

Big 30 Website – Challenges Stereotypes – Long – Transcript

LIZZIE: I hate that word normal, I do. I do hate it. I mean, normal to me is like a cycle on the washing machine.

MUSIC: See Me by Lizzie Emeh

MAT: My inspiration is the desire to have a world where me and all the other different people are treated as equals and to do that using the arts.

So I see myself as a vessel for change through the arts. I also see myself as a guy that needs to do more buttock exercises in case I get old man ass. I also see myself as a loving, caring husband with an effect that when we go out in public and are this successful, lovely glamorous couple I'm aware that you don't often get that when one of the people is disabled and that we're slightly ambassadors for that. So there's a responsibility to that, which we love to subvert. So sometimes I'll be in the supermarket and I won't be able to reach something and I'll say to Julie can you reach it, and she'll have that mischievous look in her eye and we know that there are people watching and she'll go, no, get it yourself. God, why do you have to be so disabled, and then just walk off, just to see the look on their faces.

KEITH: I remember Janet Bobin. Heart n Soul had got in these 4 by 4 risers, these aluminium risers with stairs. So you'd have one upstage left, and one upstage right. And in this performance Janet Bobbin would come up the stairs on to this 4 by 4. There was something that within the script that she didn't like, that it was scripted, she didn't like. Janet Bobin then comes to this part in the script and she goes, and you know what, sod 'em! And it was just, like, roaring.

LOLITA: We all joined a drama group

LISA: Yeah, I used to crawl across the floor, didn't I, because I couldn't stand very well because I'd not very long had the operations, and I used to crawl across the floor to get to things. Do you remember the grid what we walked across? The grid is like all the main bits inside, in the main theatre. Trish was teaching us all about the grid and all the others went up to have a look and she said, you're going up, we're going to figure up a way of getting you up there. I said, no, no, no, no. I was like this, I was sitting there and she goes, yes you are, you're going up. I said to Trish, there's no way I'm going to get up there and she said, oh yes you are. She got me up there and I walked across all that. It felt...it was a bit of a challenge, because when you're, like myself, with rollators or a wheelchair, I feel sometimes you get forgotten about, but they found a way of getting me up there.

ONO: I made a film with Channel 4 called Road Trip, where a group of us went from London to John O'Groats and where we interviewed people about the different topics. I came up with the questions and when we went to Scotland I interviewed this man and I asked him, what do Scotsmen wear underneath their kilts? And he told me, nothing, and he gave me a piece of cake.

We travelled in a really old, red double decker bus that broke down a few times. Doing the road trip gave me an opportunity to go to places that I hadn't been to before. And it gave me a chance to be on TV as well and to be on a prime slot as well. It felt good because it gave people with disabilities a face. I got to show people that people with learning disabilities can do anything.

MAT: I mean, I don't need to tell you, do I, that the constant surprise that people have with learning disabilities is based on their lack of expectations. They have just been taught that people with learning disabilities can do less than they

can, and it's tragic. And every time you do something you can see the gazes of wonderment as people realise the truth.

JB: For the past eight years I've been working directly with Heart n Soul as a tutor. When Mark said Lizzie, I knew who she was and I'd seen her do performance – I remember her doing a really fantastic AGM here at The Albany once, and thinking she had such a great energy and that more should see her. It's been real fun working with Lizzie directly and I love the fact that it's just 'can do' – hey let's go and do it then, why don't we do that. She keeps saying that she wants to be the first person with special needs to win a MOBO award. She goes, I want to get a MOBO JB, I want to get a MOBO – we'll work on it, we'll work on it, we'll get it. So two years ago, Liz goes to me, Bev can you be my backing singer in my band? I said, I'd love to! What's really nice is that the band is full of professional artists. So for example Charles, he's the MD for Grace Jones. Robbie, the drummer he tours with Courtney Pine. Everyone who's in Lizzie's band are like big, big performers doing great things out there in the world and Lizzie has that.

People have some very old, antiquated ideas of working with people with learning disabilities. And I think over the years, because of people like Heart n Soul and other organisations, people getting to meet and see that there's no difference. I see that people are getting more of an understanding and I don't have to explain. So is it hard, does it take long, do you have to change your workshop, your class? I say, I teach Lizzie the same way I teach anybody else, we do breathing, we do scales (SINGS A SCALE). I'm not changing anything, it's exactly the same. And the challenges that anybody who's learning something is no different from anybody else that I work with. I could put two of you together and you'll both be struggling, going oh my god, I'm out of breath when I'll give you some exercises! (LAUGHS) It's exactly the same.

RICKY: That's something that I really like about Heart n Soul, they bring everything to a really professional level. That's what I really love – the fact that you progress, whether you're a participant, a volunteer, into something always bigger, into something new, into something that you haven't done before.

