

## Bedding In Bedding Out audio clips

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### Audio clip 1: The social model as a turning point

Liz: One of the most pivotal moments for me was, I was extraordinarily lucky, I ended up at this two-hour session by two disabled women who were political activists who talked about this thing called the social model, that split impairment and disability and pointed out that disability is actually created by the social structures that exclude us. And suddenly, it was as though somebody was suddenly talking this language that I recognised and I could see all that had happened during those school years and realise that it wasn't me and it certainly wasn't my fault, that it was the responsibility of 'out there' and that, actually, if it was socially constructed, wow that meant it could be unconstructed. For me that was the most liberating moment I think I've ever experienced and it does change how I see the world very profoundly. And one of the things in benefits changes that I think is tragic – and it's a word I rarely use because I am nervous of people seeing *my* situation as tragic, but it's too complicated to label it that way- but the thing that for me is utterly *tragic* is that an awful lot of disabled people out there haven't had that moment that I received of realising it's *not their fault*.

### Audio clip 2: The impact of the social model on the public-private divide

Participant: I think there's something really interesting and challenging in that, that the move from a kind of medical understanding or process of disability processing from the outside to the social model in terms of changing the environment around individuals and around society to make that a more even sweep makes it a much more even keel in one way but, as you're kind of articulating, it gives us less of a way – if they're not really trusting of a situation, it gives people less of a way in to have something to kind of to form their own path of understanding.

I'm not in your body, you're not in mine, so in the same way that I can't understand what's going on in your head, clearly I can't understand what's going on in your body. I

can have insights into where those things turn up, but in terms of that kind of raw truth of things, almost the social model to a degree encourages the private and the public self, doesn't it? It encourages that complete dichotomy of – it pushes them apart.

Liz: I think it does. I think the way we, as political disabled people, have used the social model – I'll explain what that is in a moment – has encouraged impairment to be hidden.

Participant: That's what I'm saying.

Liz: In the political movement, the social model was developed to separate people's impairment from social structures that excluded people, so disabled people have impairments but we are *disabled* by the structures outside, the things that keep us out, whether it's attitudinal or structural or emotional or the myriad of things, cultural and so on, and possibly by necessity in the early days of campaigning we focused very much on structures, particularly practical structures, and made great progress. But that worked for people who could then conform to that, who knew they'd be well tomorrow or in an hour or that, whatever their body was today, it would be that next time they looked or worked with it. But for those of us with a very different experience, we couldn't conform to that so we kind of got lost within that political movement.

### Audio clip 3: Background to benefits reform

Participant: Can I just ask? I'm not from the UK, so I don't really know this social political context of when and where that things have changed recently. Can you explain just a little more so I can get the picture of why it changed and why?

Liz: What happened was that the Labour government, the previous government, brought in reforms to the benefit system because the numbers of claimants had escalated and there were concerns, particularly in austerity, that too much money was going out. And they brought in pilot studies to test the new system. The Coalition government came in, stopped the pilot studies and decided to embark on the full reform process. So they brought in a new system of assessing people's eligibility that's based on a very mechanical approach to impairment, so for example you're asked how long you can sit up, how far you can walk, whether you can pick up a coin from the table, but you're not asked the cost of those things and if you were doing it every day or doing those different things in combination, what's the impact then. There's no subtlety in it. And the result is that thousands upon thousands of people are falling through the gaps. Typically, they're people with invisible, changing, hard-to-define impairments and at the moment 32 people a week are dying having been found fit for work through this process. So what they are bringing in isn't only making people's lives very difficult, it's a really demeaning, hard, gruelling, frightening process, but people are dying and committing suicide because it is so harsh.

But that change is happening alongside a rhetoric in the press of disabled people, claimants, as fraudsters and scroungers, so when somebody is found ineligible for benefits, whether or not they actually need them, then they are slotted into the fraudster/scrounger rhetoric, and linked to *that* has been in the last two years a massive rise in disability hate crime. And the three elements are utterly linked and so, as somebody who's been involved in the disabled people's movement for many, many years, and we've fought very hard and made really significant progress, for the first time

I think we're facing something where we are genuinely fighting for our lives. And if people read the press, even if they skip the fraudster/scrounger rhetoric, the tendency is to say, Well there has to be some kind of assessment system, we have to see that people are eligible because it is tax payers' money, and I don't think anybody is arguing with that but what is not being seen are the mechanics beneath it and the just horrifying cost of them. But that is what we're facing at the moment.

