

Big 30 Website

How has society changed (or not) for people with learning disabilities - Long – Transcript

MUSIC: Life of My Own by Mark Snead

ONO: People with a learning disability are slowly breaking the glass ceiling and showing what they can do.

MARK: This was probably about 1980...

PINO: '88, wasn't it?

MARK: You're right. And we recorded a Christmas single. I remember we had somebody doing press and PR because we really wanted to make this a Christmas smash. I thought, well why can't we have a number one hit?

PINO: Why not? I always keep fighting for that as well.

MARK: I remember, he was trying to get press and I remember really being very shocked by The Sun newspaper. They said they didn't want a picture of mongols in their newspaper. It didn't hold us back but it made me realise that there was a lot to change.

JACQUI: Growing up with a deaf sister was a lot of fun, but there was a lot of prejudice and a lot of ignorance. We'd get on the bus together and we'd be using sign language, and people wouldn't be aware that I was hearing, and so people would be making comments about us. I'd say, people behind are us are talking about us, they're saying that we're dummies. Quite often we were called dummies. And then, it gave me a lot of pleasure when our journey had ended and we were about to get up, I'd say; actually, we're not dummies, my sister's deaf. She's not dumb, she taught me to tell the time, she's taught me maths, so she can't be dumb and she has got a voice so she's not a dummy. And the look on their faces was priceless!

MARK: Your Fuji film commercial in 1990 – you were the first actor with a learning disability to be on a TV commercial.

PINO: That's right, but that became a discrimination thing again.

MARK: Well, yeah, because it was really interesting – there was an article where Brian Rix, who was the Chair of Mencap, saying it was disgusting that this learning disabled man was being exploited on this TV commercial, without ever actually having a conversation with you, because you got paid, didn't you?

PINO: I was happy, yeah!

TERRY: When I first started in the day centre at Leemore, you were packing screws, nails, glassware. We used to pack twenty screws or twenty nails – do all that. We used to go to factories as well and do packing and what have you. We'd have our lunch at the workshop and that was up at London Bridge we did that. And we did very little social training, very little hygiene, very little cooking. We had 80 people in a workshop at the Leemore Centre doing this kind of work. We did work for the hospitals, packing sterilised packs; things that kept you occupied but it didn't give you that independence that the rest of us had. They wasn't giving people the skills they needed to get through life. That's what I felt was wrong with day centres.

ONO: The day centres have been closed down in the local area. All people with a learning disability had was, when they finished school, they went straight into a day centre and now they have choices.

TILLEY: I've seen almost all of the different kinds of housing. I've been in two complexes for young people. I've been in hostels, as well, for homeless people and I've been in psychiatric wards. I was never violent, although I could have quite easily gone that way. I felt so angry, nearly all the time, being there. I felt so angry that at twenty years old I've ended up there. I went to

mainstream schools and my friends are learning to drive and boyfriends and jobs and uni – why me? I felt angry, so angry with the world.

I looked at myself up and down and I thought, really what is wrong with me? Why do I have to be in a home? No disrespect, there's a lot more wrong what people are doing, and yet I wasn't free. At first they wouldn't let me out the building at all by myself. Then I was allowed in the grounds but they'd watch me. They'd give me a time limit of half an hour. I had half an hour that I could walk up and down. And then I was allowed on the sea wall, from one end of the sea wall to the other end of the sea wall – up and down. Eventually they let me walk from there to the nearest little town along the sea wall, and I think I had an hour. And I was jumping in the air. You have a curfew in the care home as well, that's the other thing and they're quite strict. Which sounds late, the curfew's eleven, but when you're in your twenties and when that's all the time, there's no flexibility, that's it.

LOLITA: I moved out when I was eighteen, I moved out of my mum's place. I wasn't getting on with my mum and I just decided, that's it, I want to move out. And it just went from there. It's fun; I get to do things on my own. Go and see my friends when I want to, come back when I want to.

