

Artlink

Disability, Value
and Touch



a conversation between

Alison Stirling &
Robert S Gale

From the beginning of March 2020 through to the present we have asked different artists and thinkers to respond to issues that were being unearthed as Covid-19 took its toll on our communities. Each writer was asked to respond to a simple brief that in some way related to their lived experience, providing the opportunity to open up these issues, to better understand what we could and should have in common.

DISABILITY, VALUE AND TOUCH

a conversation between ALISON STIRLING & ROBERT S GALE

During the course of 2020, Alison Stirling and Robert S Gale began a series of conversations intended to inform an essay on the subject of interdependence and human value. As Covid and different lockdowns unfolded, their discussions moved swiftly to the topic of touch and sex, to value and empathy. Nearly every conversation began or ended with a version of the same question: “How do we make things better?” the question taking on increasing importance as time passed. When life got in the way, the conversations were put on hold, only to start again when space was found in schedules full of zoom calls, and life events became less overwhelming.

What happened unfolds within the content of this text and takes us in unanticipated directions as the everyday impact of Covid becomes very, very real.

We begin by talking about touch and the lack of it. It’s early on in the lockdown.

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June 2020

Robert – Apart from my flatmate and my children, I don’t think I’ve touched another human for over four months. And I know I’m among the lucky; many people haven’t had any physical contact with another person during the lockdown whatsoever. I think a lot about touch; as a disabled 40 year-old man

I'm hyper aware of the touch that I have and haven't received in my life and now, in the midst of an international pandemic, it seems as though everyone has shared a little bit of what this 'denial of touch' can feel like.

Alison – Lockdown is revealing deep fissures in our society: between the elderly, people with complex disabilities and the rest of society; the people identified as 'vulnerable'; the people waved at through windows by desperate relatives; the massive space between all of us. When you mention touch and the lack of it, I can see the impact it's beginning to have on people, but is it possible to put into words that frustration? You talk about this at times in your work as a way of challenging people's perceptions of disability. But has this frustration been exacerbated by lockdown? Do you really think months of lockdown and lack of touch matches a lifetime? Do you think that it's even further alienated people for whom touch was always an issue?

Robert – No, of course lockdown doesn't give people the same experience as 40 years of being disabled, but maybe it gives them the slightest taste? My real fear of putting this into words is that it'll sound tragic: I spend a significant amount of my work and personal life trying to present the 'positive image of disability', so it can be really challenging to peel back the curtain and show a painful, lonely truth. I never want to be pitied or seen as a victim, so the sadder stories get punctuated by jokes and laughs. But yes, touch is something I and many disabled people value to a huge degree: it feels much more elusive than it appears to be for non-disabled people.

It might appear as though I'm making a leap, to equate touch with sex. I know most touch is non-sexual and that sort of touch is hugely important. These thoughts can't be reduced to 'disabled people need more access to sex',

although I believe we do and that is a part of the question of touch.

I was born in the 80s when kids with relatively mild physical disabilities like mine (cerebral palsy) were still taught in special schools, primarily because most mainstream schools weren't physically accessible. Schools only fell under the legal obligation to provide access from 2004, which feels ridiculous now. Growing up I felt an acute awareness of my difference: when other boys who lived nearby would have football birthday parties, I'd be put in goals, but no one was fooled that I could really take part. As a teenager within a special school environment, it was nearly impossible to work out how appropriate relationships should operate. There were only 110 students at the school so your 'peer group' was very small and you were all coming from different parts of the west of Scotland. So my access to touch has felt stilted from an early age.

And sadly this seems to be the case for many disabled people. Many of us have access to 'institutional touch', by which I mean assistance to dress, wash, go to the loo, or even touch through activities like physiotherapy, but this isn't the same as caring touch or loving touch. Institutional touch can take many forms and be delivered in ways that show great respect and care, but at its core it is functional and by having such a purpose it'll never replace the kind of touch we all need in our lives.

A core question for me is how we begin to make touch – sexual and non-sexual – more accessible to disabled people? If we can all agree that touch is a need – an essential element in living happily and healthily – then how do we ensure that disabled people can access it?

Alison – For me, when you talk about touch, it's symbolic of many things – of lived experiences, of being part of and being excluded from, of human rights and societal wrongs. My lived experience is in the world of learning disability – my sister has profound learning disabilities. My mother trained each of her children to make sure that my sister is respected, has a good quality of life, and gets all the care and support that she needs. I've had many, many years of fighting with social work departments and box ticking public officials: of getting talked down to; of fear of losing what you have if you complain too much; of flabbergasting frustration over talk of independence and human rights whilst the services that are needed are being cut. I think the problem is that all the policy in the world can't foster a more caring and equitable society: it's trust, respect and empathy that does.

Do you think there will ever be a time where we just accept people for who they are and where ensuring quality of life isn't such an uphill struggle ?