And that is for people who are considered 'unfit' for work. But for those disabled people that, for all disabled people who have additional costs of having impairment or facing discrimination, there's something at the moment called Disability Living Allowance which has probably been the most liberating piece of public policy over the decades and that's being scrapped and replaced with something else. And what people are saying is when that starts coming in from next April, *that's* when it really hits, we haven't really seen anything yet. Even though it's 32 people a week, just wait, is what people are saying. But we're in a time of austerity and it's a convenient reason to drive through ideological policy, that's what we're facing, and if money is tight, many, many taxpayers will understand and will support cuts and there's the whole thing of money has to be found from somewhere. Of course it's those much bigger questions, and from my perspective there is plenty of money, but it's distributed in a very unequal way. It's not actually that we don't have enough money to support each other in this society, but it's as though those kind of debates are so deep that we can't quite have them publicly. But that's what we're facing at the moment in this country. So it is a dangerous time.

#### Audio clip 4: Benefits reform and the Paralympics - a collision of message

Liz: And the whole thing of one disabled person representing all the others so that everyone's judged by, has become a *huge* thing during the Paralympics this summer. So for me that was seriously bizarre – I don't know whether I've ever experienced anything quite so surreal or collision course as that. I mean I watched the opening ceremony whilst filling in my tribunal draft. I quite liked the irony (laughter). And so looking at the newspapers it was kind of, one side was bombarding me the scrounger/fraud rhetoric and then the other side was bombarding me with the superhuman rhetoric. And then of course the newspapers caught onto these fabulous athletes – and they were amazing and I loved seeing how completely at home they were in their bodies; that was completely exhilarating for me to see that – but then very quickly some parts of the press caught on to how determined they were and how, obviously, with determination, all of those lazy, scrounging, fraudulent types could also get their arses into a job. And it was as though the scrounger rhetoric was seriously problematic and even dangerous, when the Paralympic one came in it brought it into even sharper relief. And so, going down the street, people would say "Oh, what's your sport?" and would be really disappointed when it was like "Um, yeah... right. That doesn't happen anymore" (laughter). And in the past I have been told off for being lazy enough to have a battery and motor in my chair, stuff like that, and it's just extraordinary the judgements that people are making.

Then what you've got is the athletes have a particular range of impairments, so they tend to be very mechanical, measurable, generally quite predicible impairments, so what they had yesterday is there today is there tomorrow, and they need to have those types of impairments, in fact, to qualify to be Paralympians. But then you take a group of people who go onto out-of-work disability benefits and find they are a completely different group. They would never *qualify* as athletes because what they have are

impairments that are perhaps invisible, really hard to quantify and quite nebulous, changeable, unpredictable, but because they're largely invisible they are judged by these more visible type of disabled person.

#### Audio clip 5: The power of the press

Liz: I think particularly in a time of austerity there is quite a widespread desire to look for somebody to blame and we have become one of the primary targets. People want to know why we're in the mess that we are in and, whilst lots of people say the bankers, there is a strange rhetoric that says disabled people have been responsible for the entire world recession. (Laughter) Perhaps that's an achievement, I don't know! I just think, wow, did we really do that!

Participant: Has someone really said that?

Liz: Really said that. That was a Department of Work and Pensions minister interviewed in the newspaper. (Incredulous exclamations from participants.) I know, it's staggering isn't it. And the really frightening thing is that unfortunately there are people who believe that. If you look at things like... you know, the fraudster/scrounger thing is that that rhetoric has gone across the political spectrum in newspapers and it's been tabloids and broadsheets. Since the Paralympics and the activism that went on in that two-week period, there has been some shift and more of the broadsheets, particularly the left-leaning broadsheets, are bringing in much deeper perspective, much more thoughtful pieces, but if you look at circulation figures, the newspapers that get seen by more than any are the right-wing tabloids, which also have these big shouty front page headlines that many thousands more will read and *get* in a split second. And those ideas of us as morally corrupt are reaching thousands upon thousands upon thousands of people and it's insidious. And even if you talk to people who you think are pretty well up on current affairs, thinking people, people you trust, it's really surprising how many will say "But we are in a really deep hole financially, we've got to cut back somewhere."