LISA: I live with my mum and dad at the moment and I thought it was time for me to move on so I applied for supported living to try it out. If it works out for me then I'll stay there. I feel it's time my mum and dad let me go off and do things, be able to be free and go out.

LOLITA: The reason why they're scared is because they think that you're not going to...

LISA: Be able to manage, yeah.

LOLITA: When I was in supported living we had our own key, we could do what we wanted to do, we could go wherever we want.

LISA: But I have to be in by ten o'clock, because the staff go off at ten and I don't want that restriction. But my friend said that if I'm with her, she'll come in

and take my shoes and socks off. If it comes to it, I'll kick them off or leave them on.

It still hasn't changed because there's still that restriction, you've got to be in by this time, and it should be looked into.

LOLITA: In some places it's twenty-four hours, you've got to be in at a certain time because of medication. In other places you can go wherever. If you live on your own or in supported living you can go when you want to, it's up to you.

MARK: There was a trip that we went on to Belgium. We were staying in a hotel where they were having a nightclub. And what happened?

PINO: We were not allowed to go in

MARK: That's right. Actually, they only let two people in but they didn't let any of the people with learning disabilities in.

PINO: Yeah, charming innit?!

MARK: That led us to think that it would be a great idea to maybe have our own club night.

MUSIC: Blouse and Skirt by Heart n Soul

ADELE: There was a time where people would just get dressed by their parents and they would be in tracksuits. It wasn't like you had your own money and you could go out and spend it, or go to the shops and pick what you liked. So you were getting dressed by your parents even as an adult and it didn't necessarily reflect how you felt about yourself. Things have changed massively now.

HANNAH: Lots of young people looking like they were dressed like a fifty year old. They would just dress like their mum or their dad.

ADELE: And the main person that I started to work with was Lizzie and she was wearing things that made her look a lot older than she was. We went out

shopping together and we talked about clothes and how she wanted to represent herself.

What was wonderful was that Heart n Soul were willing to support that as a process. I think it really also challenged the way that people took in Lizzie's performance. People underestimate that other side of how people are presented and present themselves to society.

What I always found uncomfortable about styling bands is that it can be quite hard sometimes, because they don't want to wear what you're...and you don't want to feel like you're telling someone to wear something. Whereas this was a little bit different; it was more about giving people the opportunity to be themselves through what they were wearing.

MAT: When I came into disability arts I was still seeing people who had clearly been dressed by someone else in clothes that maybe they hadn't chosen. That were remarkably and only designed for what seemed like the comfort and ease of the person that would have to be helping them physically, and a lot of them looked like shit. Now that is not the case. It appears now that learning disabled people are being allowed to choose their own clothes, because what do you know, they look better! People are wearing really cool stuff because they've chosen it, because they should be allowed to choose their own damn clothes.

TERRY: I just felt there was a need for a club in Lewisham, away from parents and away from rules and regulations, because it just restricted people's freedom. I remember a parent standing at the top of the stairs at Leemore, saying to the club members (and this is their language, not mine) 'girls to the right, boys to the left' – and you're talking about adults. And when they got down the stairs, they then had to go on a coach and they had to sit girls on the left, boys on the right on the coach, they weren't allowed to sit with each other. And things like, lights on in the club, all the lights on in the hall so no

one could get up to anything that their parents didn't think they should be getting up to. And it was that...I just felt this is not adult enough, this is not a club where adults go, this is a club where...I don't know who goes!

LISA: Back in the day, my mum wouldn't let me go and stay at my partner's. I was in my 30's when I was with him. It felt hard. One day, he asked me to go to France and I said, OK I'll go as long as I can sort myself out a passport. I went with him. I had to be there at 5 o'clock in the morning. It was alright! I managed to find a CD when I was on the boat, on Diana's funeral and my mum said, what a weird thing to buy!

My mum used to give him the keys, house keys to my place, but I weren't allowed the house keys. The only time he stayed at my place was when his dad died. He got a phone call and he didn't know where to turn and my mum let him stay up in one of the rooms.

