Bedside Conversation 1 of 5 with Liz Crow as part of the *Bedding Out* performance

Wednesday 10 April 2013 2.30pm with panel members and audience from a disability arts symposium held at Salisbury Arts Centre

Liz: Around the bed, I have members of the panel for that symposium. So welcome. Thank you.

What I'm going to do is first of all introduce Bedding Out and talk a little bit why I've come to be here making this piece of work. Then I'll leave open it up to members of the panel so that we can have a bedside conversation. Then I'll open it up to participants from the floor, because we have about 50 people beyond the stage here today as part of the symposium.

So first to give some of the background.

[Audio begins here]

Bedding Out has really come out of my dilemma that I face in that I have lived a life of two very starkly separate parts for many, many years.

There is public self that goes out amongst people and tries to be energetic and happening and change the world and tries to meet with social approval. And then the people who see me behave in that way think that that represents me.

But then there is the private self as well. And that's a part of me that spends most of my time at home, a lot of my time lying down, and quite a bit of my time in my bed. And nobody sees that.

And I have deliberately concealed that because I learned very early on that that way of being doesn't win friends and it doesn't accolades. And it certainly doesn't win social approval. So I've concealed it very carefully.

But then events beyond me started to change. A new government came in and there has been a complete restructuring and on-going restructuring of the benefits system. Suddenly a system that has kind of worked for me, given me the compromises for 30 years, doesn't work anymore. Because while I project my public self, it seems a sign that I don't need any other support. And what I'm required instead to do is to hide that public self as though it doesn't exist at all and parade my private self that I have concealed so carefully. And it's like a trade; if I parade that private self, I have a possibility of getting the support that I need.

Alongside those changes to benefits, there's also been a shift in the kind of reporting about disability. What we've found is an increase in reporting based on what is visible about us. So there is an idea of what it is to be disabled. And if we stray from that, visibly and in public, we are seen as being a contradiction of ourselves. Indeed, in the press, we're seen as being fraudulent.

This is proving to have incredibly dangerous consequences. So there are statistics that say that at least 32 people every week are dying going through this new benefits assessment process having been found fit for work. Those figures are disputed. People are currently researching them and believe that they are actually higher than 32 people a week.

So what was a personal dilemma has gone into something far of a knife edge. It's not just about me trying to work out how I live my life and integrate two parts. It's now life and death.

So in this work what I wanted to do was make visible a community first of all that is utterly hidden from view. This kind of life doesn't appear in public at all. But I wanted to go further than that. What I want to do is take this story and this life into the wider world so that people can understand that what is seen as an obvious contradiction, almost fraud, is actually simply complexity of real life.

So I wanted to try and get that across through this performance. And also a sense of the very, very real dangers that exist if we cannot create existence and making judgements on people without taking into account the complexities of a life like ours.

I'm wondering whether that strikes a chord with everybody around the bed.

Jo: Certainly when I heard about the piece, I could really relate to Liz and just, "Oh, my God! Someone has broken that barrier of silence around that."

I work with a colleague quite a lot who has fluctuating energy. I have reduced her tears, unmeaningly, unwittingly, simply by constantly making, or constantly pushing, for her to match the way in which I work and not taken into account some of her needs. Simply because they're so unspoken. It takes such bravery to – and I 'bravery', I know, is a really dodgy word to use in disability circles. But this is, I think, the truest kind of thing of that. Because we are so scared of admitting our flaws. Or what we perceive other people will perceive as our flaws. They're not. They're just innate parts of our humanness.

I went and sat with my friend and said, "Hey, have you heard about piece? Have you heard about this piece?" And we both just had a really strong visceral response. We were in floods of tears. I was apologising. I was saying, "I didn't…" This helped me understand what that felt like for her. I've really been privileged to actually be able to witness it in the flesh, as it were.

(Laughter)

Liz: I'm interested that you used the word 'brave'. And I'm going to take a punt and use the word 'tragedy'. Which again is a word that most disabled people would use with great caution. But I think one of the real tragedies about keeping this way of living, this complexity, out of sight is that I realised, talking to people I've known for 10 years that many of them don't even know that I'm ill. And that means that our friendship, our relationship, can never develop as deeply as they might do because I'm not trusting them.