#### Audio clip 6: The claimant on the rollercoaster accused of fraud

One particular piece of reporting about a woman who claimed she had an impairment, she was in a lot of pain, and who was photographed at a theme park on a rollercoaster with her two children. And she was accused of fraud and taken to court over it. Now I don't know anything about her circumstances – it could have been fraudulent, it might not have been – but I looked at that report and that photograph and thought, well, that could be me because as a parent you do those public things with your children because it's really important they have those sorts of experiences. What is not then seen if I were to do that, or possibly if that woman were doing it, is the amount of preparation that has gone into it and the amount of recovery. Because those are not the things you photograph. It's not only that they're not in the public eye, they're not in the family album actually, if you think about the sort of photographs you may have of family occasions and actually typically anyway we don't photograph the ordinary domestic stuff, we certainly don't photograph the ordinary domestic stuff that is lying in bed. So there's layers and layers of it being hidden even from ourselves.

### Audio clip 7: Benefit fraud hotlines

Years ago, one of the tabloids announced one of their occasional fraud hotlines so you could 'Beat a cheat dole scrounger' and people could phone up and report on their neighbours. And I lived opposite somebody who was a bit of a curtain twitcher and I had this little sitting room and, mainly I'm a wheelchair user, but I would walk from one side of the room to the other, but I would make sure my blinds were shut first because she might misinterpret it. So then you get into that whole thing of, oo, so am I scamming, because I did just walk and obviously I feel guilty because I hid it, but actually no it's back to trust again and I think I was right not to trust in that instance. But isn't it ironic that I'm considered too ill to work, according to the acceptable work patterns out there that is, and yet the amount of *work* I'm having to do to manage this whole situation is immense. But it's what I see amongst other disabled people is a tremendous amount of work and self-consciousness all of the time, you know to stay safe.

### Audio clip 8: The need to 'perform' impairment to secure benefits (part 1)

Participant: Do you foresee that more people will bring their own personal-private selves forward, so that they are assessed and can stay on and continue to have benefits? And it kind of makes a situation where one would have to perform in a sense their disability to keep receiving benefits and then potentially create more people who would fall into a fraudster category if they're performing their disability for the sake of a tribunal, carrying on and living their life fighting and managing and operating within their disability. It's wild.

Liz: And you say that- but it's so complicated actually and, being here, where I bring private and public into the same space, actually I'm confused about who I am. But, yes, people are starting to perform the private side of their lives, but I'm really concerned about that because there has been a clear response to the fraudster/scrounger rhetoric that, if you look at the comments below online articles and on Facebook, and it is a story about being victims. And you find that people are doing a litany of their symptoms and how hard their lives are, in a very unanalysed way so it all comes from impairment rather than anything to do with social structures as well. And what I can hear is people desperately justifying themselves, justifying that they are 'bad enough' not just to qualify for support but to *deserve* it. And it's actually an incredibly complex game that people are having to play and learn very fast, but given that hate crime is rising, to play to the victim mode is just incredibly dangerous.

### Audio clip 9: Having to justifying ourselves

Participant (struggling with tears): And it's hard, it's really difficult, because I want to work and I want to educate myself and I want to do all these things, and I can really relate to that doing things and putting on this public face to get accepted into the institutions, to be able to do this work... and not being able to do it in the time allotted because of these things and then having to explain myself and re-explain myself and retell my story and it's like constant justification and I feel like I'm being dissected a lot of the time. And it's a hard explanation when you have this fluctuating thing that people can't see, so these changes in the benefits are something that... makes me very sad. And I'm just really glad you're doing this work.