ONO: There is one programme that I don't like – Undateables, because I don't like the title. People with a disability are not undateable. People with a disability can hold meaningful relationships and get married and have their own family.

LISA: They put me on a lorry, and we did a...Pino on the lorry, me on this lorry. And Trish was actually pregnant at the time and she had this big yellow, I remember the big yellow dress that she was wearing. And I remember her bringing her baby in, Trish. I said, can I have a hold and she said yeah, you're no different to me, so she let me have a hold of the baby. And that to me, meant a lot to me because when you're disabled you get treated differently.

TERRY: For a lot of people with learning difficulties they don't have a relationship. If I meet someone at work, or in a bar, or wherever I can go and meet her any time I flippin' like, but they've got to wait for someone like me to

give them the OK. And I think that's disgusting, because one of our most human rights should be to fall in love and to meet someone when and wherever we like.

TILLEY: I can be a bit controversial, ooh, can I? My owner only decides to go on the stage and she says, I know this is Rehabilitation International isn't it, or something, she says, well I'm sorry but I don't know whether I like the word 'rehabilitation'. What exactly are you trying to rehabilitate with autism? You're born with it, there's no cure, I don't want a cure anyway. What is so wrong with the way I think? I have a brain in my head, it just works off a different way, that's all, but it doesn't mean it's defective, it doesn't mean it doesn't do its job – and my owner said that on the stage, and my owner got some claps. You know what, before we came on, the atmosphere was quite aggressive. There was a lady I think, that shouted out; "but it's alright for you, you're a professor or whatever, you're preaching to us about how this can be improved, that can be improved if we do this, if we do that, if we believe, if we keep on, if we don't give up. But you're in position where you can change more things. You're on this stage and you're high up in some whatever job and you're telling us." So people were quite angry, you see. But then if you can imagine Heart n Soul come on the stage and people like me and my owner and Lizzie Emeh, we've got a different point of view, obviously, to a professor.

LIZZIE: When people say to me, Liz why are you so open about your experiences, why? I said, it's because it's about education, I want to educate people. Liz, why do you sing about having bi-polar, why do you do it? And I'm like, I sing about it because I don't want people to be scared. The reason why I wrote Loud and Proud was because I wanted people to be loud and proud of what they are.

MUSIC: Loud and Proud by Lizzie Emeh

LIZZIE: We've still got a lot of education to give people, but it's changed as well because people are accepting us now. I thought me being in the music business as I am, with a disability, I ain't got a hope in hell to get what I want. And now, I know I have got a hope.

ONO: There could still be some improvements in what is out there for people with a learning disability, because there isn't very much out there for them.

JACQUI: I think that in many ways it's changed a lot, but in some ways hardly at all. I think that in society people have a better understanding of difference in general. And I think people are more accepting of difference in general. And I think as well, because a lot of mainstream schools now accept students with varying abilities; whether it's a learning disability, physical disability or sensory disability. More and more people in society are acknowledging that everyone has a right to an education, everyone has a right to live their lives as they choose. So I think that it's changed a lot for the better.

ZELDA: Chloe went to mainstream primary school. When it came to secondary school, Lewisham education said no, we couldn't go, that was never heard of. That was in the 1990's, and we really did put on quite a good campaign. The alliance backed us; parents for inclusion backed us as well. We had a sit-in in the town hall. Oh yes, we did! We had petitions and banners and posters and it went on for about two years. And then finally Lewisham said that Chloe could go one day a week to mainstream, and it was bonkers! But Chloe very much wanted to go to school, so she went to Greenvale for four days and Deptford Green for one day. But really what's behind it is to break down barriers and this social model of life, the social model of education. And really that's always been behind our thinking, because it is true to say Chloe, sometimes people look at us and look at you and look at your dad and I and go 'Uurrgh, I don't understand this!'. But the

important thing is if we are all doing stuff all the time together then there'll be greater understanding and greater inclusion.

