



Chrissie:

My name's Chrissie Rogers. I'm a professor of sociology and learning disability academic. I'm the Director of the Tizard Center at the University of Kent.

Mark:

Hello, I'm Mark. I'm the artistic director and the CEO of Heart n Soul. And I'm also part of Heart n Soul at The Hub.

Pino:

My name is Pino and I'm a co-researcher for the Heart n Soul. And I'm also singer, songwriter and actor.

Pino:

There's a few questions there, there is.

Chrissie:

Well, there's such a lot there.

Mark:

There's a lot there. It's massive, isn't it?

Chrissie:

Inclusion and education and compassion and the idea of being human. That actually, the idea of being human, kind of resonated throughout it. And it's interesting because, in a way, from the very first meeting of you guys, that was at the heart, in many ways, of what it was all about, is that actually we're all humans. And just because someone has a learning disability, or a difficulty in learning, or is autistic, doesn't mean

that they don't have the same humanity as everyone else. And so, therefore, all of those other questions about compassion, about being included, feeling included, being listened to and heard, that came through, even though it wasn't explicitly said, and the idea of being employed. I mean, all of these things boil down to what is, in our essence, of being human. And I suppose one of the big things is that we want to connect, and that came through, that connectedness between how we want to be with people.

Mark:

What was very striking is we've got one universe, which is a sort of Heart n Soul type universe, where there's a real sense of a community working together, and value and creativity and people's capabilities really shining through. And then there's the system, which is to do with providers and service users. And even as soon as you say those words, the division starts and the connectedness is reduced.

Chrissie:

The whole thing around care and rights versus... When I say care, I mean, care in the kind of... risk-averse, let's say, right? So that whole idea, that whole thing around being risk-averse, encased really in care and care about that person, so that whole idea of being wrapped up in cotton wool. When you talk about the two different factions of people, to a certain extent, those on the side of looking after, making sure that people are safe... safety first, let's say, versus the side where, actually, making mistakes and learning from those mistakes and being independent or interdependent, to be able to be a part of that thing, because let's be honest, most of us human beings, right, make mistakes and we get hurt. And we get hurt and we might burn ourselves on the

kettle, or we might fall in love with the wrong person and get hurt. Those kinds of things happen to all of us.

And just because someone has a learning disability doesn't mean to say it's going to feel any less or any more, it's going to hurt, right? But it is really hard. I mean, it is to kind of, break out of that divide, that divide between the two factions, because within disability there's a divide, isn't there? Because there's those who want to care to the point where people are then not given the freedom to make mistakes, or to perhaps even be vulnerable to hurt, versus being able to do those things. And that includes, for example, being in a mainstream school where-

Pino:

Well, that's where I wanted to go. You see, this is what happened.

Chrissie:

Yeah. It's a tricky one, because I'm philosophically, I think, and... Well actually, practically to a certain extent is that all inclusion is the right way forward, because I think one of the things that you guys talked about in terms of education was that-

Pino:

We never had any education.

Chrissie:

But also that we need to educate everybody.

Mark:

Yes.

Chrissie:

And the problem is, if we're not including people with disabilities, then nobody sees people with disabilities. So the kids around aren't actually engaging with someone with a hearing impairment or someone who's autistic, someone who's got significant learning needs. If people aren't actually being in that environment where we have these diverse differences, how can anyone learn about disability? You know, feel the pain when someone is bullied, whether that's got... because they're your friend and then stick up for them. How can we know these things if we don't actually get involved in the lives of people?

Mark:

I mean, I was really interested around this whole area of risk and overprotection, which actually did feature in our second survey because as people were... Well, I wasn't surprised, but it's not a point of view that you often hear from people who were-

Pino:

Well, we were overprotected, Mark.

Mark:

I know you were. I know you were very clear. Everybody... It was like a major theme that was coming across. And I think it was really important that you shared that and that you asked the general public where they feel overprotected, but just bringing these subjects out and hearing you talk about them and what's important to you is so... it has so much resonance and meaning for people. And it just really points the fact that as, I think, Michaela was saying, why aren't we in your conversation?

Pino:

That's it. Why are we not in your conversation?

Mark:

When you're in the conversation, then your point of view and what you think, is heard. And things begin to start changing because... It is so simple, isn't it? It is about understanding and it's about-

Pino:

Yes.

Mark:

It's about people not being frightened of what they don't know.

That was what was, I think, such a radical move, in terms of both the surveys, is the fact that the people asking you the questions, you could see who they were. You could see why they were asking the questions, the way they were asking them, and I think I've never seen a survey where that's the case before. And it kind of encourages a bit more honesty.

Chrissie:

You talked about misunderstanding, and I think that's probably a bigger problem, misunderstanding... misunderstanding and misrepresentation, than anything else, because otherwise we end up in an either/or situation. And in a situation, Mark, where you said you've got those on that side and those on that side, because if we make an assumption that everybody wants to do something independently, we are then opening someone up to fail, perhaps. Because we think

historically about the heinous crimes, basically, that have happened against disabled people in terms of locking people up and segregating them and not giving them an education and all of this sort of stuff, and not enabling them to have the life and love and passions and work and all of these sorts of things. But, if we make an assumption, therefore, that someone doesn't want support, we are going to then set someone up to fail, because if we assume that independence means that you don't get the support... and this is where the divide happens. It's that interdependence.

Mark:

Yes.

Chrissie:

When it comes to the policies, right, it's hard to sort of have that messiness. And life is messy.

Mark:

Absolutely.

Pino:

Not everybody knows what to do...

Chrissie:

Yeah.

Pino:

Not everybody knows what to do.

Mark:

No. You have to learn what to do. You have to find that. And I absolutely agree. It's not one thing or the other. It's always about the middle. It's about the bit in the middle, where things are less obvious and less clear and where you don't make assumptions, but everybody's different and support is a really important word that came up a lot. I mean, Pino, at the beginning of this project, just before this project, you were still living with your dad, weren't you Pino?

Pino:

That's right.

Mark:

And then at the beginning of the project, finally, after trying for many years to be living more independently in a supported house, with someone else to support you... Your life, I've seen, even during a lockdown, how much happier you have become, Pino, and I've known you for 34 years. And I-

Pino:

That's right.

Mark:

And I've never seen you happier.