

Bedside Conversation 4 of 5 with Liz Crow as part of the *Bedding Out* performance

Thursday 11 April 2013 3.15pm

Liz: Welcome. And I want to welcome everybody watching this on the internet and joining in the parallel conversation on Twitter.

This is the Bedding Out performance and this is the fourth of five bedside conversations. We're live streaming from Salisbury Arts Centre.

Bedding Out has been going now for 25 hours and it carries on for the next 23 hours. So we're over the half-way point.

I just wanted to start out by giving you some background as to why I'm doing this performance. It really comes out of a dilemma that I've been facing which is that for a very long time, I've lived my life in two really very separate parts. So there's been my public self which goes out into the public spaces and tries to be energetic and animated and happening. And if people see that side of me, that's what they presume I'm like.

But what they don't see is the private self that takes place away from that visibility. That's where I spend most of my time at home and a lot of it, quite a lot of it, in my bed.

That's about preparing to do the public self. And recovering from the public self.

I learned very early on to hide my private self. Because I found that it doesn't win friends or accolades that are fundamentally socially acceptable to wear that part of yourself.

So I've concealed it very carefully. In the compromising of doing it, I think by having to use that extra surge of energy for the public face, I'm probably more ill than I need to be. If I could only find a way to integrate the two. But I haven't found a way to communicate that whole self to other people in a way that feels secure.

So I've chosen this much starker route.

And although in compromises, as I say, for 30 years, it's kind of worked. So I've stuck with it.

But then events beyond me shifted. Suddenly what I'd found had worked no longer worked because what I found is that we've got this major benefits' restructuring and a system that fundamentally works on what is visible. So it sees the public self and looks at what I'm doing and says, "Well, you're not eligible for public support. You don't need the support of benefits."

So suddenly, I'm find that what I'm being required to do is actually to conceal that public

self. To stop that and certainly not be seen in that way. But to bring out this very carefully concealed private self and parade it in order to get the support that I need.

But alongside that, because of the change in benefits and the cuts behind it, and the idea that austerity is what is right, which I dispute, is a whole newspaper campaign that has escalated all these ideas, that carries an idea of disabled people as scroungers and workshy and that has been associated, has been very much tied in together, with policy and benefits changes and it's been associated with a massive increase in hate crime.

So, what was just a personal dilemma suddenly has become something that's much more of a knife-edge, much more dangerous.

At its extreme, it is life and death.

The statistics that have come out are that 32 people a week are dying going through the assessment process for benefits and having been found fit for work.

Some of those people are dying through suicide because of the distress of that experience.

So this is truly life and death. And where once I could kind of just grapple with it on my own, no longer is that the case.

So I decided to try doing this piece of work. First of all, to make the incredibly invisible community more visible. The first version of this performance, I realised that it felt as though I was the only one living this life. Actually, there are thousands upon thousands of these people. But we are all hidden. So I wanted to shift that balance.

But I wanted to do something more than that. I wanted to start telling the story about the complexity of our lives. We're not just the publicly visible. Nor are we just the private. But that it's some complex interweaving. And that unless we get that story out there, we can't begin to invent systems that actually incorporate our needs. And therefore we can't have systems that meet the needs of people who need them most of all.

And then the other thing I wanted to put across is the very real sense of danger that exists if we don't incorporate that complexity.

So that's what brought me to this point.

I can see in your faces that there's an awful lot that's sounding familiar in that.

1: I saw your clip of your previous show and heard you talking about a bubble and a knife edge.

I almost thought I was listening to myself talking. Because I thought, "I know that bubble.

I've created this safe bubble for myself so that the control is with me. And that, in that, if I need to take to my bed, I can take to my bed. I can go off and manage things myself in this little bubble...

And then all of a sudden this bubble was burst by these political things. And suddenly feeling that you're a target and seeing these headlines in the paper, I felt completely overwhelmed by instead of people being supportive, people being so negative and looking for any group or individual to scapegoat and use as their – yes, just a scapegoat for their own inadequacies.

I think the work that you're doing in doing this, I've found it really inspirational. That's why I've come here today. I was so happy that today was a good day and I could come.

I get let down by myself so often that I can't think like of wanting to do things. Knowing when you want so much to do something and you can't. Feeling despondent in your own fault. Because it's your body letting you down.