I remember meeting Tilley and Del for the first time and just being amazed by the two of them. I love the way Tilley can talk and be very clear in her way of speaking. For me, especially English is really beautiful hear someone using that language so well. And there's been a moment where we had a celebration for a Christmas party and Tilley at a certain point stood up and read a little thing that she wrote that basically reduced everyone in tears. It was so well written, it sounded like a President would have wrote that. There's little moments where people are just themselves and show themselves for what they are, that teaches you so much about life and about yourself.

MUSIC: Sabrin Summer Funk by Dean Rodney

DEAN: Two years ago, back in 2015 I was doing this song about the superhero by using the VT3 Vocoder. I tried out different ways to make music by using different apps on the iPad, using different equipment like a drum machine. The mi.mu gloves, they control instruments, they control your voice, they can control different effects like voice or music. I was using them to experiment and I started doing vocals on a remixed version of a song I did last year.

CATHERINE: I think you're talking about Mark Roland. He's got cerebral palsy and is a wheelchair user and is non-verbal but he's got control over one of his feet and he used to play the most amazing, loud rave music that he'd composed just using his foot and a switch, and he'd often play at the clubs, wouldn't he?

DANNY: Yeah

CATHERINE: And there was another guy as well who had very little movement, but he could control his head and they'd put switches on each side of his head, like a sort of frame around his wheelchair and they'd attach these switches to this frame around his wheelchair and so he could just operate the switches with just the movement of his head, creating music like that. I think it's extraordinary, the way that technology has developed so that now lots more people can access making music through technology.

PINO: 1982-1986. I gave it up in 1986 because I thought, this isn't for me, that's it, I'm going, I'm going away from the day centres, I'm not staying there no more. It was my decision to leave. Well, I'd spend my time helping somebody in the tea bar so I did that instead of playing with silly toys. Well, they had things that you didn't really want to do, you wanted to do interesting things, things that grownups stuff people should have, learning grownup things, they didn't help you much with that. Well, I always keep doing something, I always keep doing some writing or helping my dad or mum, I was always helping. I helped people with disabilities as well, since 1989. I do all these groups as well, 1:1, Speaking Up, Lewisham Voice – advocacy groups, yeah.

Earning money, it's a shame for people with disabilities that can't earn their own money. Because it's all from the council, I mean social services. We've always got a problem with social services, they're always wanting to know what you've got, and that's why we can't earn anything.

ONO: I got to do some talks as well to councillors about real roles for people with a learning disability. Because not everyone with a learning disability wants to stack shelves, we want meaningful roles.

MARK: We tried to get people into work, jobs. I think we must have been 7 or 6 times around the country – Wiltshire, I think Liverpool, Newcastle – to show people that there is jobs out there for disabled people, to get money to be independent, to show who you are. To be having a job, you feel like you're doing something. When we went to Wiltshire, we saw these people and they worked in a kitchen, they cook. And to me, they run their own restaurant, people with learning disabilities. I said well done, you're getting the message across to other people, it can be done, it can be achieved.

ONO: When they see someone in a wheelchair, they think, ahhh! And then they start babying you and they think that we can't do stuff for ourselves, but we can do stuff. The changes that I would like to see is for the media to represent people with a disability in a positive light, because they don't. They don't show the good stuff that they can do, all they show is the bad stuff. Like, around the Paralympics; we're not superhuman we're just regular people who can do stuff. And we can have relationships as well. Sometimes it may be tricky but we can do it. There is one programme that I don't like, Undateables, because I don't like the title, because people with a disability are not undateable. People with a disability can hold meaningful relationships and get married and have their own family.

ARTHUR: I actually think the Paralympics had a really big influence on a national level of consciousness about people with disabilities and how they're viewed and how they're depicted in the media and in advertising and everything. I think that was a really big step and I felt like, having worked with Heart n Soul for quite a while at that point, I felt like people were catching up a bit with Heart n Soul and the way that Heart n Soul do things – the rest of the country is coming on board a bit.

MUSIC: The Fish Police Anthem by The Fish Police

DEAN: That was in 2012 in late August. I was working with a theatre company called Graeae, they were doing the opening ceremony for the Paralympics. At the beginning, before the ceremony, my band The Fish Police were performing one song and Lizzie was doing a song called Loud and Proud. Backstage was quite funny, I was getting very excited and someone was telling me to breathe.

CHARLES: For me it was just everything, just the smells, the colours, all the different people that were there and they were all wearing different costumes. Because we mingling with everyone backstage so there were people with their really shiny tinsel costumes, really nice hats. The atmosphere was really nice and everyone was smiling and it was just a joyous occasion.

DEAN: We hadn't performed in a stadium before. We'd performed in clubs and different places like pubs but performing in a stadium was quite big. I could hear people cheering, that's the only thing I heard at that point. And I was walking with Charles and Matthew, I felt very overwhelmed and I was breathing very heavily.

CHARLES: The noise was deafening when you walked out. It was an experience that none of us had ever had. You're walking out into an arena, a vast, vast arena with thousands of people and you're going to do a song or two.

