

# **Equality +**

**Disability Policy in the 21<sup>st</sup> Century –**

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## **Introduction.**

- 1. Human Difference Viewed Negatively: The Long Shadow of the Medical Model in Public Policy.**
  - i. Early Assault on the Medical Model – the Social Model in Public Policy.
  - ii. Equality as Sameness – viewing difference negatively:
  - iii. Equality accommodating Difference – but with limited systemic change:
  - iv. Inclusive Equality – a new high ground that most States don't (yet) aim for:
  
- 2. Going Beyond Equality in the CRPD.**
  - i. Personhood – a Deeper Well of Values.
  - ii. Social Inclusion & The Social Self-breaking new ground.
  
- 3. Going Outside the CRPD to drive Structural Change - the UN SDGs.**
  - i. Social Development theory is no longer exclusively tied to be economic development.
  - ii. Social Development Theory is now inclusive of all.
  - iii. Synergies between the UN SDGs.<sup>7</sup> the UN CRPD.
  
- 4. From Challenging Policy to Making Policy – Co-production and the new 'politics of disability.'**
  
- 6. Some Conclusions.**

## **Introduction.**

Thank you for the high honour of addressing you today.

I have watched with admiration from afar how your network is evolving. There is great reassurance from the fact that we can all draw on each others' encouragement and support. Every leap forward for humanity requires that we reach beyond ourselves and connect across boundaries. You are certainly doing that and we notice this and applaud it around the world.

My chosen topic has to do with the past, present and future of equality in the context of disability. I do so as someone in the field for about 30 years and as someone who helped (with others here in this room) to draft the UN CRPD. Indeed, I do so as the father of a daughter with a disability.

I want to start by making some personal reflections on the nature of the medical model and why it is still so powerful. No matter how devastating our critique, it still exerts power and especially so in the policy process. Why? I have my own views which I will share.

I will then reflect on the different stages of the equality ideal – stemming as it does from the social model. I'm not completely sure that the equality ideal – even at its most robust – will ever on its own finally eradicate the medical model. I'm not a pessimist – but I want to add some context to the pursuit of the equality ideal.

Even though the UN CRPD is recognizable as a thematic equality UN treaty, it actually imports some other ideas – ideas that I think can help eradicate the medical model even better than the equality ideal. These ideas include personhood, the importance of social inclusion and belonging and the democratic idea that we create our own future – not anyone else.

I will reflect on the fact that widespread cultural change is necessary as well as systemic social development. We used to call this economic, social and cultural rights. We still do. And one of the unique things about the CRPD is how it blends both sets of rights. But added to this now are the UN Sustainable Development Goals.

Social development never included people with disabilities. Social development tended to entrap and leave people with disabilities behind. But now we have a new instrument with the prospect of positive social development under the UN SDGs. Hence the critical importance of understanding that there now is a web of instruments to advance the rights of persons with disabilities – all anchored on the UN CRPD but all doing potentially very valuable jobs in their own right.

Enough preliminaries. What of the cursed medical model!

## **1. The Long Shadow and Sheer Weight of the Medical Model in Public Policy.**

Nobody here needs an introduction to the medical model.

Let me just say this.

To my mind, the problem with the medical model was never really medical practice. Indeed, the medical mission is (at least in theory) defined very broadly by the WHO and is, in essence, a highly humane one.

The real problem is that policy-makers adopted some of the perspectives of a supposed medical approach and enshrined it far beyond the medical field across a broad swathe of public policy fields (education, employment, housing, etc.). The essence of this mind-set is to *problematize* people with disabilities – to treat them as ‘objects’ to be managed and cared for rather than as human ‘subjects’ to be listened to and respected and empowered.

Now that led to policies, programmes, and intricate funding mechanisms that effectively isolated persons with disabilities.

There is an air of social Darwinism about this. The more you instantiate these presumptions about persons with disabilities as objects in institutional practices the more unquestioned and unquestionable the ideas become. Before you know it funding mechanism are there to 'compensate for' a disability rather than to build pathways for persons with disabilities. The subliminal message is that they are costs – and not people - passive beneficiaries and not citizens.

The many followers of Max Weber among you will also notice how ideas become institutions, how they become ossified and how they assume a momentum of their own. Turning that ship around is not easy. The interesting thing about costs is that this becomes almost an evidence-based free zone. That is to say, the very best evidence-based argument against policies based on persons with disabilities as objects are almost immune to evidence and facts.