Liz: I think there is something about this way that we're called on to justify ourselves. And I employ personal assistants to assist me with everyday stuff and I come from Bristol and that local authority has actually been really pioneering in setting up this Direct Payments system, but they've brought in a system now to make sure that, people are means tested, and one of the things they do now is come out every year, and you're now expected to keep receipts for all sorts of things in your life that have to do with your impairment. So, on the surface that doesn't sound such a big deal, it doesn't seem like such a big deal to fill in a form for benefits: it's tax payers' money, etc, etc. But the way it's done is so unlike real life and so intrusive that it's really problematic. So this particular person came in, a complete stranger, and was asking me questions about my life and when I started to bridle was saying "I'm trying to help you here. I'm trying to save you money." One of the questions she was asking was do I do lots of extra loads of washing, and I said to her, "So what you're really asking, as a woman of my age and a complete stranger coming into my home, is am I incontinent." "Oh, no, no some people dribble." (Participant laughter) You're so missing the point here! But now I am expected to keep receipts for everything related to impairment so they can "help" me, and I was trying to get across to her that I don't divide my life into *crippled bit* and *the rest of me*. I am a complete person. And if I choose to buy organic vegetables, well some of that's a health thing, but some of it might be a choice I'd make if I could anyhow, so do we agree a percentage, and how much *work* do I have to do, as somebody who's considered not fit to work, to actually manage this system that bears no relation to anybody I know? And it seems to run through everything, because one of the things that underpins particularly this new benefits system is the idea of economic productivity, that it's really, really essential we're all contributing in a tax paying sense, paying our way – you know, that people who are working part time are now being called up if they're not working enough hours and earning enough money and being required to extend – and it seems like it's so driven by this economically productive drive and it's as though we need to go so deep into the rules we live by as a society and to question what really *matters*, what do we mean by contribution, how do we redefine that, what kind of society do we want to live in, what matters to us? And they're such enormous questions, but actually they're the most human questions of all.

#### Audio clip 10: The need to 'perform' impairment to secure benefits (part 2)

Liz: The other thing that I'm going to say is, for me, I try and turn the whole benefits thing into a performance because this is a game that you have to play. If you know for yourself what your support requirements are then somehow this is a system that you have to make work as well as it possibly can. It still will be imperfect, but you have to play a particular kind of game. And that takes practice. I've gone to an appeal for Disability Living Allowance before now, which was a critical thing for me to get and I'd been trying to get it for four years, and on this particular day, well, I had a run-up of several days where I decided, no, I'm not going to wash. I put some grease in my hair (participants laugh), I wore my sister's mustard jumper which is a really bad colour on me, and it's like, this is the game, it's like game on. If *that's* what I have to do to manage my life, yeah okay, I'll do it. But I'll mark it and I'll use it. And I don't know if that's the advantage I have in the work I do, is that I *use* it.

#### Audio clip 11: On biting back and taking risks

Liz: I suppose one of the things I'm kind of intrigued with in this particular performance is that, there's a little bit of news interest in this and should it get picked up on, I'm quite interested to see what would happen at the tribunal, because am I being productive now or am I being ill in bed, which one is this, and am I jeopardising my tribunal outcome or am I helping it? I did lie low for the first 18 months of the benefits reform because I was scared of being seen to do something that would contradict it or jeopardise it and then I just got to the point of thinking, this is *life* from now on, because even if I win at the tribunal, in a few months it will all start over again and it will be repeated. And I just thought I'm not prepared to lie low, so it's trying to find ways of not being afraid of it, of biting back, which some people are succeeding at and others are struggling at.

Participant: You're being a productive activist right now. But there's a lot of personal risk in that because in those anecdotes you've told about closing your blinds and wearing a mustard colour jumper you're performing a simplistic notion of your ability, disability, where you are on the spectrum, and quite deliberately placing yourself in a more simplistic thing, and therefore reinforcing all those codes that you disagree with but, in order to engage the conversation around complexity, you put yourself at significant personal risk because you might make change but in the process you might be misunderstood, you might have your benefits withdrawn. I suppose that's the dialogue, that's the space you enter in.

#### Audio clip 12: The stereotype of tragedy

Liz: And I don't know what this thing is that makes it so very difficult to trust other people. One of my fears is that by being honest it permits people to go, "See I knew it was awful, I knew it was tragic to be a disabled person". And it's not a description of my life that I recognise. There are things in my life that have been extremely difficult, and there are things that I grieve for, but there are doors that have opened. I've actually had a more imaginative, unpredictable life than I would ever have imagined before this started. So the idea that I could be labelled as tragic doesn't fit what I know of my life but I am afraid that by revealing too much, many people will have confirmed this stereotype of tragedy.

