

## TRANSCRIPT



Centre for Disability Studies

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### Title:

**New Materialism: Opening New Lines of Inquiry within Disability Studies**

### Abstract:

**In this seminar, I will present a new-materialist (specifically Deleuzian) theoretical framework for thinking differently, and creatively, about the capacities of bodies labelled as impaired. Adopting a Deleuzian perspective towards bodies means avoiding the temptation to ascribe them fixed identities or inherent, and context independent, characteristics (for example, ‘an impaired body’ or ‘an infertile body’). Instead this approach asks us to think of bodies as always existing within specific material-discursive contexts, which will enable some of their capacities while restricting other potential capacities. It then encourages us to think about the capacities these bodies could gain if their material-discursive contexts were altered. The approach can be used to think about the capacities of any body but, in this presentation, it shall be explicated using the example of the reproductive capacities of male Down syndrome bodies. While these bodies are – from a**

**narrow biological perspective – almost universally infertile, a Deleuzian approach suggests that this infertility is better understood as something that is produced and maintained by a range of potentially alterable biological, technological, economic, legislative and attitudinal forces. Ultimately, I suggest that many men with Down syndrome could become fathers if we, as a society, wanted to allow this.**

**I end the discussion by considering how new-materialist ideas might open up new lines of inquiry within Disability Studies and also inform new types of disability activism.**

### **Biography:**

**Michael Feely is an Assistant Professor at the School of Social Work and Social Policy in Trinity College Dublin. He is interested in theories of disability, embodiment and cognition. Additionally, he has been involved in supporting self-advocacy by adults with intellectual disabilities for many years. Currently, he is working with a group of self-advocates to co-design, co-deliver and co-assess a disability studies module for undergraduate social work students.**

### **Details:**

**University of Leeds, School of Sociology and Social Policy,**

**Research Culture Seminar Series**

**11 December 2019**

**Feely:**

**“I wanted to – 3 things today. So im going to outline the Deleuzian materialist, or New Materialist framework for thinking about bodies and then Im going to show how you could apply that to a real world problem, hopefully to ground the theory and then the final thing I want to do, with some of the issues I’ve brought up then, is to consider where this fits in to the kind of broader disability studies array of, kind of, theoretical approaches and methodologies and so on.**

Ok, so just to start with – the ways we think about bodies and the problems with the ways we think about bodies is, I suppose the classic way to think about bodies and entities more general, is essentialism, and of course, that is the idea that for every entity there's kind of a list of ideal characteristics that that entity should have. And individual examples of that entity are judged by how closely they resemble the ideal characteristics. So, in the case of the human body, it might be things like: a certain amount of limbs, a certain configuration, an ability to walk, an ability to reason and so on, and individual humans are then judged in relation to that. Similarly, a bicycle has a list of essential characteristics around it having 2 wheels being held together by a frame and so. And if something doesn't have 2 wheels, if the bicycle doesn't have 2 wheels, it's not a full bicycle – there's something missing about it, it's not a proper bicycle.

Ok, so this type of thinking isn't new, but something someone like Lennard Davis would say that it 'emerges in different guises in different ages'. So you can go right back to the classics with things like Aristotle and Aristotle talks about species essences and that's idea that for every species, including humans, there is an ideal set of characteristics and then you see it emerging again in things like – before Darwin, naturalists used to go out in to the field and they'd compete with each other to find the best specimen; so the most badger-y badger or the most foxy fox and things like that. It sounds ridiculous, but it's that kind of thinking again. We see it again emerging again. Well according to Davis anyway, in the 19<sup>th</sup> century, as eugenic scientists start calculating norms for the full range of embodied and cognitive trends and again, what you get, here is the norm becomes the essential idea and people who fall below that norm (to the left of the bell curve [referencing slide]) are pathologies as somehow not full examples of humans. So, along with that, it's not just a statistic or exercise, you get tied up with that eugenic measures to try and target those people and ultimately get rid of those people.