Liz: I'm really glad you made it today.

I think there's so many things in just what you've said now.

The first thing that really strikes me is that the impact it's had on me, and I think a lot of people, is back to the bubble, is that fragile sense of security that we build up. The systems we set up are hard work. The relationships we develop are hard work. Because it takes so much more for us to do it than it does for many people.

And so we shape those and then we rely on them. And when they are taken away because of bureaucratic changes, that very fragile sense of security is taken away.

For me, that's been the biggest personal impact. That where I was managing a complex situation in a way, some of it very tough, and some of it really interesting. But, you know, a really demanding life. I was managing it.

Then suddenly I realised I'm not as in control as I have been. Which has all sorts of implications. Including how I manage my home life and my child. How I do the work that I do do.

The other thing that I really wanted to comment on was when you were saying about your shifting health is that we have a system that is all or nothing. So either you're well enough to work or too ill to work, and however it shifts, little bits that suggest you can do that piece of work here and there, there actually isn't flexibility to allow for that.

We have a culture of employment that demands that people contribute in very particular ways. So you can't wake up in the morning and go, "You know, today's not happening for

me. (Laughter) But I'll get to it as soon as I can." Because that doesn't fit the mode of work.

If we shifted that culture, and we shifted the social-security system to reflect it, then we could respond as we're able to. Which is actually a very grown-up way of managing your life. (Laughter) You know, actually that's what we're meant to be going towards is working out ways of managing our own lives. And we become very good at that.

But the systems that exist don't allow for that.

Dawn: A question I think that hasn't been raised. If someone is working hard to manage a severe disability, why on earth does the country want them to work if they don't want to?

Liz: Do you know, there's a huge amount of work in managing impairment. There's a huge amount of work in managing other people and their unease and discrimination we face and negotiating all of those situations, and that whole idea of editing ourselves when we are amongst other people. We're back to the public-private thing. Actually already we're working very hard.

But I also think, through that work, very often we're making a huge contribution.

Just managing those relationships. And I think how, over the years, I've employed personal assistants for 20 years. And in that time, people have come to me with very different experiences, very different needs. I've been a counsellor and I've been a career's counsellor and I have employed people off benefits and therefore helped the unemployment statistics. (Laughter) And my PAs pay tax. But none of that contribution gets recognised.

Disabled people contribute socially and economically just by being and managing their lives.

2: I just wanted to say how pleased I was that you were doing this and how it reflects the reality of my life. And also the reality of lives to my friends.

One of my friends was meant to be coming with me today but she can't. Because today's not a good day and she's at home in bed. And people just don't recognise this. And I think you're quite right that because we want to portray ourselves as capable and effective and 'normal' if you like, we don't tell people about the downside.

But now with all these changes to the benefits, I certainly am absolutely terrified that I'm going to get seen being out speaking at a meeting, speaking up for people at a meeting, and it's then assumed that because I can do that, I therefore don't qualify for the benefits.

People don't see the reality that if I go to council meeting for three hours and sit there and say my piece, I then end up spending the rest of the next day unable to do anything.

Also if I know I'm going to one of these meetings, then I spend the whole of the day, because they're normally in the evening, not doing very much in order to ensure that I can actually do that. And that just doesn't get seen. And even when you explain it to people, they still don't get it.

I think the fact that you're doing this and doing it in the way that you are, I think really is just demonstrating what the reality is. And I'm so pleased that you're doing it.

Liz: Thank you.

I hope it's starting to tell a different story. Because, you know, as I say, I've guarded that part of my life for 30 years. I have lied for 30 years. And it's been a really big cost for me.

But actually, I think, for other people too. Because when I think of friendships, some people have known me for 10 years and haven't realised that I'm ill. Well, that doesn't say much for my trust in them as a friend.

It also doesn't allow them to do right by me. Because they don't know me well enough to do that.

So there are all kinds of consequences, personally, about keeping that separation.

But I think with what's happening in current government changes, it's become really, really urgent to bring in another story.

The problem for me has been that in order to answer the whole fraud-to-scrounger narrative, what we've found is another narrative to bring out in the newspapers and blogs and all sorts of places on social media, of people effectively becoming a victim. So saying, "This is how awful my life is." Having to say, "Do you what? My life is completely and utterly tragic and that's why I deserve benefits.