#### Audio clip 13: The benefits 'contract' to be miserable

Participant: What you were saying about the woman at the theme park, that the cost of these benefits is that you can't be happy.

Liz: Somebody said to me recently there's a pact in the benefits system, as though you sign this contract, that the trade is that if we the tax payer support you, the trade is that you must be miserable in return. We cannot see you taking pleasure in your life. And I think that one's really embedded. And yet the thing that connects us with people, and particularly strangers in the world outside, is smiling and making contact that way, so there's this constant double-edged thing that if you look the way you're meant to look, it fulfils a stereotype but it also distances and it also plays into victim and it plays into hate crime and you get this awful spiral down, and somewhere that has to be broken.

I think where you guys come in is to start talking about this and when you see things like the scrounger rhetoric to challenge it, to be active allies, because that's what we need.

We need that kind of groundswell that starts to be outraged by what is happening and really to say “Not in my name”.

#### Audio clip 14: Becoming an artist-activist

Participant: There’s so many things I could ask you, but I’ll just stick to a kind of activist, artist, where those two sit, and the history, because you said you’d been engaged in the movement, direct action you spoke of as being highly effective, and I think it is, where we’re actually very polite as English people, you know (chuckles), it’s difficult sometimes to do that.

Liz: I guess I’ve been involved for a long, long, long time actually, I guess it was the early 80s really that I first identified as a disabled person. I’d had an impairment for years experienced lots of discrimination, but I, as far as I’m aware, didn’t know any other disabled people, and I certainly didn’t have a political concept of it. Everything told me that the difficulties I was facing were because of a pain syndrome that I had. And then I went on a two-hour disability equality session and about 30 seconds in everything changed. I mean there was a moment in my life and nothing has ever been the same since. And somebody just separated impairment from disability and I recognised everything that had happened to me for the previous ten years and overnight became an activist and I became a disability equality trainer and worked directly with groups of people really to look at that separation and to establish the idea that somebody’s impairment in this situation is a given and you’re not going to have any significant influence on that unless you’re their medical assistant, but actually all of *this stuff* is socially created – and therefore can be socially uncreated and everybody has some role in doing that. So that’s the angle I came from.

And then direct action started to build up within the disabled people’s movement and we started blockading buses. So we’d kind of move out into the road, put our hands up, stopping double decker buses in the centre of London and we’d get our handcuffs and we’d cuff ourselves to them and we’d stay there for a number of hours, and it was incredibly televisual and we got masses of coverage because what we were presenting was an image that was just so *polar*, particularly then, from the image of disabled people who, really, we weren’t much *seen*. I mean there was no public transport, you couldn’t get into taxis even, you couldn’t get into buildings. I come from Bristol: disabled people couldn’t get organised because there wasn’t a single public building we could even meet in, and it was dire beyond anything. I have to remind myself how far we’ve come. I mean, I went to university and I got kicked out for being a cripple and they could do that then and there was no comeback, and they’d have to be much more canny to achieve something like that now, but then they could be completely blatant about it. So we made enormous progress because technically and legally you couldn’t do that sort of thing now.

But I think where the direct action comes in is it’s done two things. One is that it’s done something very theatrical to draw attention to what’s happening or not happening and particularly with transport actions it was so direct (you’re blockading inaccessible transport to campaign for accessible transport; it’s a very simple picture for people to get hold of), so I think it got a message across that was brand new. But I think there were also spokespeople at that time who were trying to get across this idea of the social model, and they were just thought to be so militant and radical that they couldn’t be



heard in a mainstream context. Then those of us who went out onto the street took the flak; we suddenly become the militants and the radicals and suddenly these guys seemed quite reasonable. So now we actually have a few people in the House of Lords, for better and for worse, but who are actually able to speak direct into government policy because the people on the streets made them hearable.