This is what we are up against – s struggle to turn the dead weight of disability policy and history around after decades, if not centuries, of ploughing in the wrong direction.

What then is the default, in the dusty halls of policy-making, on the street and in services funded by objectifying people? Well, it is to see difference as material and to build atop that image of difference a web of social exclusion. Funnily enough, the man or woman on the street just sees this as difference and the different treatment as 'natural' – something that follows from the difference and not as a matter of public policy choice.

We feel the weight of this legacy everywhere in the world. Medical practice may have moved on – but public policy has not.

One word about cultural exceptionalism.

Of course we experience the medical model differently in different parts of the world. Let me put this another way. The stubborn persistence of objectifying people doesn't just come from the medical model. It interacts with and is powerfully reinforced by other deep-rooted assumptions in all our cultures. Northern Europe has trouble getting beyond a near Bismark-like insistence that social policy just means compensation for a deficiency – with money transfers. Southern Europe sees disability as a family issue – and family support as the main solution. America sees disability partly as civil rights issue against the backdrop of an underdeveloped social welfare model. It is the interaction of these background cultural assumptions that differ between all our countries with the insistence of the medical model on the objectification of persons that cements the medical model into place.

It was against this backdrop that the social model evolved – with its attendance emphasis on equality as a kind of rust solvent to dissolve away the barriers that resulted in public policy from the medical model.

There were – and are – at least three variants of the social model.

#### **I, Early Assault on the Medical Model – the Social Model/s:**

Perhaps the most famous variant was/is the UK social model. The essential building blocks were that (1) disability does not objectively exist, it is a product of social construction and labelling, (2) those doing the labeling have interests in the process and that the oppression of persons with disabilities is one of those interests and outcomes (hence the sense of victimhood) and (3) not only are people *marked apart* by labels they are *kept part* by negative public policies that operationalize those labels.

Therefore, it follows logically that the main focus of attention should be breaking down the myriad of barriers that these public policies have thrown in the way of persons with disabilities. Instead of fixing the person one should focus on fixing the system that creates arbitrary and unequal barriers.

This leads naturally into the fight for civil rights and equal opportunities – a key demand of British civil society in the early 1990s. This was so successful that it helped inform EU level

treaty changes and new EU anti-discrimination law later in the 1990s and into the early 2000s.

Its easy to see how re-focusing a reform agenda on the barriers facing the person rather than on the person was morally and indeed politically urgent.

The US civil rights model is generally seen as a sister to the British social model. It is less concerned with victimhood and oppression and more focused on the liberating power of an equal opportunities, non-discrimination model. This re-focusing was a natural fit with the long (and painful) US civil rights tradition. The big question was always why wasn't disability included as a beneficiary of that civil rights tradition. No doubt the medical model – as reflected in public policy – was largely to blame. For example, in the US there were even 'ugly laws' prohibiting the presence of persons with disabilities on public streets in the 19<sup>th</sup> century. This was despite the fact that everyone – in theory – was a beneficiary of the equal protection clause of the 14<sup>th</sup> Amendment.

So, if disability is not primarily a medical issue, or it is not primarily a social welfare issue then what is it? It is an issue of justice and, viewed from this lens, the basic problem was the unequal enjoyment of rights by persons with disabilities.

It will be recalled the drafters of the UN CRPF had three big drafting choices. First, they could have drafted a one page anti-discrimination treaty. Finland even tabled a non-paper to that effect. That would have been practically useless. Secondly, they could draft a full-blown treaty on the model of the Convention on the Rights of the Child. No State wanted that. Or they could take each right, identify the barriers to the equal enjoyment of the right faced by people with disabilities and then forge detailed obligations to become them. That's basically what they did. Article 5 on equality infuses every crevice of the treaty. But which theory of equality and is equality really up to the job of eradicating all vestiges of the medical model in public policy?

**ii. Equality as Sameness – viewing difference negatively:**

We all attack formal or juridical theories of equality. Called 'equality as sameness' by one eminent scholar (Arnardottir) – it simply means treating everybody formally the same. As Aristotle said: 'treat equals equally and unequals unequally.' Putting this another way, if there is no material difference between two different persons or groups and if they are similarly situated then treat them the same. But – a big but - if there is a material difference then by all means treat them differently. This is the interesting thing about formal equality – human difference can be flipped negatively or positively. Usually it is flipped negatively. And usually this has nothing to do with the inherent circularity of equality analysis from within the formal frame. It really has to do with the pressing weight of the medical model on formal equality analysis.