But equally, they have no possibility of doing what's right by me. Because they don't know me.

So it ripples out. Whether it's the structures or the systems that we're trying to fit into. But it comes right back as well to the most intimate –

[18" break in audio]

Hassan: – reveal to the world something which is private and was private for a reason. That would be something particular to you.

Now, having kind of seeded that and made this stage and gone public with it, do you think it might be a bit of a double-edged sword. I don't know. Because you never know how something's going to be received. "But of course. If only Liz had told us that. If only disabled people were not so coy about it when it's a problem. If you display it, then we can all understand it." Do you think maybe, I don't know, it could be received in some quarters as a dovetailing into their argument. Which is, "If only we can list it, measure it, see it, then we can judge it and then what have we got to be worried about?"

Liz: Yes. I mean, absolutely. I think that's a really fair point. I think the greatest risk I see in doing this is that some people will look at my life and go, "I told you it was tragic. I told you your life worth living." And it's so much more. It's back to complexity. There's so much more going on in my life than just being ill puts across. But the being ill and the need to retreat is part of that big picture.

Because there's a really sound reason that we are not honest about our lives. That talking to disabled people in the run up to this, many people have got similar bed life who instantly recognise it. But I found that amongst a much wider group of disabled people, there's also instant recognition because it is just so commonplace that in public we edit how we present ourselves.

We edit how much we smile at people. We edit how much we catch people's eye. We edit how we try to please people. How we massage the social situations that are so complicated; made complicated by discrimination and unease and so on. So it's an immensely difficult navigation.

Through this people I want to resolve that for myself or for disabled people. Also what want to do is to present a kind of counter story. Particularly to the stories of things like fraud. But that kind of collective picture of what it is to be disabled that just doesn't fit anything that I've experienced in the years I've lived as a disabled person.

So it's really about just trying to start the conversation. And if it gives permission to some disabled people to be able to integrate those sides of themselves, that's fantastic. But I also realise that it's too dangerous for many of us. Or too dangerous in some situations. Or a place that we just can't go. Because the costs are pretty too great.

Sue: I think, for me, I'm relating it to what Hassan has mentioned about standpoint theory as well. About the difference between, if you're in the centre, you don't need to reconsider. Because you have the power.

But for me, it's working on many levels. That you have an alternative narrative and through your decision to open up something that's intensely private, you're creating, laying a path, or creating a narrative for other people, a) to identify with, so that they can start, through your process of public integration, for me. Because obviously I very much recognise the experience you're talking about. And I understand these costs. Intimately understand those costs and I've navigated them myself personally, as have many people I know.

But through that process of making it a very public process of integrating and expressing those complexities, I feel that not only are you creating a pathway for other people to begin that process of integration and create a public debate, you're also creating a pathway for the people who haven't yet had to negotiate those situations. Because it reminds me that one of the things about disability as Paddy Masefield said, it's that anyone could, anyone of us, could experience it at any point in our life. And most of us only experience it through the aging process.

So it feels, the personal and the universal, for me are sitting powerfully alongside each other. And for those people who feel it isn't relevant to them, their lives, I think you are perhaps, if it doesn't feel relevant to their lives now, you are perhaps placing a little seed there that people will then have an empowering into the future.

Liz: Thank you.

I hope so. I hope it's starting to pave the way so that other people don't have to make the bumpy journey that a lot of people here will be making.

I think it's also about trying to find ways to counter the narrative that's going on in the press at the moment about how we are all scroungers and workshy and so on.

It's such a powerful narrative. I have been looking at the fraud rates recently. Some of the early headlines actually put fraud rates at 100 times more than the figures given out by the Department of Work and Pensions. And people are buying those statistics that are against us. Hate crime has doubled in the last three years. And it is being linked very closely both to certain government briefings and also press coverage. So getting this story out is absolutely critical.

And I suppose the people I most want to reach for it are the good and the kind and the compassionate people that we all know, but who have been misled by those lies. Or feel that they can't speak out. Or feel that it isn't really anything to do with them yet.

For me, it's that question of how do we take these kind of conversations to them?