So, it's not surprising, I'd argue, that Critical Disability studies has spent an awful lot of time, in various ways, trying to challenge this way of thinking. And I think one of the most productive ways we've managed to do that, is through Social-Constructionalist and, to an extent, Post-Structuralist epistemologies. Methodologies like Foucault's 'Genealogy' and so on. And what that does is it focuses on changes in the language we use to describe bodies over time and what emerges when you do that, when you take the long, historical perspective, is these things that we presume to be trans historical ideas, the essential characteristics. They're not. They've changed over time. Similarly, things like the distinctions we make between normal and abnormal bodies are not trans-historical or trans-cultural. They're very much embedded in that time and that place even though

they don't seem that way. So that's been the great strength of Social Constructionism and I hope it opens up a whole new range of politics that we might discuss later, but that idea of you can resist labels that are applied to you; they are not an objective truth; they can be contested and so on.

Now, it is powerful [Social Constructionism], it's absolutely powerful, but there have been discontent as well, so and you see this across the range of kind of gender studies and critical race studies and all the rest of it (it's not just Disability Studies). The limitations of social constructionism and this risks of over simplifying, is that in focusing on languages and changes in language, you somehow forget or don't pay enough attention to materiality and what it is to have a material body feels emotions etc., etc. For some Disability theorists, and I'm thinking of Tobin Siebers would be one guy that articulates this well. He would say 'it's just not good enough to have it as your way of talking about disability' – something that can't talk about the very real problems around an inaccessible environment or the very real problems that go with some impairments around the experiences of pain, and stuff like that – we need something that can do that and can talk about those aspects as well. He goes down the critical realist approach but I'm going to do a different approach here. So, in response to these kind of criticisms over the recent years, we've seen the emergence of New Materialist theories and they've been giving a dizzying array of titles; so we've got the ontological term, the post human term, the non-human term etc. etc. If there is something that unite all those things, it's, I suppose, an appreciation of the legitimate insights of social constructionism but a commitment to marry those with an increased attentiveness to the material world and to having material bodies and so on. So it's not rejecting social constructionism, it's trying to broaden its focus.

There is a number of methodologies for doing that and I think they're all productive for Disability Studies – and I really think I'd love to read more on all these avenues – but things like the actor-theory of Latour and agential realism of Barad. Today I'm just going to focus on one branch of New Materialism though and that is the Deleuzian Materialist ontology and I'd hesitate to call it a..It's kind of towards what I would call a methodology of assemblage analysis. So I just want to do a sort of crash course in Deleuzian and how it differs from the Social Constructionism that we might be more familiar with. The first difference is Deleuze unequivocally embraces reality, I suppose even a mind independent reality and so on, a material world out there. Now, this has been problematic to Social Constructionists for a long time because one of the starting points of Social Constructionism is that everything you say about the material world, doesn't just describe it, it shapes the meaning of it and that means that Social Constructionists

often limit themselves to exploring how the language we use shapes the meaning of the material world – the material world becomes relatively passive. I am aware this is a huge over-simplification [referencing flow chart on slides], especially in relation to Foucault and later Foucault, but this is [referring to same slide], as an over-simplification, the problem is a passive material world. Deleuze doesn't disagree that language is important. He would say that it is absolutely important as well. But he would say that material entities are just as important and that both discursive statements, so the things we say and laws and policies and so on and material entities are equally real – they're part of one reality. And they're real because they have effects in what happens in this material world and also because they effect each other. So, for him, discursive statements and material entities are both different types of real things. So, something like a city, is made up of, for Deleuze, of materials things like roads and buildings and so on but also discursive components like the rules of the road and planning permission and that all of those things are real in that they effect what goes on in this city and they affect each other – they're mutually affecting, supposedly.

Second big difference about Deleuze is his stress of everything in motion. So he really rejects the idea that there are any fixed identities whatsoever. Social Constructionists have done that, in relation to language already, they showed that what we think are our fixed linguistic categories actually change over time. Deleuze, again, extends that to the material world. So what he's saying is that there is nothing that stays the same. Even things we think of as very stable – if we think of the planet earth, we think of that as something that has a stable identity, but of course, when we think a bit deeper, it doesn't – it's moving all the time; so the continents are moving apart at 5 cm a year. It looked vastly different millions of years ago and it will look vastly different again. So his argument there is that you can't possibly have an eternal essence in that type of world; it's an illusion produced by slow rates of change.

Ok, so this is the most important thing, I think, for Disability Studies. So Deleuze suggests that instead of talking about entities in terms of their essential characteristics that we should talk about them in terms of their *affects*. That often confuses people about Deleuze – when he talks about *affects*, he's talking about their capacities; the things they can do in different contexts. So will we give that a go [to everyone in room] – so just 2 types of questions; so 'what is a pencil?'