Robert – I don't know what needs to happen to make the general population chill-the-fuck-out when it comes to disabled people. I make theatre – tell stories about disabled people to make us more relatable and more approachable – but that isn't enough. What makes people shy away from 'others?' Why do we only want to touch what we can understand?

Research carried out about eight years ago shows that around 83% of households didn't have a disabled person within their circle of family and friends, i.e. a disabled person has never (knowingly to them) crossed the doorway of that home. One of the main reasons that I make theatre is to tell the stories of disabled people. By making these stories part of our culture we surely must move towards greater understanding and empathy

and maybe this gets us to a place where more connection – and more touch – happens?

Perhaps the more useful thing to think about is interdependence. I feel our society has grown over the past forty years or so to value independence above all else. We're seeing so many people living by themselves, in small flats designed for single occupancy, going to jobs which don't require much social interaction and they are having less and less connection to other people. For many years, whenever my mum would talk about her own mother she would always say "... And she never asked anything of anyone," which was seen as being a great quality. Why is that so? What's so great about independence? I honestly believe this is a chronic problem within society. The way we hold independence in such high esteem has led, amongst other factors, to a loss of connection with one another and a loss of opportunity for interaction and touch.

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July 2020

Robert – We value our independence more than ever before. We live in small, one-person flats where we cook meals for one and pay single occupancy council tax. We don't rely on each other in the ways we did thirty, forty, fifty years ago.

So when you need to rely on others – to cook, to wash yourself, to dress – you're seen as 'sub-optimal.' What's so great about independence? All I can see is that it can more easily be ensured – guaranteed. Whatever happens

you can rely upon yourself. How sad. How do we re-value interdependence?
How do we create more connection?

Connection must bring with it more touch – more awareness that other people exist and have bodies that take up space in the world. How can we celebrate the space that we each occupy?

Alison – That connection hasn't been visible and it's taken a pandemic to show us exactly how dependant on each other we are. I agree with you: we need to empathise more, to respect and understand each other and touch has a big part to play in that. We are all in some way connected to each other and as a result have a duty of care towards each other. It's important that we become a hell of a lot more aware of each other and the space we occupy. Our lives depend on it. If people could just think for a while, "What would I do if that was me?" then perhaps it would be a bit different. But instead it's this weird power imbalance – those with power and those without, those who make the decisions and those who have the decisions thrust upon them. My personal experience is that most of the time, the people making the decisions haven't a clue what they are doing.

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September 2020

Alison – How do we make things better?

Robert – We need to hold on to the question and keep asking it. How do we make things a bit better? I don't have the answer. Maybe that's all we can do.

Just keep asking.

There's a gap in the conversations. Emails go back and forward as we try to make sense of what's been said. In this slow time, days repeat themselves: we are limited as to where we can go and who we can be with; time feels like it isn't moving. But in our bubbles people are adapting, things are happening, some of them positive and some of them not very nice.

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March 2021

Robert – It's important to have conversations with people about the reality of what is going on. I think truth is at the root of what we are trying to do and the fact that that's a radical thing is pretty telling. The trouble is there is such massive inequality. Do you know that philosophical exercise where you get to design a society, you make all the rules and laws but you don't know who you are going to be born as within that society? You don't know your gender, your class, your race, your wealth, whether you have a disability or not. How would you design that society? Well, you would design a society that is as fair as possible because you don't know where you would end up within that structure. So you try to make it as equitable as possible. The trouble is that the folk in power know that's they are never going to not have power and the problem is that they want to keep that power.

Alison – What do we do?

Robert – All I've got is writing bad jokes! (laughs)

April 2021

Alison – I've been around a long time. I've seen attitudes change, people continue to fight for their rights and if I'm honest its cyclical. We reinvent the wheel again and again. Same thing described within a slightly different vocabulary. What's gained in some areas, we lose in others. If only we could learn from past mistakes. If I'm to be more positive then we do make steps forward. But it's so slow and my concern, as a result of the pandemic, is that it's going to go backwards. We need to take the time to understand exactly what's just happened, what connects us and its value.

Is it possible for people to value each other as much as they value themselves?

Robert – You only achieve that if you show people the value, or the benefit to them, of that system. The problem there is that the people who can look after themselves are going "Well, I'm fine. I can look after myself, I've got money, I've got physical ability, I can cook my dinner." So, it's "How can you show those people the value of our interdependence?"

Alison – But what drives people apart and creates a lot of the division is our ignorance of each other. We really don't know what exists outside of our particular bubble. Perhaps we don't have time, or maybe we are not interested in finding out what others think or experience but if we could find a way to slow things down to listen to someone else's experience and find connections, even if it's as simple as reaching out and touching someone's arm or agreeing we both don't like the colour yellow. It's a start.

Robert – And that’s where the tension is. It’s why some people engage with the arts. It’s because we want to understand other people’s narratives. But there are people out there who are not interested. I think we get used to our own worlds and the people that we know and work with but the rest of the world is not like that.

Alison – We need to be forced out of our comfort zones. All of us! That’s the challenge.