But that's not why somebody qualifies or entitled to benefits. It's on the basis of need.

And actually, to be able to have an interesting life, integrated in all of this, is really, really crucial for all of us. For you to go to the council meeting, that is a part of who you are. And we as a society gain from that. Why would we not want you to do that? Why would we not want to give you the necessary support to be able to do it? It doesn't – it only makes sense if the rhetoric is to divide people and to scapegoat them. Even to get larger policy and ideology through, it doesn't make any sense in a way of systems of support, or economic savings, or any of the rationale that we're being fed.

Dawn: In mental-health campaigning over the last three years, there's been a big shift towards destigmatising mental health. A whole lot of work has been done to say that people with mental health can contribute as we can to any walk of life, workplace, or anything.

However, we've almost made the mentally ill seem so successful that when they do become unwell with their mental health, there's sudden backlash of, "Ah, wait a minute. Weren't you all saying you were too well? You were perfectly normal."

So then now we have dilemma you've just mentioned. Of it's not about how well we are when we are at work, it's about the need when we're not. And how do we ever get round that? How can we live as being normal and being seen as normal, but then say, "Hang on. But you sometimes actually do need help."

Liz: It's as though we almost have to do in extremes. And certainly, I've been a disability activist for about 30 years. For a very long time, we presented a different image that said, "We're strong. We're proud. And the only thing we're dealing with that limits our lives is discrimination."

At the time, it was essential to put it that starkly.

But actually, we have moved certain things along and now, in particular with the current changes, we have to try reintegrating with the reality of our lives.

It's still a shift from what happened before that ideal of out there and proud. Because that was all about tragedy.

Now what we have to say is, "Look at our complicated lives."

And the strange this is that non-disabled people outside these systems are allowed to have complicated lives. They're allowed to have good days, bad days, happy days, sad days. You know, call in work because they're poorly that day or the kid's off school or any of that sort of thing.

It's not that they're completely unaccountable. But they are not judged in the way that we are judged.

It seems to me completely obvious that people vary. And it's almost as if there's idea that we are really inconvenient and it's rather annoying that we're here.

Do you know, actually, we just need to get to a point of going, "We're here." (Laughter)
Let's just get over this and now let's deal with the practicalities and make a system that is

humane for people who need it right now and for people who need it in the future. And for the people who are living alongside us. It just makes sense to integrate that.

1: One of the things that I've noticed myself is that there's a false economy in this and the wasting of public taxpayers' money.

Through the incapacity benefit, I was receiving about £5,000 a year. And I felt, although I couldn't be extravagant in anyway, it gave me autonomy and self-control to do things.

When I'd had recently got involved with the ATOS assessment, I thought, "Oh, I'm going to go to my MP." I thought, "I'll do a bit of research on my MP." I realised, this is not an MP who is going to really be sympathetic my position.

Then when I looked up his expenses, a couple of years ago, in one year, he claimed £180,000 in expenses.

And I thought, "In one year, that's my life for like 90 years paying for me and I'm a scrounger."

This man who was born into wealth, who had the top education, went to St Andrews University. So I'm making a lot of assumptions about him. He thinks nothing of claiming that money at taxpayers' expense. Yet would be one of the people that would point a finger at somebody like me.

And I thought, "There's no point in making a meeting to go and talk to him, because I don't think I can sit in the same room as him."

Liz: And he was also, whilst claiming those expenses, voting through the Welfare Reform Bill.

1: And all other kinds of things. When I looked at his voting past, I thought, "Yes, I have made assumptions about him." Most of them have kind of been based on the pattern on his voting. He's not in any way what I would call a socially moral person at all. He's a very me, me, me person.

Liz: I've given up contacting my MP because I decided that I could use the resources I have more effectively.

I think for me, the kind of final obscenity in all that's been happening – is it just Monday of this week or Monday of last week – I've lost track – but it was the point where we were looking at people on very low incomes and low pay having their income cut at the same

time as we were watching the richest swathe of society having their income tax cut and corporation tax loopholes still being allowed to continue.

How those two things can be permitted to exist alongside, I don't know. I don't know yet why people aren't rising up against it. Except they are, I guess, believing the lies.

2: I think the problem is that the system that we have of media is so controlled by those very wealthy individuals that that is all people are hearing. And this drip, drip, drip. This has been for the last three or four years massively intensified that we're scroungers, that we're this and we're that and the other, is what's leading to it.

