselves to the world. And that there's a huge cost in that and an enormous amount of work. So the bed becomes both my reality and a symbol of that bigger picture.

Then in terms of art, I'm very consciously using art. I call myself an artist-activist. So I come from an activist background, alongside my creative work. I think if we look at the way that people campaign and protest, there are so many different strategies and so many different people that we need to reach. And the very overt, direct action, like blockading roads and handcuffing to things and so on, absolutely has an impact. It reaches a certain section of people who are very empowered by that and have their ideas challenged by that. And others it doesn't reach. Others will turn from that.

And you can say the same about petitions and letter writing and blogging. You could say the same about newspaper articles that are really investigative and analytic and so on. And then you can say the same again about art.

So there will be people who look at what I'm doing and will go, "That's not for me." And there will be people will go, "That's ridiculous. What is that woman thinking of?" And that's okay. Because what I want to do is reach the people that the other methods are not.

And I think it's such an enormous thing we have to do. It's such a huge task, that we actually need to draw on every possible front.

Speaker 3: There are also similarities with the John Lennon and Yoko Ono thing. I'm probably repeating what you've already discussed several times in the past.

Liz Crow I've blogged on this before. But nobody has raised this in these.

(Laughter)

Speaker 3: I mean, the fact of the bed being the place. And I know the messages are different, but they're also messages for the public from the bed.

Liz Crow: Absolutely. And I guess if John and Yoko would give peace a chance, I think this is kind of the other side of the coin. It's kind of – I don't know if it's justice or humanity. But it's about – it's time to hear these stories. It's time to set the record straight. So there are parallels. And in fact Yoko Ono does know about this and did send a message of support. So she's made the connection too.

Trish Can I ask – there's a lot of power in telling the different stories. But is there anyone working on offering an alternative to what we've been presented with, with the new benefit system and assessment process? Is anyone working on an alternative?

Liz Crow I think people are beginning to. I think there's been, over the three years since coalition came in, there has been an enormous amount of campaigning. But it's actually very disparate.

So people have fought their corner with an incredible sense of urgency and, in many cases, desperation. So it's not that they've just fought their corner and ignored everybody else. That has been all-consuming.

But the result of that is, it's back to the connectedness and the relationships, actually. That what is happening to disabled people is happening to immigrants, is happening to single parents, and young under 25-year-olds, and is about to start to happen to people who are considered not to be earning enough.

And if you go below the surface of that, it ceases to be about those individual groups and it's actually much more about this very deep idea of some people are more equal than others. It's this far more dangerous and divisive idea. And actually at some level we need to tackle the entire campaign there and become far more united in those different groups.

So, it is necessary to campaign, for example, on the change from Disability Living Allowance to PIP, because there are specifics that relate to this community. But underneath that, underpinning those changes, are the same kind of values that are underpinning changes to other groups. So we need to be very careful about how we focus.

What I think is happening at the moment is a sea change actually, where those groups are starting to coordinate. The People's Assembly was launched a couple weeks ago, and there's a big event on the 22nd June in London, which is really worth checking out, whether you can get there or check it out online. And that is a really major bid to bring all the different groups together and coordinate action on all kinds of fronts. So again, bringing in all kinds of tactics, from the direct action to, hopefully, creative approaches. But also, I hope this really, really solid research approach, the facts, the figures, the true stories.

But also very much what you said, is that, in the wings, we have to devise an alternative. There are absolutely much better ways of doing this, but we need to develop those in policy terms. And, if nothing else, it's been proved that neither the coalition government nor the political opposition has anything very much to say on this that gives hope.

At the moment, for me, if there was an election tomorrow, I truly wouldn't know how to vote. It's got harder each election for me but, on this one, I just would be at a complete loss. And that's why I think this mobilising now becomes even more critical. It's no good waiting until the election when we will have to vote from that very limited range.

One of the things I keep hearing is about public opinion, and the government keeps saying, "Well you know public opinion is with us on welfare reform or changes to Social Security." Actually, looking at the polls, they're right because they've told the strongest story, the most compelling and dramatic story, and people have bought it.