Can each of us go, literally, to somebody we know and have that conversation? Just try and right the stories that are told about us, the lies that are told about us, with some stories based on truth?

Marc: I was struck by the 32-deaths statement. But not totally surprised.

Two things spring to mind. The situation for people with learning disabilities. The impact on their lack of day-care provision. They're cutting services. Nearly all moderately learning-disabled people in Sussex for example have lost any day-centre service whatsoever. They're a sort of voiceless group of people that not offered the support or the capacity to articulate, make clear, their situation. I think that's something I'm very aware of.

And also about the knock-on cruelty that's happening in our society at the moment for people with mental-health issues. In those snap-shot moments, you might be assessing people, people that were functioning in a certain role. But the impact on people to end up with far worse positions in a way and the costs will be far greater for society.

Liz: Yes. I think to navigate a system like this, you almost need to not need the system. (Laughter) You need to be well enough, educated enough, articulate enough, well-resourced enough to be able to fight your corner. Without those resources in yourself, or incredibly good support from other people, the people who need that support most of all are those most likely to fall through the gaps.

And it is an incredibly cruel process.

I went through the Employment Support Allowance assessment last year. And was placed in the wrong group. I was placed in the work-related activity group, which for me endangers my health. So it became absolutely critical that I fight and win to get in the support group.

But that meant waiting nine months for my tribunal date to come through.

And I realised the night before my tribunal that in that year 240,000 other people had gone through that same process, which was terrifying actually. I found myself having to go through this whole legal process of going in front of a judge to argue for my existence.

And on the surface the idea of assessing people and having this right of appeal sounds so reasonable. And we need a process of assessment and a process of appeal. But they have to become humane. And they can only become humane by taking account of how our lives and bodies really are. That is not happening at all at the moment.

The other thing is that the cuts that are happening centrally, and having a huge impact on disabled, are of course exaggerated even further by the cuts that are happening on the local level.

So where calculations are made about the impact on disabled people, they're often not taking into account the local services that have changed. It is becoming increasingly difficult even to get legal assistance to go to a tribunal now.

So in fact that legal right to challenge the decision is becoming more and more precarious. Local services are being cut so people who are already fairly isolated are becoming more isolated. Which again, ultimately will have an impact on the numbers of people who need to apply for support anyway.

So in the end if all you do is come at it from the economic angle, it doesn't make any sense. All these measures combined will now, or in the future, cost more money.

Jo: There was an interesting thing. I know a theatre company of learning disabled people where four people this year were told they no longer have learning disabilities. Which when you've been statemented at school, you've been through special education and you've been discriminated against all your life, you've found support, you've found a degree of community, a degree of comradeship. And then you're told you're not in that group anymore.

The impact on the individuals is absolutely profound. A complete lack of identity. A loss of identity. And support and networks.

It amuses me in a really kind of cruel way that we can play with these labels. You know, we were talking about labels earlier and the damage that labels do. But also taking away the label with no support, no preparation, nothing like that, is just as damaging, if actually that label is the only thing you've got to hold on to.

I think ‘inhumane’ is a really strong word. But I do think that’s an inhumane thing to do to somebody; to take away something that you’ve had.

And what does mean? What does it mean to have a learning disability? What does it mean to suddenly not have a learning disability?

People hadn’t become somebody different. You may learn new skills. You may be able to do new things. But this is just simply a goalpost shifting. And it damages people. It really, really, really damages people.

Liz: I think those identities, what is happening now reveals how fragile they are. I think the thing that struck me, certainly the deepest unfairness for me, personally last year, was that I felt over 30 odd years, I had built up a fragile sense of security. I was managing my life well. But it was always precarious. And these changes have taken away those grains of security that I had.

So that I went to tribunal, and I did win, and I came out and I had an hour of being elated and then I realised it had just pressed the pause button until the next time I will be required to be assessed. Which in some cases, with some people, is two or three weeks later after they’ve just won a tribunal.

Where once I kind of knew what my circumstances would be in a week or a month or a year, barring changes in health, that rug has been pulled from under me. And when we are going through that system of assessment, it really does become life. It is a full-time job to manage that system, that assessment, effectively and with a good outcome.