Person in room: A writing implement.

Feely: yes, there you go. We have a characteristic related to its function in one context. Yep, so that kind of thing. We might say its wood with a....

Person in room: I think it could be other things as well though. It depends on the circumstance...what else can we use a pencil for?

Feely: Exactly. So what else can a pencil be used for?

Person in room: Stab someone!

Feely: Exactly! Now we're talking!...going straight to the stabbing! What else could we do?

Person in room: Chew on it. For pondering...

Feely: Yes, exactly.

Person in room: Hair clip.

Feely: Absolutely. So what we've got here is an ongoing list. We've got something that never is fully exhausted. So, for Deleuze, that applies to the human body too. We don't ask 'what is a body?' because that gets us back to the trivium man and the ideal characteristics of a human body, instead we ask 'what can a body do?' and what that produces, as we saw with the pencil, is an open ended list of context dependant capacities – so, a body can swim in the water, a body can walk on the moon if it's got a spacesuit and so on.

So, for Deleuze, the body has no imperative characteristics; that's an illusion, this idea of fixed identities. They only have, and he would define them as, and only by their context dependant capacities. So that means we should avoid the temptation to describe the body in any kind of context dependant limitations. So we shouldn't say that this little guy here in the corner [of slide] that he's just too short to reach the top of the counter. If we have a different context and he's got some stools he can climb on, that becomes a capacity of his body that becomes something he can do. Similarly we should never say 'this lady cannot walk' [image on screen] as a context free thing. As you can see there [on slide] she has access to some kind of bionic suit – walking then becomes a capacity.

Deleuze again and again and Spinoza again and again stresses this; that we never know everything a body can do. We don't yet know all the things a human body can do and that means for everybody it is possible to discover more and more and more capacities. And the only way we can do that, is thinking creatively like we started to do with the pencil or experimenting the real world, doing actual scientific experiments. So, even for something like when we think of a body that's capacities are utterly exhausted, we've got a dead body there [on slides], there's an infinite number of capacities that body can have. So you see. In terms of creative new capacities that body can have, and the start-up of the states now offering to compost your dead body and then the compost is given back to loved

ones to plant a tree etc. etc. So it's a new capacity for a dead body. And even something we think of as absolute and context independent as death, while that may well prove to be unreturnable from, there's lots of people in silicon valley who're betting it's not and getting themselves cryogenically frozen because they hope for a future where the context will have changed and technology will allow them to come back from that state of suspended state of cryogenics. Whether or not that will ever be possible – I'd be dubious – but we don't know for sure.

Ok then. So we need a way of talking about bodies within their contexts and for that Deleuze offers the concept of assemblage. What assemblage is, is you can think of it as a network of discursive statements and material entities and these things come together for a time and they work together for a time to produce something – and its temporary. It'll fall apart in time. If you think of something like a traffic jam for this assemblage – bodies stuck in traffic. So, for Deleuze, that is a collection of material things like cars, the bodies within them, roads and so on and discursive things like the rules of those roads, the signs on the roads etc. etc. – they come together, for a time, and they produce the jam; it's not permanent. It will dissipate. But, if we think of things in those terms, we need to ask a certain set of questions. So the first thing we can ask about assemblages like a traffic jam is 'how is it working?', which means identifying the different types of components that are important and how they're effecting each other in complex ways to produce, in this case, a traffic jam. The second question we can ask is 'how could the assemblage be made to work differently?' So that means; could we intervene and make changes that are either discursive or material that would change the context and ameliorate the problem? So, by changing the width of the roads, would be a material change with traffic jams, or changing speed limits and so on. You could intervene with the assemblage either discursively or materially.

Ok, so that's our framework. So I want to just give an example of how I think this..well, the kind of problem I think it could be used for. So this issue – I was researching the treatment of sexuality within disability service, much like some of the PhD students here are doing similar things, and I collected loads of stories and one of the themes that kept coming up was hopes and fears around having children. So, the service users, by and large, said 'we want to have children in future. We want to settle down and have families'. It was in the distant future, but it was the aspirations for the future. Staff members, meanwhile, were terrified of that happening because they would be held accountable by people's parents. Now, I was starting to research that theme, when I discovered – and this was a surprise for me – How many people..can I just do a quick poll, how many people before, kind of, this [presentation slide] were aware that men with Downs' Syndrome were nearly all infertile? [one person raises hand]...ok, so we've got