I believe the recent book by Anna Lawson and Lisa Waddington on the CRPD in national courts shows that courts all around the world still use this approach. And I sometimes think this thin conception of equality still exerts control because underneath it lurks the medical model.

We applaud more sophisticated theories of equality. Yet I'm pretty sure States have not progressed much beyond formal equality – beyond seeing material difference and reacting negatively to it. Curiously enough, they do not even see this as negative. They just see it as a direct result of material difference. It's almost as if equality theory *requires* us to notice difference and accommodate it (negatively).

One more thing about formal equality. It's all about relativities - how one is treated relative to another who happens to be similarly situated. One commentator calls this a 'morally empty' theory of justice. I tend to agree with this critique. Justice is surely not just about relativities. Let us return to this anon.

Remember, many States were in fact very happy with the formula used in most Articles of the treaty to the effect that the relevant right was to be secured 'on an equal basis with others.' At least some of them were happy because all this phrase triggered in their eyes was a very thin theory of equality – which meant no obligations to really change things on their part. Which of course leaves the medical model largely intact.

### **iii. Equality Accommodating Difference – but with limited systemic change:**

Arnardottir next identifies a second phase of equality thinking in the UN system in the 1990s that created an opening to acknowledge specific human difference and to respond positively to it. To ignore material difference is to effectively deny rights and indeed invite cynicism about justice according to the. This is where the celebrated concept of ‘reasonable accommodation’ comes into play.

Interestingly the concept did not originate in the disability field. The 1964 Civil Rights Act in the US prohibited discrimination on the ground of race, gender and religion. It was the Federal Courts that implied the obligation of ‘reasonable accommodation’ into the Act on the ground of religion to ensure that the observance of different religions did not prejudice people in employment. The difference of having to respect a holy day on a Saturday (under the Jewish religion) should not disadvantage someone. They were due some ‘reasonable accommodation’ on account of their faith – or the difference of their faith. When Federal legislation prohibiting discrimination on the ground of the disability (the first in the world) was enacted in the early 1970s (Rehabilitation Act) the Federal Courts similarly wrote in the obligation into the Act. Of course, it was made famous in the Americans with Disabilities Act 20 years later in 1990. But it really stems from the period that Arnardottir describes as one that is positively attuned to difference.

Equally famously, the UN disability treaty lifts the obligation to engage in ‘reasonable accommodation’ from the ADA and applies it right across all rights. I don’t know if many States really understood what was going on. Some viewed it and feared it as a thin edge of a wedge to enforce ‘socio-economic’ rights. Some even argued that while failure to achieve it was regrettable – such a failure in no way amounted to discrimination. Eventually it was accepted that a failure to achieve ‘reasonable accommodation’ was a violation of the non-discrimination norm.

This at least makes a decent effort to try to flip difference positively – to trigger positive responses to the difference of disability. It is not really designed to bring about systemic change. Systemic change can sometimes happen as a result of landmark court decisions

(e.g., the famous Olmstead case of the US Supreme Court on de-institutionalization) but that is not part of the design of the concept of 'reasonable accommodation.' Hence much of the rockface of barriers and institutional practices generated by the medical model remain largely intact.

**iv. Inclusive Equality – a new high ground that most States don't (yet) aim for:**

The third phase Arnardottir identifies is the phase of multi-dimensional and accumulated disadvantage (late 1990s onwards). This is quite a mouthful. What she is getting at is a certain disenchantment with identity-specific approaches and law. One identity – disability – does not define the person or exhaust all dimensions to the person's life. We all have multiple identities that interact and intersect. Traditional non-discrimination law hardly ever gets to this. And indeed, the disability treaty makes a decent stab at acknowledging overlapping identities especially with respect to gender and children. If I have a regret it is that we paid too little attention to older persons in the treaty. Nevertheless, relative to the other treaties it does innovate with respect to intersectionality.

Perhaps more importantly this newer approach also serves to focus our attention on the effects of these intersecting identities. They can bring in their wake multiple disadvantages that accumulate and feed off one another over time. That being so, then the function of equality analysis is not just to take a snapshot of the person as they currently present (synchronic) but to interrogate how they got to be where they are through time (diachronic) and – crucially – how these disadvantages can be addressed and dissolved.

Here it is obvious that more programmatic approaches are required than had been the case under traditional non-discrimination law. And such programmatic approaches are of course the natural domain of traditional economic, social and cultural rights – our main tools to bring about structural change.