So there is a fundamental contradiction isn’t there, isn’t it? Because of course if you are too ill to work, then how can you ever win through that system.

My own daughter was listening to me blathering about it one day and she just said to me, “You know what? It’s like witches.” If you survive this process, it’s taken as an indication that you never needed the help anyway.

I mean, that’s an extraordinary indictment on a system that claims to be there to support a community.

Hassan: When you were talking about the assessment process, it triggered off something. A kind of Kafkaesque process. It triggered off something for me around my work supporting people making claims as asylum seekers. I think maybe some of these processes which you’re describing, and you’re trying to open out for people, have been honed in areas of life beforehand.

Because if I think if you're an asylum seeker, first off, you were a person somewhere, located somewhere, who had a full identity. Suddenly you become an asylum seeker. So you are stripped of humanity and you become a supplicant on the nation, you know, for a nation to take you in. Then you are involved in this tortuous, demeaning, draining, frustrating, contradictory process, by which you have to prove that you have been persecuted.

So, for example, you have to prove that you've been raped in another country. Or you have to prove that your parents have been killed in front of you. Or you have to prove this, that and the other.

And the way that these tribunals normally go is that in the first instance, you're always refused asylum. Every immigration lawyer knows this. In the first instance, you're always refused. Then you have to appeal. Because they know, that way, they put you on a defensive to begin with. Then you have to appeal, so you have to find something to appeal.

You are caught in this Kafkaesque situation. And I think of individuals who have been through that asylum process, it is an extraordinarily inhumane process.

But of course, that's not an accident. It's designed to be.

And that's what you were talking about. That's the kind of parallel that it sparked for me in terms of my experience.

Liz: You k now, the parallels are huge, aren't they and I'm really glad you've raised this.

I think, within the benefits' restructuring and the cuts that have that been happening, there have been so many different groups fighting their own corner. Absolutely through necessity.

But actually, if you start to look beneath what's happening with specific benefits, with specific groups, the kind of values that are propelling it are really, really similar. And there is a narrative through what you've just told and through all the different groups fighting what's happening at the moment about how some human beings are more equal than others; some people are of less value.

With all that we're doing this area, we need to start tackling those assumptions and those beliefs and have permitted them to be built into systems that are supposed to represent us.

One of the ways that I think we need to do that is beginning to happen. There's beginning to be a groundswell of those groups starting to come together and fight it in a much more united way.

So things are beginning to happen with the People's Assembly, which has just been launched, which will meet in June. And there's a research document come out from a group called Compass, which gives an overview of what's happening and looks at the deeper issues that are behind it.

If we still splinter as separate groups, there is no possibility of us changing the course that this is on. But actually, if you look at how many of us are being affected by this, directly and indirectly, we are a vast majority. Potentially, we're actually very powerful and could turn the tide.

So, I think what we need to do is just open it up to the floor and see if anybody has got any comments or questions.

Trish: Can I just do a quick housekeeping thing here. Because we're live streaming this event, we need to – Hassan has kindly agreed to repeat the questions so that it can actually be picked up by the live stream. So if we can keep your comments and questions quite succinct, that would be very helpful indeed.

Also very quickly, you have permission to take photographs.

Who has got questions or comments?

Audience: Hi, Liz.

Liz: Hi there.

Audience: I'm really excited. No, not excited. I'm really just happy that you're doing this performance due to the fact that I have loads of people that say to me, “You don't look disabled.” And I feel that I don't want to show them me on a bad day. Because if I do, they'll start thinking that I'm weak, I suppose. If you know, me, I don't come across as weak.

(Laughter)

So I'm really, really glad that you're giving people the confidence to show the other side?

Because I know I find it very, very difficult to do it. I don't tell people when I'm ill; I stay home on my own.

So, yeah. Thank you very much. I think you're really brave in doing it. (Laughter)

Liz: I think in the run up to this piece, I started to try answering that question that we all ask, or are asked, in a different way.

You know, when people say, “Oh, hi. How are you?” And you’re meant to go, “Fine.”

(Laughter)

I started trying out, “Not so great.” And invariably people would come back and say, “Oh, I know what you mean. I’ve had a terrible cold recently.”