one. I was firmly with you [referring to person in room]. It was completely a shock and a surprise to me! And exception to that are very rare. The first documented case is 1989. So that raised all kinds of questions; did the men I was interviewing about plans to have families know they were infertile, or most probably infertile? Did the staff members that worried about them having children know? And also, was this a necessary thing or could these men access fertility treatments? So I went and started researching that and I found was a big blank. No-one, it seemed, was interested in finding out – well, there was a few people about the biology but no-one about ‘would it be possible to let men with Downs Syndrome have children?’ So if we study this issue of men with Downs Syndrome and fertility as an assemblage, what we’re saying is that we’re suspending the belief that infertility is a characteristic or an essential characteristic of the Downs Syndrome body. Instead, we’re assuming that it is something that is something that is produced in a network of discursive statements and material entities and out of this network of discourse and matter, emerges infertility. So the first question, if we want to treat this problem as an assemblage, is ‘how is it working?’ So that means identifying the different kind of material and discursive forces that are working together to create the problem. So, where we started is somewhat arbitrary, but let’s look at the actual bodies. If you start researching the literature, the biological literature, its striking how little is known. So there’s a few articles out there on the causes of infertility and various things have been suggested – you see a whole a range of things there [referring to slide]. Interestingly, the recent review of the biological literature, concludes that it’s still kind of a medical mystery. Not much effort has been put into it and we don’t know for sure. Other literature documents rare exceptions to that rule – the 3 documented cases of men with Downs Syndrome naturally (having used that word reluctantly) fathering children – but what’s interesting about them is that all of these are presented, the kind of conclusions, that the authors come to in this, is that ‘this is a threat, let’s get them on contraception’, rather than ‘wait a minute, this is interesting. Could more men with Downs Syndrome be having children’, So, in light of all that, we might imagine the biological forces to be the anomalous biology of some men with Downs Syndrome and the lack of interest in that. So the lack of our knowledge in that and our tendency to construct exceptions in that as a threat rather than something to learn from.

So, Deleuze is all about taking leaps from the discursive to the material to the economic and so on. So if we take a leap to legislative context now. We find more of the tendency to construct the sexuality of people with intellectual disabilities as a threat. Now, Ireland was particularly bad case in this because up until 2017, if you had consensual sex with a person with an intellectual disability, it was



effectively criminalised. So, within that, theoretically, a man with Down's Syndrome impregnating his partner could be seen, I suppose, to be used as evidence of statutory rape – so it was outright forbidden up until 2017. So that has changed and there's been significant developments. The UN – Ireland has finally ratified the UN convention – so now there's huge changes in the landscape. We now have the UN statement that 'persons with disabilities should be able to decide freely and responsibly about the number and spacing of their children'. So the relevant legislative forces here are, historically, legislative prohibition and so forth, but interesting changes happening...

Ok, so there's no legal prohibition any more, in the Irish context, so at this point we might jump back and look at what the technologies are out there for other men that are experiencing fertility problems. So what you find when you look for that is that these technologies have been around for a long time. IVF – the first case is 1977. The really big development for men that have fertility issues is ICSI, in the 1990's – and that's when scientists discovered you can inject a single sperm into the egg and that means a lot of men that had motility problems (sperm that weren't moving very well), they could suddenly reproduce. And you got that, when those technologies arrived, you got people applying it to all kinds of syndromes. It's interesting if you read the literature on syndromes that affect physical rather than intellectual functioning, you get a different tone. So something like Klinefelter Syndrome, that affects sex chromosomes, the literature on introducing these kinds of technologies to people with that syndrome is celebrated as kind of a scientific breakthrough, albeit temporary, with the possibility of disability in the next generation. So when I came back to this a huge development had happened. So, in 2013 there was a big blank about using reproductive technologies with men with Down's Syndrome. In 2015, for the first time ever, in California, someone did. A man with Down's Syndrome with his partner, who was chromosomally typical, went to a fertility clinic, they got a reduced price (they had some sort of a scheme there) and they had family support and the doctors agreed to help them...and it worked! So this is a big development. We now have reason to suspect, this could actually work. It could be something that lots of men with Down's Syndrome could do.