And the truth isn't being told.

I mean, the fact that if you are assessed for ESA and you qualify for ESA because you are not fit for work, but they decide that you are fit for work-related activity, you then have to go and attend for interviews.

If you fail to attend without good reason, they cut your benefit to £28 per week. I mean that is simply not – nobody knows about this. Even when you go online and you look at benefits-advice websites, they are using the old figures that were the case last year, where they gave you – you continued to receive the £71 and they took away the £28, which was the work-related activity thing. They changed that in December. They now take away the £71 and leave you with the £28. And that's just not being told to anybody.

Liz: There are so few facts out there. I've been really disturbed by a conversation I had with my mother recently who is extremely supportive and a brilliant advocate for disabled people, but was talking to a family friend about what is happening. The friend came back and said, "Well, there is a lot of fraud." And there are so few facts out there. I have read a headline that claimed that 75% of people on incapacity benefit, which has now been replaced by Employment Support Allowance, but a claimed fraud rate of 75%, which is 200 times the real figure that's put out by the government department.

I think - this is the reason I'm not writing to my MP anymore - that information is going to change nothing with him. I think what we have to do is reach people like that family friend who is a good and kind and compassionate person. She is a lovely person. But she has been misled by the lies.

We need to be having direct conversations with those people and saying, Overall fraud: 0.7%. ESA/Incapacity Benefit: 0.3%. DLA: 0.5%

42% of social security goes to pensioners.

And this one really knocked me for six. Over 20% goes to people who are in paid work, but their incomes are so low that the state is basically topping them up and subsidising employers, allowing employers not to pay properly. Actually when you come down to unemployment proper, it's 3% of the entire social-security benefits.

If people take in those figures, if they're willing to hear that, actually it changes everything.

If you realise that unemployment's current spend is just 3% of this budget, even ESA and DLA only comes to 12%. And a lot of the people on DLA are taxpayers.

2: They're working.

(Laughter)

Liz: And so the figures get smaller and smaller and smaller. And it changes our understanding of it.

2: And also the fact that for many, many people, their receipt of DLA is what enables them to work. I don't work. But if I didn't have my DLA, I wouldn't be able to run a vehicle, I wouldn't be able to go to council meetings. I wouldn't be able to do any of the other things I do. I wouldn't be able to parent my children effectively because I wouldn't have a vehicle.

So the idea that DLA is somehow funding people to sit around and do nothing, it's just ridiculous. It's actually enabling people to play an active part in public life. Which on the one hand the government are trying to encourage. Hence the idea of having these area boards for local council meetings. Part of it was, the whole point of trying to get a wider cross-section of the community to be involved. Including disabled people. And yet, on the other hand – and the figures are just being manipulated and totally misrepresented to justify something which is absolutely appalling.

I think you're right. I think the majority of people would be horrified if they knew the truth. But because of the way the media's controlled in this country, that truth just isn't getting out there.

Liz: What we do have and we didn't have in the past, as well as one-to-one contacts and the people we do meet personally, is social media. I think that is the primary thing we need to make use of. We need to be getting out this different and more complex, more nuanced, story. And tackle the lies that are out there.

Every time we see it, we need to jump on it within whatever our own personal resources

are. Whenever we can reach, and whenever we are able to reach them.

And when somebody we know can't do that, we can take up the slack. We need to be doing that.

And it's about meeting fire with fire. I think the only people who we can absolutely rely to do that are all of those people on the sharp end. Which are a lot of us if we join forces.

I think it's time up.

(Laughter)

I just want to say thank you very much for contributing.

Everybody looks really worn out. But at the same time, I think it's a conversation we can probably carry on for hours. There's so much that needs to be covered.

This is the fourth of five bedside conversations. The next one round the bed is at 10:15 tomorrow morning.

But Dawn and I are holding an extra Twitter sessions tonight at 8 o'clock. That'll be purely on the Twitter feed. So there will be a picture on the internet, but not audio, not sign-language interpretation.

So if you'd like to be part of that, do get involved in the Twitter feed which is #bedding out.

And thank you for everybody on the internet and Twitter being involved. And thanks very much to you guys for being involved too.

Bedding Out created and performed by Liz Crow

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