Looking back, I find it fascinating that some DPOs during the beginning of the drafting process insisted that these ESCR rights were part of the problem rather than part of the solution. What they were getting at was the fact that social supports in the shape of

economic and social rights were traditionally distorted by the medical model – effectively segregating and purchasing the absence of the other.

The solution of course, was to blend these two sets of rights (civil and political with ESCR) and obligations into every right in the treaty making sure they sub-served a higher purpose which was human liberation by creating structural reform. This dovetails very nicely with Arnardottir's idea of multi-dimensional and accumulated disadvantage equality.

Of course it makes life really difficult for lawyers who have to wade through each right to see which is 'immediately achievable' and which is to be 'progressively realized.' But the fact they are melded together shows the power of the multi-dimensional and accumulated disadvantage approach in the treaty.

Prof Fredman calls this a 'transformational' theory of equality and Theresia Degener calls it 'inclusive equality.' Regardless of fancy labels it is clear that we have travelled a long way since 'equality as sameness' even though that's where most domestic courts and Parliaments are still stuck.

So much for equality. We aim high – but States tend to aim low. Material difference is still used as a basis to treat separately and even segregate. Even in Europe, segregation into institutions is not generally seen as discrimination.

Playing the relativity game only gets you so far. Some deeper well of justice is needed. And the CRPD actually provides it. It is equality plus these other considerations that offer a better hope of demolishing the relics of the medical model.

## **2. Going Beyond Equality in the CRPD.**

**i. Personhood – a Deeper Well.** Barrier removal and equal opportunity is fine. But what if the mind-set that allowed barriers to exist was not itself tackled and changed. The

barriers would just reappear in a new guise. The real reason those barriers existed was because the medical model failed to see persons with disabilities as *persons*. They were shrouded in a cloak of invisibility.

We didn't see it then (or at least I didn't see it then) but looking back over n it now it was obvious that these deeper personhood rights would take centre stage – the right to be in the world (Article 19) and the right to make your own way in the world (Article 12). Many would say – myself included – that these rights form the very 'object and purpose' of the convention- going deeper than equality theory. They are emblematic of the shift from object to subject and they most directly attack the suppositions of the medical model.

Although couched in the language of equality one cannot help but feel that they go much deeper and broader than equality – no matter which theory of equality you favour. In other words, these provisions aren't just about securing equal treatment in the enjoyment of rights with others – they are really about an acknowledgement of the very personhood of persons with disabilities as persons. It is this emphasis on personhood and the natural entailments of personhood that distinguish the treaty (in degree if not kind) from the other thematic treaties. Of course, similar discounting of the person takes place on other grounds – especially on the ground of gender. But this discounting has been extremely stubborn on the ground of disability precisely because of the medical model.

What's my point? My point is that Articles 12 and 19 more directly challenge the background assumptions of the medical model.

Another surprising thing about the treaty that more directly challenges the medical model is the very image of the person in the CRPD. People like Anna Greer have long noticed a rather formalistic and wooden view of the person in UN human rights treaties – a sort of deracinated self. The disability treaty is a bit different – it sees the 'social self' alongside the atomistic self. It goes beyond the familiar role of protection to value belonging and to try and ensure it happens, It is a frank acknowledgement that we are all social animals – this being only more obviously so for persons with disabilities. This is the real key to understanding the support paradigm in Article 12 and the community living paradigm in

Article 19. These Articles are not just about relativities with others – they stand on their own ground.

Of course, this focus on personhood and indeed shared personhood gives life to the ideal of social inclusion. As carriers for this vision, Articles 12 and 19 stop you from focusing on material difference and to start focusing on personhood.

**ii. Social Inclusion & The Social Self- breaking new ground:**

One might be tempted to see the CRPD as a libertarian tract – a **series** of rights that inure to the benefit of atomistic individuals each pursuing their own egoistical ends ends. This picture is incomplete. The image at play beneath the surface is that of the social self. If we share our personhood, if we are a function of past interactions, if our social capital is vital to us in the formation of a healthy sense of self then it becomes highly logical to focus not just on individual autonomy but the quality of our social experiences. This explains a lot. It helps situate the support paradigm in Article 12.

It is by immersion into social support- something that occurs naturally for most – that we grow in confidence and competence in decision-making. Our autonomy is relative. Similarly, we grow in our independence as we are actually primed to connect in and with our community – it is this community immersion that underpins our independence. That is why Article 19 is about both living independently and being included in our community.

