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***The Decline and Future Reconstruction of the US Civil Rights Model on Disability***

***The Mothership is Adrift***

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To us the rollback of civil rights and the loss of US leadership in the international community isn't just regrettable - it cuts to the very foundations of international disability law and policy.

***A long familiar world is gone.***

For years we argued for much more inclusive development assistance when it comes to disability. We got it last year in the admirable USAID policy on disability. Now it is gone.

The demise of the Civil Rights division of the Department of justice - the gold standard for the world especially on disability issues - is deeply lamentable. A similar fate faces the Civil Rights divisions of major Departments like the Department of Education which was so central to securing the inclusive education rights of children with disabilities.

The US Institute for Peace was one of the very few bodies in the world doing incredibly important work on the involvement of persons with disabilities in peace processes worldwide - gone. Added to this, the office of special adviser on inclusive disability matters in the Department of State - an office pioneered by Judy Heuman - looks uncertain.

The soft power that always represented US disability law and policy - has vanished.

The impacts are felt first for persons with disabilities in the US. And the ripple effect around the world through the loss of USAID and the loss of the office of special adviser in the State Department is also tangible.

But I want to focus more on the loss of ideas and moral leadership. That hurts even more and probably has more long-lasting effects.

One reason for our deep hurt is that, in truth, we never saw the US as just another Nation-State - formed around a discrete nation of 'us' versus them. We always saw it as an *idea* where everyone could belong provided they subscribed to certain basic values like dignity and equality. Now, In place of *e pluribus unam* has come a sharp divide between 'them' and 'us' with gradations of exclusion. This, to us as outsiders, is a nightmare inversion of the American dream. Maybe we were naive - but that image we had has been well and truly shattered.

One of the bedrock elements to this nation of ideas was civil rights. The re-making of the US in which civil rights are sidelined and the re-framing of society into 'them' versus 'us' is damaging all round and especially in the disability context.

Let me remind you that the simple message of the Americans with Disabilities Act - still the most admirable civil rights law in the world on disability - that every person counts - was profound. Like the shots that 'ran out around the world' it lit a spark in the international disability community. We in the international community were in awe of the raw moral urgency of the ADA - celebrated at the time as a bi-partisan move. And we built on it to advocate for a new UN convention.

We were especially impressed with the assertion in the ADA that persons with disabilities were an '*insular and discrete minority'* - a phrase pregnant with meaning in US constitutional law. Essentially, it means a group who cannot always or ordinarily count on the political process to address their just claims and who therefore require their claims to be endorsed by law.

In our admiration we overlooked the fact that this civil rights vision was not really accompanied by an equally well developed social model - with social rights to accompany civil liberties. In retrospect, and in light of these failings in social policy, the ADA looks like Hamlet without the prince. We put that down to a *work in progress* and did not condemn the American experiment because of its absence. The hope was that an American social model would evolve over time and that it would be enriched by the civil rights model. The impending demise of MEDICAID shows we were dead wrong.

***What has gone wrong?***

It seems to me, as an outsider, that you are back to a time when people are valued simply because of their use value in the economy. So much for inherent civil rights. Now, you will say this cannot really be true since the use-value of persons with disabilities is constantly overlooked. I completely agree. And yet here we are - back in the common misperception that persons with disabilities cannot contribute - or contribute less - to the success of an economy and society.

And we are almost back to a market-based conception of democracy. In this crabbed vision there are definite winners and losers - and you (persons with disabilities) are the losers. This is not mediated by any fancy theory of 'discrete and insular minorities' that warrant enhanced protection. Your inevitable suffering is perversely your own fault on account of your disability.

And what of the American Social State - the imperfect bundle of rights that make the formal freedoms of the ADA real in everyday lives?

The Regulatory or Administrative State is now in decline. It was originally put in place to guide economic development (and nudge economic actors) to avoid dislocations, to compete effectively and to meet real social needs. With respect to disability this meant that smart demand-side tools were needed - like capital grants for employers or tax incentives. That served the overall public interest in a market economy that valued all. The decline of this regulatory approach affects all and especially persons with disabilities.

A social rights system and health care was needed to take care of those who cannot take care of themselves due to their inability to thrive in an open market economy. Yet they are in full retreat. In a way, such social support is key to enabling market efficiency. You simply cannot compete with an uneducated and unsupported populace. However, the real rationale for social support always had more to do with valuing each individual regardless of the size of their economic footprint - big or small. That commitment seems gone now.

If you combine the rise of the use-value theory of persons in the economy with a winner-takes-all philosophy of democracy and the erosion of regulatory and social support then you get the current nightmare. You cannot be heard complain if the civil rights protections of the past are eroded. Thats just democracy and elections have consequences. But what an absolutely empty theory of democracy this is!

***The UN Convention Builds on and Improves the American Model.***

While disability rights was an American invention, it became a global challenge. We took the American model and built on it in the UN CRPD. The CRPD blends the best of the civil rights tradition with a developed social model. T

And the convention took the idea of '*discrete and insular minorities*' a step further by insisting that all future law and policy be based on the voices of those directly affected. What is more, the convention built on American ideas about equality and explicitly and unashamedly connected to a philosophy of inclusion - a sad orphan now in America.

Now we are left with a convention that can trace many of its foundational ideas to American Civil Rights but which now has to live without its beloved parent. And yes it can.

The loss of the mothership has not dented our self-confidence. The innovative blending of civil rights with smart social supports that the CRPD represents can provide a model of sorts when it comes to the eventual reconstruction of American disability law and policy. Civil rights without social rights is like Hamlet without the prince.

The UN convention now looks much better suited to the kind of economy and society we will have in the future - one driven by artificial intelligence - one which can create more space for all human talent. The convention requires a revolution in how services and supports are framed and implemented. This is not about the fraudulent search for fraud, waste and abuse. Its about re-purposing social supports to meet the 21st century. Even if USAID is out of the picture, the UN convention requires all other States to make their development assistance truly inclusive and to break cycles of poverty at a time when you seem to be dooming your own disabled citizens to poverty.

Above all, the insistence of the convention that the voices of those most directly affected must be listened to helps to fortify the disabled community in the US - everywhere - to make themselves heard. We have Judy Heuman to be thankful for this - and we owe it to her memory to work for the revival of American disability civil rights.

Rest assured, the worldwide children of the American civil rights revolution will be ready to help rebuild. We owe you that. But first you must fight for what you have and then reimagine what you need in the 21st century. May the fighting spirit of Judy Heuman and the political acumen of Marca Bristo be your - and our - guide.

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