And that’s when I realised that people I thought I knew well didn’t know me. And it keeps coming back to that thing. It is. It is so complicated trying to reveal those parts of yourself that are not strong and in control and do it in a way that makes us still feel ourselves at the end of it.

In the run up to Bedding Out, there’s been a load of people posting photographs on the internet of their own bed lives. And there’s a few people who have been making videos of themselves in their own bedrooms, revealing their bed life.

And you know the thing that’s really come across to me? They are actually incredibly moving videos. Because what I see when I watch them is people who have really tough lives. You know, it’s time we were able to say that having an impairment, sometimes aspects of it can be really tough. But it doesn’t make us less as people.

Alongside realising how tough those lives are in those videos, I’ve also been so struck by the strength within the people who have made the videos and the kind of levels of compassion that just shine out of the screen.

And you sort of think, “But hang on. Isn’t that what we want to be as a society?” And therefore if those people are starting to show that that’s there, and it’s intrinsic to this kind of life, then actually we need to get those stories out there even more.

Trish: Anyone else?

Liz, just a reminder that Hassan needs to repeat the question for live streaming.

(Laughter)

Audience: It’s not really question. It’s more of a commentary.

It’s very dangerous for me because over the last two years I’ve had people jumping on my chest to keep me alive basically…

But you know, in between the skinny old body there's a soul with a great deal of tensile strength. You know.

Of course, I want to be appreciated as an entire person, so you tend to put the urine bags and things on one side and come forward with your best ___ and all the rest of it. (Laughter)

But again, relying on practices in 2013, suddenly you can ask why I've [inaudible] live in this country and do something damn quick to sort it out without any resources at all.

Hassan: I think just the first part of that comment really. The question of feeling on dangerous ground. In the sense that, I guess what this represents or what it reveals.

Liz: Yes. And I think it is dangerous ground. Of course, all those questions about how we make public those sides of our lives that we concealed. But also dangerous ground in the sense of, "This is scary stuff." You know, I've done 30-plus years of going out of my way to hide this. I don't know what the implications are for being honest yet.

Although actually, the first signs are that I might get closer to finding a way of integrating those two sides myself and I could actually get better. And the people I want to be with most will understand me more and those relationships will develop more.

So actually, by taking the plunge, in my own life things actually might improve.

But it's also about – this keeps coming back to that thing of putting your story out there. So what it means is that in some ways by my doing this, not everybody else has to. They can make that leap as and when it becomes appropriate for them. But what they've got is something they could begin pointing to and saying, "That's actually how it is. My version's a bit different. But that's an idea of it."

It's a place, it's a starting point, for the kind of conversations that just haven't been had and have become so absolutely essential.

Audience: Hello, Liz. I'm so happy you're doing this as well.

But I wanted to say, I think, that I'm so happy that it's a visual art piece. That it is an art piece and it is in an art gallery. Because, you know, as we're always saying, the media is saturated at the moment with this Channel 4 / Channel 5 freak show variety. But then in a way the contrast to that last summer – I don't know if I'm going to say something controversial or not, but the way that the Paralympics and Paralympians were such a success was a slight – that's been about the, in a way, the successful body. Again.

Whereas what you're doing is trying to portray, I think, if you like, you unsuccessful body. (Laughter)

Yes, so I don't really know what I want to say about the Paralympics. Only that I feel, yes, that there was elements of it that were amazing. But I'm not sure where it's taken us right now in this huge tsunami of media hatred.

And I'm glad you've said it's the majority of us that could fight back. It doesn't feel like that, you know, even with this latest thing with Thatcher now, there's a lot of weird stuff going on.

So that's it really, I think. Thanks.

Hassan: I'll try and sum up a little bit. I think – this is difficult. First to say glad that you're doing it. That was the first thing. And then, in one sense, that the questioner was glad that it was a visual arts intervention, as it were. And also this notion of the Paralympics maybe representing, still representing, a notion of the perfect body. Maybe what you're doing representing that question for the imperfect body and what that might mean.

Liz: I think the labels are fascinating.

So much happened last summer in the Paralympics with this kind of collision of images from the superhuman to the fraudster and the scrounger. All these polar ideas of who we are.