I often think people miss the social inclusion mandate of the convention. I believe it is not for nothing that Theresia Degener calls her new theory of equality ‘Inclusive Equality.’ I think what she is trying to get at is that equality is not just about the relativities of treatment – it is about making space in our societies for persons with disabilities because belonging and participating is just as important as protection against unequal treatment.

In sum, all our cultures define themselves relative to the medical model. Being against it is one thing. One has to acknowledge that it has sunk deep roots and expunging it will take time. The social model – or more accurately variants of the social model – has done a lot of heavy lifting by taking the focus away from the problematizing of the person and toward the

systemic changes that need to take place to get rid of the effects of the medical model. The early emphasis on non-discrimination as a panacea has been replaced by a more realistic appraisal of the strength of the barriers and the need for a newer model of equality. The addition of personhood rights going deeper and beyond traditional equality theory is one of the hallmarks of the newer human rights approach.

### **3. Going Outside the CRPD - the crucial Social Development Dimension.**

But how do we even more directly bulldoze away the mountains of policies and programmes that have been built up on the medical model. These policies represent the caked-in detritus of the medical model. Breaking them down takes more than the episodic testing of policies in individual non-discrimination cases in the courts.

One would naturally hope that social development process would move in the right direction.

The past and even the recent past was not good.

Recall, disability was not traditionally seen as an issue of justice or human rights. Instead, in as much as it was seen, it was more often seen as a social policy or social welfare issue.

Indeed, symbolically, the UN body that took the most interest in disability in the UN prior to the CRPD was the Commission for Social Development and not the human rights side of the house.

Indeed, the original Special Rapporteur on Disability reported to the Commission for Social Development and not the human rights side of the house. The first distinguished holder of that office (Bengt Lindquist from Sweden) did of course voluntarily report to the UN Human Rights Commission but that went beyond the original terms of his office.

Lets unpack this a bit. Social development is of course a good thing. It provides the necessary policy backdrop with attendant resources to elevate the status of many groups including the so-called 'vulnerable.' But there were a number of problems with the traditional approach.

**i. Social Development theory used to be tied to economic development.**

First of all, social development was traditionally seen as depending sequentially on economic development. You have to wait for economic progress before there can be social progress. A rising tide will lift all boats!

Well, that's not true. Haven't you noticed that even in times of prosperity the status of persons with disabilities may not similarly rise compared to others. I think this again has something to do with the medical model which weighs down social policy. We used to call this the social dimension to the market in Europe – meaning social policy is legitimate only up to the point that it reinforces market logic. And that of course excludes those whose use-value in the market is less.

**i. Social development Theory used to emphasize compensation and not empowerment.**

Secondly, the default in traditional social development toward disability was compensation – not empowerment. It is at least worth noticing that the UN Millennium Development Goals (2000) nowhere (nowhere) mentioned disability.

So persons with disabilities weren't even the subjects of welfare! Trickle down welfare would presumably take care of them.

**iii. Breakthrough – the UN SDGs (2015-2030).**

Now, persons with disabilities are expressly mentioned in five Goals of the UN Sustainable Development Goals and are impliedly covered by an expansive definition of 'vulnerable' groups – which is of course highly questionable terminology.

What does this really mean? It is obvious that social development is needed to advance disability and to remove structural barriers and create a more inclusive society and economy. There is a natural symmetry here between the expansive theory of equality in the disability treaty (multidimensional and accumulate disadvantage equality) and the smart inclusion of economic, social and cultural rights in the treaty alongside the UN SDGs. It is obvious that positive social development is needed to remove a wide variety of barriers and create a more inclusive future.

How then can and should social development efforts help achieve the overall goals of the UN CRPD.

Just as economic, social and cultural rights were rendered secondary to the overall goal of human liberation in the disability treaty, so too is social development. Remember the warning of DPOs during the treaty negotiations. Social development processes can easily lapse back into the medical model – a focus on *compensating* for human deficits without more. This is the actual history of social systems in most countries. The answer was to make it plain that social development is to be progressed in line with existing international legal obligations including the CRD. This is in fact made plain in the UN SDGs. The non-discrimination tool can be flappable – it might be perversely used to rationalize different treatment for those who are ‘different.’ The ‘reasonable accommodation ideal – no matter how robustly applied – will seldom bring about the systemic change needed to defelect the mountain of practices that have resulted from the medical model. Permission to engage in positive action is just that – permission. And the progressive achievement of ESCR might not be progressive enough to tackle that mountain, That is why an emphasis on structural change though the UN SDGs is so important as playing a more direct role in pushing back the detritus of the medical model. Provided always that it sub-serves the UNCRPD and does not become a substitute for it.