DEAN: I became so excited when I went there inside the stadium for the first time and I was like, wow look at all these people! They were cheering, going, yeah!, like people who watch a football match. And up above the stadium there were helicopters flying around and the music was so loud and there were people walking around and I was like, wow, look at all that stuff! Everyone was looking at me and thinking, is Dean all right, is he OK? And I was like, yeah I'm ok , I'm ok, I'm just a little bit excited about what's going on. I was like, whooo! Ahhh!

CHARLES: I don't about you Dean, but I felt really small in such a big space. I was very excited as well. I was so excited that I actually forgot to unmute my bass guitar once the song had started so I started playing my bass and I wasn't hearing a bass sound coming out of the bass. I looked down and I realised that it was on mute, there was no sound coming out of the amp, by that point half the song had already gone.

DEAN: No, I wasn't nervous. When the performance was over I was so happy and I fell to the ground, fell down to the ground with excitement!

CHARLES: It was just an incredible experience. Just the spectacle was incredible, just being there was incredible.

JACQUI: With Lizzie on the main stage as part of the opening ceremony, that was spectacular.

JACQUI: In anyone's lifetime to be able to do a big event like that is phenomenal. Apparently 80,000 people saw it live, in the stadium 80,000 people saw it live, so yeah I was under pressure to get it right, but then so were all the other performers as well. That was a turning point for me, because it made me really stop and think about my work. Gosh, this is really important stuff because it means that a lot of deaf people will get to, for the first maybe even, see people with various disabilities perform – not just deaf people perform. So it was a big thing.

JB: The Paralympics, Lizzie was going to do a duet with Beverley Knight. All of Heart n Soul were in that stadium watching, it was very lovely. And the sound, I thought the sound would be rubbish. You know how in gigs the sound is really bad and I thought what's the sound going to be like for that? But I tell you, it was like I was in my house, and it was, I felt it through my bones. You know

when you feel that the sound is so...and it was beautiful. And the lighting, and of course they always have the fireworks. So it actually felt out of this world, for me. Lizzie on the stage, in front of millions, is it millions or billions? How many people watched it? Around the world. I'll remember it for the rest of my life.

TERRY: Favourite memory...oh, I've got thousands of really lovely memories. You know, every day I look forward to going to work, every single day. People have given me confidence. There was a time that I wouldn't go into a shop and change a shirt I didn't like, but I do now because people with learning disabilities have given me that confidence. I was quite a shy guy and I got involved and there's things that happen with you when you work with people with learning disabilities that you've just got to get on with it. And that's given me that confidence. I've got a lot back – look at the friends I've got. I can walk in Catford, Lewisham, Hither Green and I normally bump into someone who I know from the Gateway club or from the Day Centre. And I would like to feel visa versa – we all enjoy each other's company, because we're all the same. They take the mickey out of the way I dance, we support each other.

TERRY: Happiness, yeah I mean, Lee Grove Gateway club you go there to be happy. You know happiness is not an easy thing to find in the world. You switch the news on and there's children being blown to smithereens, oh it's so, so sad and there's not a thing we can do about it. But you turn up to the Gateway club tonight, where I'm going, and you stand and just see people enjoy themselves. The world outside's not there. That's the happiness that you get from being with people with learning difficulties.

RICKY: I learn so much about myself from working at Allsorts and Do Your Own Thing – not just professionally but as a human being. Being confident, just letting go of inhibitions and shyness and just learning about how to communicate with people, which is not always easy. There's been a really amazing connection with Dele. When I first arrived, Dele's a really big guy and I

was like, oh my god, how am I going to get to talk to this kind of guy – Chris is a big guy, Michael is a big guy and at first I was a little bit intimidated. And then the guy comes there to me and says, oh so you play chess? And I go, oh well I just started. And I think, this is good I'm going to, beat him very easily – what does he know about chess? And in literally 30 seconds the guy just ripped me off and I just go, OK, so, shall we do another one? Yup. And it went on for about 6 months and I never won Dele a single match of chess, which was quite frustrating and quite beautiful at the same time. I was just, how does he beat me so easily? And he was just taking the piss out of me so badly and laughing his head off and I was, well I deserve it! And then you've got this connection through really simple things like a game of chess with people. And then obviously with Dele, we've become really, really, well I believe that we're really good friends and that we have a really nice connection. It meant that we open the door to each other and we could let each other in.

KALI: I always knew I was different from other people. I kind of felt like the phantom of the opera. You think people see you as somebody with a learning disability and that you can't do zilch. When you grow up with a learning disability it is so difficult, it really is, because you don't want to feel that you can't approach people but I knew I was scared of people. So now I can say, no I'm not any more and I can approach people. I think now people are starting to take more of an interest because they're like, wow Kali can really do this, she can really do that. And it's like yes, you know where have you been, you know, where have you been all this time? I moved into my own house, I'm with Heart n Soul still, I'm doing lots of different bits and pieces. So that's how my life looks – it looks peachy. (LAUGHS)

MUSIC: See Me by Lizzie Emeh