So that's my background and involvement in that. and I guess I come from a creative background and a creative family and for me it seemed a natural meshing of the two. As I said, I still very much think of direct action as as much a performance as this and any number of things that are happening at SPILL. That said, within the disabled people's movement, there is a very strong divide between the academics who have sold out, the artists who are the kind of bourgeoisie and just away with the fairies, and the activists who are there on the ground doing the real thing. And I've moved between the three repeatedly over the years and personally think you can't make progress without drawing on all three, because the academics get the evidence, the activists go out on the streets and push it forward, and the artists have a creative approach to communicate effectively. So I think there are still strong elements within the core of the disabled people's movement that will completely misunderstand what I'm doing here and then there are other people who are very excited because they feel they've got a voice that they've not had before.

#### Audio clip 15: Integrating the private and public – obstacles and openings

It would be extraordinary to find a place, if there is one, where I *can* integrate that public-private. I have no idea whether that's possible but, in a sense, I suppose this sort of setting is the place I start to experiment with it. In fact, I had a, for me, very interesting situation recently. I've started a doctorate, and it's like the world's slowest doctorate - I have officially eight years and I think I'm probably going to need an extension – but I'm a really good department at Bristol University and I have been experimenting with the idea of lying down in public spaces and why that's so unbelievably difficult and the kind of ideas from that – how even in various countries now, including Westminster Council is trying to do the same thing, they're bringing in statutes to forbid people from lying down in the street. And it's about homelessness, basically it's about moving people on. What does that mean for those of us who need to lie down? Do we have to not exist in society because it's really unacceptable. So I started working with at, then, for this doctorate I periodically have two-and-a-half days present in lectures which is just massive for me, and I realised I couldn't carry on like that, and so last time I took a bed in – a *huge*, huge thing to do, but it was the most incredible experience because what I found was that within five minutes of being there someone was saying to me “Uh, these chairs are really uncomfortable and *why* don't they provide us with a table so we can note-take without hurting our back?” I just said, “There's some tables down the corridor, why don't you just go and bring one, no one's going to mind.” She said, “Oh I couldn't, I couldn't.” And I persuaded her and she went and got one. And somebody else said “Oo, where the table from?” Fifteen minutes later the tutor said, “Right before we get underway, anyone else want a table, go and get it now.” (Participant laughter) Half a dozen people set themselves up with tables. By mid-morning, the first person perched on the corner of my bed. By late on day two, somebody was sprawling on the ground while we were having our lecture and by the third day the tutor brought the laptop with something for us to watch so that I could see it from the bed. Somebody perched here, somebody perched

there, the rest gathered round like this, and somebody else did a dog-on-a-hearthrug in front (participant laughter), and it was absolutely extraordinary.

My experience as a wheelchair user is that if I go into public spaces, I end up sitting on the end of a row. Very often they fill up with people and there's a sea of empty chairs around me. I've had this on crowded trains over the years, where people will stand in the aisles, but they won't sit next to me. And I'm used to this sense of, actually, incredible isolation in very populated spaces. On that course, my bed was surrounded by chairs which I thought was going to feel really exposed, but it felt like having a *hug*. It was absolutely incredible. I have never felt so completely incorporated into that social side of things.

I guess one of the things I realised is that doing that wasn't really about me in the end. I was more comfortable but actually it was about the other people there. And by doing that it actually gave all these people permission to break the rules and be comfortable and make better use of the two-and-a-half days because they were relaxed. So if each of us can just find one thing that's hard to do and break the bloody rule anyway, cos who says we have to do things a particular way?

#### Audio clip 16: Safe-guarding the progress we have made

I think for me one of the concerns at the moment is that as a movement we've kind of got our eye off the ball. I thought a long time ago that if you won something you moved on to the next thing; what I didn't realise is that part of you has to stay behind and guard it. And perhaps we haven't guarded it well enough. But our focus has shifted from what you're describing simply because with benefits changes literally we're fighting for our lives. So at the moment, linked to these benefits changes, we are aware of 32 people dying every week, so campaigning on that is *absolutely* critical - and so if anyone's looking for something to campaign on, please we need your voices in this. The result of that is, we're not watching all of that stuff as well, and part of that means we're then reliant on somebody like you to stay on that because the risk is that, if we win on benefits, we'll come back and everything we've won will have shattered in the meantime. [Sound of very heavy rain on window.]

Participant: That's dramatic. (Participant laughter)

Liz: I'm glad we're in here!