What we have to start doing is back to true facts, true stories. Our job is actually to influence public opinion, to shape it just as significantly.

Now, the government has all kinds of resources at its hands that we don't have. Not least very strong connections with the powerful press. However, there are things we have to our advantage as well.

One of those is in newspapers such as the Guardian that has changed its reporting. Now there's a kind of roll call of journalists from Shiv Malek to Polly Toynbee to – I'm sorry but all the other names have now escaped me. But there's a whole core of people doing stunning reporting work now. One of the

things we need to do is keep feeding them with stories, because they rely on us for that for their reporting, to help them get the word out.

But the other thing is that we have access to social media, which of course 10 years ago it would have been a very different campaign. And so the Twitter feed running alongside Bedding Out has been completely extraordinary. For me this has been a complete experiment, and it's been infinitely more powerful than actually I could have imagined. Through social media, we've had people in 18 countries involved in this project, and incredible ideas, really thought-provoking questions and discussions that are rippling out.

We start off talking to people who think like you, and that has value because it strengthens us. But it doesn't get the word out. But then I realised last night, one of the people on the Twitter feed is a Paralympian. She's become a very strong spokesperson about the benefits cuts. And I realise that on the one hand that she's tweeting back to us, but on the other, as a Paralympian, probably now with quite a significantly large number of followers, she's tweeted to a lot of other communities too who actually might not know about this.

So each time we get the word out there, it's thinking about how do we get the word out to people who don't know this stuff, yet who we feel sure that, if they only knew, would be outraged and would start to say, "Not in my name. This is not going to be done and put across as representing what I want."

So that thing of public opinion becomes absolutely crucial.

We've got another five minutes. Have you brought anything else you want to?

Speaker 1 Well, I'm going to go and claim. Because it's like you say, it's very much about a public face. So I think that's what kind of got to me. That you're showing the other side. And I guess that's what I'm trying to do as well.

Liz Crow Yes, yes.

And I think something to remember in all of this is that when you're able to live your life, actually get on with your life as it truly is, just by doing that, actually it

has an impact.

I remember years ago talking to a friend, a disabled person who had very strong politics but didn't regard himself as an activist. And I realised just by going out there and doing stuff, he was an activist. We are changing people's minds just by doing it.

I am just going to sum up, because I think we are near the end of our allotted time on this.

But I think there are times when it does feel as though there is a colossal mountain to climb on this. I think there really is. I think, as a community, we have amassed incredible resources in the time that we've been fighting it. That people have skills that I don't think we'd realised, that I don't think they'd realised and built alliances that were not there before. And they've shown, they've modeled, ways of working that are truly extraordinary and we can learn from.

But I also think there's one thing that is going to sound very bizarre, if I say, "Actually we have this going for us and the government doesn't." But something we have as a community, and as individuals, is actually desperation. It seems really, really odd to pick on that, I know.

But we look at the government and we think, "Wow! They're really, really powerful." But actually, they don't have the same imperative to battle this one that we do as a community. And for many individuals within that community, as disabled people and as claimants, there is a very real sense that we're fighting for our lives. And actually what that means is, we, unlike the opposition, have everything to lose but we have everything to gain. Actually that makes us the most formidable opposition.

In all of those really bleak times, it's holding to that fact that actually we will win this. Because we have no option but to win this one. But we have to be together to do that.

So I am going to close the conversation here and just to say thank you so much for participating and thank you so much to everyone who's watching this on the internet and taking part through the Twitter feed and social media.

This is the fifth and final bedside conversation from Bedding Out. The conversation is very much going to continue on Twitter and please, anybody who's following, continue to get the word out. Because that's really, really where the kind of future of this lies.

If nothing else, Bedding Out has shown what that kind of drawing together of people can do. So please continue it well beyond the performance.

I believe there's three more hours of Bedding Out to go.

(Laughter)

So let's keep going with that Twitter feed. And thank you so much to everybody who's participated and made this possible.

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