Look at the athletes. And they were extraordinary. At the same time, they're no more superhuman than the rest of us. To expect anybody to live up to that label is asking them to fail. They are ordinary and they're mortal. They happen to be incredibly good athletes.. (Laughter)

But there's an expectation of us that we have to slot into these categories.

So we can be superhuman. Or we can be work-shy fraudsters. But we can't be the ordinary people in the middle.

And because those labels are what speak so powerfully, because they're shorthand for complicated situations, it's easier then often then to revert to them.

So what we've found in the last three years, again, with all of this benefits upheaval, is that in order to answer the chargers of 'fraudster', very often what disabled people have found themselves doing is returning to that old label of the victim. And you see in the newspapers and the below-the-line comments where these awful fraud articles appear, you see people doing kind of a litany of how awful their lives are. And that's not an image that represents us either.

Again, yet again, it comes back to how do we get those other stories out there? We may not have access to the most powerful elements of the press. But there other ways. There are ways of talking to people. There are ways of using social media. Just constantly getting the word out there.

Every time you come across something that contradicts what you know of disabled people's experience, don't let it just go. Just acknowledge what's been said, and counter it. Arm yourselves with the facts. Because there's all sorts of information now on the Roaring Girl website that other people have prepared that gives information on the real levels of fraud which are – you know, they matter, they need to be dealt with, but they're almost infinitesimally small. They give real information on the distribution of benefits and what a small proportion actually goes to disabled people and people who are out of work.

We need to get those facts out there. And it's not about saying what it once; it's about again, again and again and spreading that word and building more allies.

Sue: Yes, I've been struck the debates. That actually, within the benefits system it's pensioners and people who are in work who receive in-work benefits who receive most of what's seen as disability or support budgets. So there's already that distortion there in terms of the debate about fraudulent claims and so on.

But the thing that I'm finding extremely empowering about this is creating a link to my own work which I started with some work by Sartre talking about how we live in our bodies. Body for self, body for other. And alienation from the body.

And alienation from the body is when you vividly and continuously see yourself, not from your own perspective and your own experience of life, but from the perspective of another person.

And I've just been really struck by the power of an arts practice, a) to create that thinking space that you've gone through this process of gaining a great deal of information, relating it to theoretical structures and an understanding of the ways in which administration and finance and so on works within society. And how that impacts in terms of power structures and so on. Sorry, I'm getting a bit detailed.

But I'm just struck by the power of an artist's practice to enable you to create a narrative that's body for self.

So that creative process therefore empowers other people to create that body-for-self narrative. And then accumulatively, it’s a process of reclaiming power. Because I understand that there are power structures that exist that shape our lives beyond ourselves. But it first starts with how you feel internally. And if you’ve internalised those messages, and alienated from yourself, then people are disempowered from the start. Before when they start engaging with those processes.

So I feel I’m struck, yet again, by the creative process that enables these dialogues. But I’m sure, from these dialogues, a creative solution will occur that enables us all to move forward.

Liz: I think amongst the many, many groups that advocate for change, the creative process is one of the areas that is sometimes resisted amongst activists.

We have got a massive battle on our hands. (Laughter) I actually think it is one that we can win. But what we have to do is marshal all the forces available and different ways of communicating reach different people. So there is room for blockading traffic, handcuffing ourselves to things. There is room for petitions and writing to MPs. There is room for talking to friends and neighbours and getting the word out there. And there is room for works like that.

And with those we will reach increasing numbers and affect them in ways that they could become part of the solution.

I think we’ve run out of time.

And so thank you very much to everyone who has taken part. And this is the first of five conversations. The next bedside conversation happens at 6 o’clock tonight. So people from the symposium are very welcome to stay on and I hope lots of people will tune in from the internet as well.

Thanks very much everybody.

(Applause)

Bedding Out created and performed by Liz Crow

Panel members: Sue Austin (artist), Hassan Mahamdallie (Senior Strategy Officer, Arts Council; Creative Case for Diversity), Marc Steene (Deputy Director, Pallant House), Jo Verrent (producer, curator and writer)

Tweetmeister Dawn Willis

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