LIZZIE: What I want and what would benefit me more is if people with learning disabilities were to step out and people listen.

ONO: For companies to give people with a learning disability a chance, because we can do everything, it just takes us a bit longer.

MARK B: We need to get the message out to people about caring because people don't know what it means today and get that word out and tell them what caring's all about, it's important. Because when you've got mental health problems and you're getting no help and support it's damn hard. And you get people giving you funny looks, they think there's something wrong with you. Well, we're not, we're human beings like people in the street, we haven't got labels. We've all got mental health but we're still human beings. The welfare just makes me so angry. If you've got mental health, learning disabilities they'll still be on your back. They're not stupid, they want you in to work. The government just don't listen. There should be a protest to say stop the assessments of people. They don't understand; it's too much.

LISA: You're seen as different. Sometimes I get people saying to me 'turn round and face the wall!' – people in cafes- if I've dropped a bit of food on me, or because I have to use a special knife and fork sometimes, 'turn round and face the wall' they say to me. I think it depends on the level of disability that you've got, if you've got it worse than others you seem to be treated differently. When I was in a wheelchair I used to get it on my head. 'Are you alright?' - Bang!

LOLITA: I've got friends and they treat me the same as anyone else, and it's good fun.

ONO: For women who have a disability to have more choices about their bodies, because we don't. Because it's our bodies and we know how our bodies work.

SHALIM: I think it's changed because of the Paralympics, I think it's opened the eyes of people who want to be inspired by Olympics, or artists being very creative.

NICOLA: People with a learning disability, they've got more freedom and they're also learning new things at school, that's what I think.

LILLY: It's really difficult for me to say; I'm only 26. When I was growing up I think things were slightly different. Shalim's right in the way that 2012 was a massive turning point and society now believes in people with disabilities more.

MARK: After Donald Trump was elected I came to Allsorts because it was the next day. And actually it was the perfect antidote, because what I was a really diverse group of people in a community being creative, looking after each other, trying things, supporting each other. And I thought, well actually we're doing this; this hasn't changed. And if we can find ways for those sorts of values and that way of believing in our own power and be able to take that, I think we can make change happen.

JACQUI: I would like to see more equality for people with a learning disability and with pan-disability. I would want society to accept that everyone has abilities in some areas, and so being given opportunities to develop skills and talents.

MARK: In terms of where we are; this moment of great shaking up of everything, a bit like we're all in a big bottle and it's all being shaken up and we're not quite sure how it's going to settle. My hope, the glimmer of hope is that actually if we're bold and brave enough to share what it is that we think needs to change and to give some solutions and some ideas that we have a real opportunity.

ONO: I hope for the future that people with a learning disability can do anything and they could be a prime minister or a TV presenter or a cameraperson. I wouldn't mind being the prime minister. I would give more money to the arts and I would give more money to the NHS. I would improve the public transport and I would improve the services for people that have learning disabilities.

MARK: Again, going back to what Pino said, it's about what we can do and just shifting the whole discussion from rather than seeing these problems and these barriers to see the opportunities and the things that we all add. I think there's so much that the rest of the world can learn.

JB: In this world everyone has a space, and we know it's not a fair world or an equal world. And I think that what Heart n Soul is doing by putting your members, our members forward that they also have a space at the table, which will make the world a better place - because if you exclude me or you exclude anybody from something, you're losing out from the richness of everything. So I just think rock on, keep going Heart n Soul because we need you at the table, along with everybody else.

MARK B: If I was a hero, superman, I'd make sure the world gets better. Make sure we live in a safer world, say hello to people, give them support and they can trust you a bit more. Tell the whole world, let's get back in the community,

start loving your relationships, your neighbours, your friendships. Stop all this knives, stop gun crimes. Let's live in a better community now, let's show the world that we can do it, not just London but all round Europe. Make sure people have somewhere safe to live, give people the housing they deserve, respect they deserve, listen to people's voices for a change.