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Theme: Self - determination for people with cognitive impairments in health and care services and the need for a new self-decision-making system

(Articles 12, 14, 19, 25  in the CRPD.)

Hello. My name is Gerard Quinn and I am the UN Special Rapporteur on the Rights of Persons with Disabilities.

I thank you for the high honour of addressing you today for your important event.

I used to be a member of my own country’ human rights commission and am always appreciate of the role of Ombuds offices throughout the world in advancing the rights of persons with disabilities.

In the time available, I just want to stand back and emphasise the importance of the issues you will discuss.

Before I do so, let me remind you of a famous report published as far back as 1995 in Europe called ‘Invisible Citizens.’ The core thesis of the report – which was very impactful at a European level – was that persons with disabilities count less than other persons, and this applies particularly to persons with cognitive disabilities. The intent behind the report was to get policy-makers to see that reality and then to commit to open up the equality ideal to encompass it.

This worked up to a point with new treaty changes and legislation.

But in the process, we stumbled across an embarrassing feature of modern ethics.

Ethics draws a sharp distinction between persons (subjects) and things (objects). And crucially, it contains a middle layer called ‘persons of lesser moral worth.’ What an astounding and fundamentally de-humanising category. If ethicists think like this, then it comes as no surprise that popular culture also treats persons with cognitive impairments as somehow less worthy as persons and human beings. And much law and policy followed suit. This is an affront to all of us.

Quite how, or why, or when, cognitive ability became the alleged touchstone of what it means to be a person is debateable. It was not always so. And it should not be so going into the future.

We started drafting the UN disability treaty [the Convention on the Rights of Persons with Disabilities] as if the equality ideal would solve all our problems.

But something interesting happened during the negotiations – and it was all down to the strong presence of civil society in the process.

Something else bubbled up to the surface. Civil society groups began saying: “why treat the symptoms (inequality) without treating the cause?”. And the root cause of inequality was felt to be invisibility.

Putting it bluntly, that is why personhood is the foundation stone of the treaty – alongside a refreshed and broadened view of equality. The questions of personhood may be safely ignored on other grounds – but not in the field of disability. It had to be confronted.

That is why – to me at least – Articles 12 and 19 are the essence of the Treaty. They are carriers for a new vision of what it means to be a person.

[Let us] reflect on this for a moment.

Decades if not centuries of treating persons with disabilities as non-persons has meant the growth of law and practice that not only viewed persons with cognitive impairments as invisible but treated them as such. And even when the law does to formally replace your autonomy, it allows others, or signals to others, that they may informally treat you as invisible.

In effect, persons with disabilities were treated as objects and not as subjects. This could be, and was, rationalised, by insisting that decisions would be made “in your best interests”. This standard was hardly ever enforced and it could be used in any event to justify a pattern of decisions that was really reflective of resource scarcity.

So the key message of Article 12 is that *I count as a person regardless of my cognitive capability*.

One of the interesting by-products of the age of guardianship and substitute-decision making is that there was no incentive to find new ways to explore the self behind the mask of disability. Now, there is an explosion of interest in ways of understanding informal communication to try to reveal the self behind the mask of disability. I commend the work of Professor Jo Watson in this regard.

Another interesting thing happened when drafting the treaty.

We are used to thinking atomistically about the person – the self – in human rights treaties. We treat them almost as if these treaties are libertarian tracts extolling the masterless man operating in a complete social vacuum.

None of us actually behave that way. We are all dependent in our own way on the wealth – or the poverty – of the social capital that surrounds us, holds us, reflects us and gives shape to our own biographies. That is why the image of the person in the treaty is both individual ***and*** social.

The emphasis on ‘supported decision making’ in Article 12 [of the CRPD] brings this vividly to life. When you peel it away, it is not really about new services, new support regimes, new State-driven regimes. It is about the myriad of supports we all enjoy in our own lives in making our own way in the world.

I like to say that personhood is something that is naturally shared as well as enjoyed individually. This is conspicuous by its absence in the lives of many persons with disabilities and Article 12 [of the CRPD] is all about a faith in the existence and vibrancy of our sense of self once properly supported.

Article 19 states such basic ideas that there was no need to emphasise them in previous treaties. We are social animals. We come alive once connected. Even the neuroscientists now say the human brain is wired to connect.

And our homes play a critically important role in enabling this to happen. Home to a human being means much, much more than shelter from the elements. It is a place of repose from the world – where identity is forged in close association with others; it holds our sense of identity and enables us to be nurtured. But it also connects us with the broader world – with our neighbourhood and community – with the social determinants of ourselves.

Lying back of Article 19 is an intense positive faith in human capacity to flourish and expand once immersed in the rich social capital that can only come from the security of one’s own place connected in the community.

Now of course, we can and should change laws, policies and practices to signal a shift toward all of the above. Being an avid student of Max Weber, I know this is not enough. You will find old thinking encrusted in funding mechanisms, administrative structures and the way services are designed and delivered. And in a way, if you don’t transform them, then the subliminal message, no matter how well-intentioned in law reform, will be ultimately undermined.

Changing high-level law and policy is not easy – but it is the easy part compared with changing funding, services and administrative structures. Ten years ago, I would have been a bit downhearted about this. Now, there is a wealth of information – hard guides – on how to do this, including for example an amazing publication from the EU Fundamental Rights Agency, on how to move budgets from traditional services to the community. And the trend toward e-platforms as a window onto services has many risks but [also[ opens up many new transformative opportunities – something we at the UN Special Rapporteur’s office, will focus on a lot on next year.

To my mind, it is futile to work on law and public policy without an associated transformation of services. Otherwise, power structures and power imbalances will only appear to change but won’t really change. We might grow a ‘myth system’ of centering persons in their own lives – but perpetuate an ‘operations system’ that continues as before.

This is why your debate about the [future of the] Nordic social model is so important. It needs to be refreshed to make sure that the way it operates helps give reality to the centering of persons in their own lives. This, to me is the main challenge ahead. And this to me is the big prize.

We look very much forward to your deliberations and I encourage you to stretch the policy imagination to embrace not just the ‘myth system’ of law and policy, but also the ‘operation system’ of social service reform and support.

Thank you and we look forward to hearing the outcomes of your deliberations.

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