Just because it's something that they could do though, doesn't mean it's something that they can do...and if we jump to something like – we've been talking about Marxism – and if we jump to level of analysis of Economics, we find that we get real barriers here. So, basically, I think this might be different in the UK, but in Ireland IVF is not socialised so you have to pay for it privately and it costs 15000EUROS or more with no guarantee of success. So, if you think of men with Down's Syndrome, they're on 198EUROS a week of Disability

Allowance. And that's means tested, which means that if you have savings, the Disability Allowance cuts off. So if you're saving up for IVF treatment, the very process of saving cuts off your Disability allowance. It's a welfare, kind of trap, if you like. A step that makes it pretty much impossible. So, to summarise, there are also issues around economics that are important that I don't want to go into here because of time, but around all the resources needed for people with intellectual disabilities to raise children as well. It's not just economics. If we kind of take a leap back to the discursive level and look at that issue of knowledge and sex education we find that the literature on sex education makes it clear that (and I don't know but would be interested in finding out about the UK context) but in Ireland there is no overall strategy at all on sex education for people with intellectual disabilities. It's piecemeal and they're small scale qualitative studies where people go out and ask people with intellectual disabilities about sexual knowledge – and then they suggest that these people don't have good sexual knowledge of their own bodies. So we've got that most important question which is 'do men with Downs Syndrome know that they are most probably infertile?' And that's another really important barrier, I would say, because if you don't know that you are infertile then there is absolutely no way that you can take action on an individual level or a collective, political level to try and access fertility treatments.

So the final thing we want to look at here is that it's looking more like a political issue here rather than a biological issue at this stage. So we might look at attitudes, and if this political, is there support for change in there...in the system as it is or the assemblage as it is. But we do have good data on this, well in Ireland anyway, the NDA (National Disability Authority) record attitudes every 7 years. So we know that in 2011 the majority of people were opposed to the idea of people with intellectual disabilities becoming parents even if they wish to do so. That has changed though in the last 7 years and now we have a majority, not a huge majority, but 62% were in favour of that. On a smaller scale it's still very contested amongst, sort of, family carers of people with intellectual disabilities and their staff carers too. So the final thing we might need to look at is the kind of widespread hostility to this but significantly it's reducing as well.

Ok, so when we do this sort of assemblage analysis, what we're saying is 'the problem of infertility we can no longer locate in the body, but rather it emerges through all those things I was talking about there', interacting and affecting one another in complex ways' and no doubt, a myriad more of things as well. There's always more, and Deleuze always says that we could always look at more. But there's some I think are kind of important [referring to chart on slide]. Why we do all this – we map how an assemblage or a system is working so we can

understand it in order to intervene in it. Again, getting back to the traffic jam, because it's something made up of material and discursive components, our levels of intervention can be at any level really. So we could, if we wanted, as a society, we could change that...it would involve things like funding, about biological research about men's biology, socialising access to IVF, providing resources for families with intellectual disabilities, introducing sex education so people know about their bodies and ensuring men with Downs Syndrome know about their Rights, let's say the new UN convention, so that they're aware that this is a Right they have. Important to note – intervening in complex systems like that is notoriously tricky and you get unintended consequences so you need to continually monitor any assemblage you go tinkering about with. Ok, so my case on this is 'infertility amongst men with Downs Syndrome can no longer be thought of as a biological inevitability, but something that we're all involved in. Whether that's consciously or unconsciously, we're all involved in producing or reproducing'. So the relevant question is probably not '*could* men with Downs Syndrome have children?', but rather a societal question of whether we want them to. This approach leads to taking responsibility for these kinds of things I suppose.

So, finally. Just to finish up. In presenting this, I don't wish to have this utterly pluralistic approach to disability studies and critical disability studies – I see them all as lenses that are appropriate for different situations. So I think Social Constructionism, Phenomenology, the Social Model, Historical Materialism are all incredibly valid and useful tools for exploring different aspects of disability and disablism etc. This [referring to slide], I think, is useful. Particularly useful in that it allows us to get back to engaging with science and questions around science and materiality and technology but it allows us to do it in a critical way, so we can bring the whole, kind of, critical studies disability approach to developments and I think that's appropriate to things like genetic privacy, genetic screening, access to assistive technologies, bionic suits and so on..although I would qualify that with the Deleuzian theme of 'it's not up to me to say how people should use it'. Use it whatever way you want! At that stage I would just like to say thanks very much for listening to that and I'd be delighted if there are some questions.