

16th Informal ASEM Seminar on Human Rights
Keynote Speech for the Opening Plenary on 8th November 2016
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Thank you for the high honour of addressing you this afternoon.

I speak to you today in my capacity as an academic interested in ideas, as a 'scholar-activist' interested in change and as a father of a daughter – now a young woman - with a disability.

Permit me a few minutes to share with you some personal reflections on how we have come to this point today and what its significance is.

Every first year law student learns that because we are humans we all have human rights. What we don't tell our students is that throughout history and in all countries some humans count for more than others. It's a sad reflection on history that countries tend to define themselves not just by whom they include but also by whom they exclude. The great English legal historian – Sir William Blackstone – once wrote that upon marriage women suffers civil death. Her very person becomes invisible – she becomes literally an object in the possession of her husband. Likewise I and many, many others, have said that people with disabilities have suffered a similar civil death throughout history, invisible both literally and figuratively.

It never ceases to shock me that in the field of ethics there still is serious debate about whether people with intellectual disabilities are less morally worth – or less morally considerable - as humans as others. This just goes to show that the ethic of exclusion that has manifested itself in law and public policy has very, very deep roots in all our cultures.

One of our esteemed colleagues in the LSE – Prof Conor Gearty – calls the disability rights revolution a **Visibility project** – uncloaking the person behind

the disability, affording to him or her the status of a subject and not that of an object, and taking their talents, hopes and dreams equally seriously alongside those of others. In short, this visibility project entails viewing the difference of disability positively. It is no accident that the publication that really launched the disability rights movement in Europe – was entitled **Invisible Citizens** (1994).

So the myth system of human rights was to the effect that humans, in virtue of being human, held human rights. The operation system means that some had their humanity discounted. What we aimed at in the UN CRPD was to close the gap between the myth system and the operation system – not to generate new disability rights but to ensure that the rhetoric of equal human rights for all would finally reach and benefit our fellow citizens with disabilities.

By definition, a Visibility project means shining a light on the person and restoring power to him/her to shape their own personal destinies. So the baggage – the laws, the policies the fiscal arrangements – that we have accumulated to treat persons with disabilities as object and not as subjects needs to be rolled back.

Critical to the task of restoring visibility and self-determination to the person is voice and choice. You might say this is the centre-piece of the whole convention. And it entails not just voice in one's own life or with respect to entities like services that touch our lives – it also entails having a collective voice in the policy process. After all, what's the point in changing one or two bad laws if the process by which these laws came about is not itself changed.

If this collective voice were not present during the CRPD negotiations the treaty would lack its sharpness of vision. That's why the convention converts the slogan 'nothing about us without us' into a legal requirement. And that is why we focus on Workshop 3 on legal capacity and in workshop 1 on political and cultural participation.

Don't just look on the treaty as containing a set of substantive norms and obligations in the traditional sense. Look to it as an instrument to transform processes of change. The vision of Article 33 – a strong focal point within government, the strong presence of civil society and a reality check in the shape of a framework for independent monitoring through national human rights institutions – sees a virtuous circle of mutual engagement and even co-production of policy.

A word about cultural participation. Its not just about benefiting from culture – and feeling valued and belonging. Its also about sharing in collective self-conceptions and shaping them into the future. It was once said that the first obligation of an artist is to tell the truth as they see it and let the chips fall where they may. Having this cultural freedom allows for new imaginations of the future to emerge – a benefit to all of society.

In truth, none of us exist as an island – whole unto ourselves. We become who we are as a function of our interaction with others. Perhaps in the field of disability that is more obvious than in other fields. The social inclusion dimension to disability not only opens up pathways into the mainstream alongside others, it grows social capital, it generates an ethic of belonging regardless of difference, and it helps generate a much more open and inclusive society and economy. It is right in itself and it generates what we call in Europe a productive factor in our economies. That is why it is important to make our educational systems genuinely inclusive of the difference of disability. That is why we are all searching for better ways of nudging our markets toward more inclusive employment. Its not easy since the ethic of segregation is etched deeply in all our cultures. And it takes time to turn the ship around. And of course the very concept of inclusion needs interpretation in order to avoid a formalistic kind of mainstreaming that is oblivious to the difference of disability. No doubt these 'dilemmas' of difference as Dean Martha Minow of Harvard Law School refers to will emerge throughout our discussions on inclusion.

The challenges of social inclusion strategies is one reason why the link between the CRPD and the UN Sustainable Development Goals is so important. The underlying political economy of the rights in the CRPD depends on positive social development. The rights can be achieved faster if accompanied by positive social development. Equally, social development that is not informed by the CRPD may end up entrapping people with disabilities. This was certainly the case in the past.

Adopting the UN SDGs as a guide to reform does not mean postponing, delaying or lowering the sense of priority of the CRPD rights which after all have the force of international law. But it does mean that we now have a unique opportunity to blend the two together to mutually reinforce the process of change. Perhaps the first responder to this challenge is the Council of Europe whose draft Disability Strategy (2017-2027) is the first in the world to blend together human rights and the UN SDGs in the context of disability. I commend it to you as a way of positively harnessing the power of human rights with social development.

If no man (or woman) is an island then it is true that no country is an island. Lets be clear. The shift away from old laws and policies is not easy. It shakes up received wisdom, it places huge question marks over previous practice – practice that was considered ‘normal.’ It forces us to confront ourselves as societies, to take stock, and to change. That's not easy. Whether one expresses it as a ‘paradigm shift’ or an evolution from one model to another – from the medical, to the social, to the human rights model and onwards to the UN SDGs - it still entails upheaval. The shape and content of reform will depend on how one understands this shift of ideas. This is by definition a worldwide debate. We need each other in this dialogue. We need to reach beyond our own situations to grasp how others see this revolution of ideas. So, to me at least, the most important thing about international cooperation is conceptual – a sharing of self-reflections on where we are coming from and what kinds of ideas that will shape our reform processes.

As a process it will embrace know-how and know-what. It is important to understand that when it comes to disability we are all developing countries and we must help each other. And in this process, the role of civil society as well as knowledge providers like universities is critically important.

We in Europe are proud of the European Disability Forum – our umbrella body for civil society. I think its true to say that it has evolved from being not just an advocacy body that highlights problems but a policy entrepreneur body that comes forward with blueprints for change and solutions. Civil society groups like this have a lot to offer each other in helping move the process of change forward – as constructive partners in the process of change.

And both Europe and Asia/Pacific now have a critical mass of university-based research centres and disability law clinics. Universities are both apart from society with academic independence and a part of society in that they provide fresh frameworks and understanding so vital to process of change. This power of imagination and re-imagination, together with an entrepreneurial civil society is a critical success factor in the process of change. Any international cooperation programme that is meaningfully aimed at reinforcing change must embrace and support exchanges between civil society and the newly emerging academic environment.

Why is this meeting significant? First of all, there is a richness of experience on both sides that needs to be captured and shared. We will return home better informed but also with better questions. Secondly, there are many different process of change on both sides and we might reflect together on how mutual engagement can be stepped up to help inform processes of change. Last but not least, maybe we can better situate the debate about human rights and disability into a broader frame about human difference and its positive value in our societies. Although not formally on the table for discussion, I believe it is important to zoom out from disability to connect it with broader currents of change affecting other groups and with other identities such as old age (intersectionality).