## **5. Taking Seriously the ‘New Politics of Disability’ - Co-Production of Policy.**

Where are we? We have moved from the medical model to the social model to the human rights and justice model. Law, in itself doesn't change the model.

Medical model thinking – especially in public policy - still predominates.

Equality thinking has also moved on to 'multi-dimensional and accumulated disadvantage.' But saying it is so doesn't necessarily make it so especially in public policy.

Social development theory and practice is now slowly coming into alignment with the CRPD. But great care needs to be taken to ensure that it doesn't lapse into out-of-date approaches to social development that become easily captive to the medical model.

Let me take this a bit further. I previously wrote that we have to 'resist the temptation of elegance' – the easy assumption that because the treaty says X that X is inevitable.

And the reality is that the medical model still drives assumptions in the disability policy field. The reality is that the voices of persons with disabilities have been relatively absent in relevant policy debates – creating a self-perpetuating echo chamber in public policy. The reality is that the odd or episodic victory on a policy topic can easily be reversed since the process that created it can too easily revert to type.

Long term reform doesn't just mean a proper understating of, say Article 24 on inclusive education. It means changing the *process* by which law and public policy is made. This is what I call the 'process-based' perspective in the UN CRPD. Indeed, I probably view it as more important than a substantive focus.

When people are present as 'subjects' in processes that otherwise objectifies them then this transforms the process. When the raw edge of human experience is communicated it cannot be ignored.

Voice is in fact a cardinal feature of the disability treaty. Famously, Art 4.3. converts the desideratum of 'nothing about us without us' into a legal obligation on the part of

Governments. By the way, I do not interpret that to mean civil society must always win every argument. To govern is to choose – but at least now Governments can choose not on the basis of lazy suppositions but on the basis of what people say for themselves.

Just as important, the treaty innovates by laying out how the process of change should work in Art 33 – with smart and connected-up Government, active involvement of civil society and an independent reality-check in the form of an NHRI or something that is functionally equivalent. By the way universities and disability studies centres also have a crucial role to play here.

Getting this triangle of change to work properly is the real key to change – not the elegant jurisprudence of a remote body like the UN CRPD Committee no matter how august. This is what creates and transforms the ‘politics of disability.’

All sides need to adapt. For civil society this means as much emphasis has to be placed on crafting blueprints for change as it has traditionally been placed on protest. This means new kinds of alliances – and especially with universities which should stop producing research that merely explains the obvious and start producing research that contributes to new ways of changing reality – good citizens as well as good academics.

Of course, our political systems – our official opportunities to advocate for change – differ. International law does not dictate that we all have the Westminster model. However, no matter how open or transparent or interactive the process of change is, it does exist in all places. One size will not fit all. Your openings to impact change will be different in Taipei as it is in Dublin. This requires a high degree of ‘situation sense’ – an ability to put forward the right arguments at the right moment and fitting the right opportunity. And it isn’t just because our political and policy systems differ. It is also because the way the medical model interacts with other local cultural assumptions also differ. The ultimate goal is to make these assumptions appear contradictory and unnatural. I know how to do this in Ireland – but not in Italy.

This is why voice is so important. I suppose what I am really saying that the human rights model on its own is not enough. Even a robust notion of inclusive equality is not enough. A focus on personhood gets us beyond traditional human rights. But reverting to the medical model is still too easy. And tying social development to disability rights is not enough. It is the process of change that itself needs to be changed to secure long term change. Luckily, the UN disability treaty imagines a 'new politics of disability' at the domestic level. This, to me is the key to change and you -as researchers – have a key role to play in supporting that process.

Finally, a personal plea. I have seen how impactful disability studies centres have been around the world, from the granddaddy of them all in Leeds University to NALSAR in India to UNSW in Australia. We are all part of an eco-system for change now in the 'new politics of disability' created by the UN CRPD. This fits with a philosophy of the university as a temporary custodian of knowledge that comes from the people and has to be given back in service to the people. It comes from a philosophy of seeing universities as good citizens – ready and willing to play their part in the process of change. It comes from an openness n Governments to co-production of social policy with the people who matter most.

I see great potential in your network and wish you well for the future.