Robert – And that’s about people living amongst other people who are different to themselves. To do what you and I do, you have to have a little bit of faith that human beings can change and develop empathy at some point. We can only develop empathy if we can understand each other, so either we can go to the theatre and see other stories of people who are different from ourselves or we can go to art galleries and see other people who are different or we can live amongst people who are different from ourselves. The problem is that at the moment we live amongst people who are from the same socioeconomic class, the same race, the same...

Alison – It’s about taking the time to understand and value different realities.

Robert – Completely, but it can go to that deeper level where you actually value difference and you actually empathise. It takes the issue to a whole different level – you actually have to give a fuck. You’re asking quite a lot there Alison. It’s a lot easier to just write a policy, get a few diverse folk on your board, tick a box and go home. We say that word value but if you ask most people I imagine they would say “I

value everyone equally.” I think loads of people would say that, but we know it’s bollocks. In some way we need to get people to realise that we don’t value people equally.

Alison – I know. It’s all really difficult and it will get harder. I find myself getting angrier and tired of it all. It’s the same old same old, we say we value people and I agree with you that we don’t really. But maybe there is some hope, maybe something will come out of all of this that is more about people and our interconnectedness. I’d like to think that the positive fallout from the pandemic would mean that in time we realise that we are all vulnerable, that we depend on each other and that we better value care and caring ... Och ... How do you keep going?

Robert – I genuinely don’t feel like I’ve got a choice. If I stop doing it then I can’t live, you know? I want to go to the theatre, I want to have kids, go to a park to do things that are ... that’s what we call being alive. At the moment there are so many fucking barriers to all of that, and they’re not half as bad for me as they are for a lot of other folk. So then you go “OK, if I want to do all of this then I have to fight to make it better”, but you find ways to do that fight that keep you sane. I remember when I was twenty or twenty one. I got really angry for about a year with everything. I was angry all the time, I used to argue with people about how fucked up everything was but then I couldn’t sustain that because it wasn’t a way I could live – I had to survive. So you find other ways to channel that and I know that if I heard myself now back then I’d go “Oh you’re wimping out ... get back on to the barricades.” I know that because I said that to other people at the time. But you know things change. We need people to be angry, we need that as well. But you can’t spend your whole life being angry – or at least I can’t. Part of the reality is that I, and

people like me, are good at saying things in a way that people want to hear because we don't shout, we make jokes and make it funny – we make it engaging and because we do that we get listened to. But if I became 'shouty angry Robert' I wouldn't be listened to. That's not fair. I've written about disabled people being palatable; really ingratiating themselves to people. It worked well for me, I'm alright but it doesn't actually achieve the longer term goal at the end of the day I've only got 60/70 years to get through this life...

For me, it's about what you put on stage – not about the world as it is – but as you want it to be. The idea is that the arts show us a possible way of being that we work towards.

Alison – I have strived to use the arts to open up conversations that involve people who have no voice. I say that with people who have very complex learning disabilities in mind. I believe that alternate and incredibly interesting conversations happen through actions, through building different relationships and funnily enough, through touch. And I think that this way of being of understanding is transferable across different communities. If we are more open to slowing down and taking the time to watch and listen, if we are imaginative and generous in the ways we involve, then we might actually learn something.

Robert – Yeah, it's about conversations. It's about how to understand each other to try and understand different perspectives and wanting to understand each other. That's the thing I talk about when I ask, "Am I making it too palatable?" But I do think there's something about making people want to understand. It's a challenge though.

Alison – You do that through your art. You challenge people. It's not that it's too palatable: it's actually bittersweet. You make them feel comfortable, getting them to laugh and then you throw them a curve ball. I love that in your work. You force people to think outside of their comfort zones and that's important. It's what I love about art when it's at its best. It makes you have to think. It challenges you to take on different perspectives.

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May 2021

Robert – I've no bloody idea how we wrap this up, Alison. We're now 15 months into Covid and nothing has changed yet everything has. I'm someone who always wants neat, tidy answers but those don't exist with the questions we're asking. I know I want more touch in my life – I want more connection and more understanding. At some level I think most of us want that. So why is it so damn hard to find?!

Alison – It really isn't the time to make sense of any of this. It's far too early. We need to let things settle. It's too raw. We have to stay alert and not knee jerk. We've been through a lot. There needs to be a drastic change in how we include, in how and who we listen to and ultimately in how we care.

Robert – Maybe drastic change doesn't look quite so drastic when it begins to happen? Maybe it's about the small things we can do to start the ball rolling? Maybe we just need to touch each other a bit more – with full consent and when it's safe, of course.

Artlink

Established in 1984, Artlink is an arts and disability organisation. We believe participation in the arts has an important role to play in realising personal and social change.


Artlink Edinburgh & The Lothians
13a Spittal Street
Edinburgh EH3 9DY
artlinkedinburgh.co.uk


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 artlinkedin

info@artlinkedinburgh.co.uk
