Putting the Human Back into Human Rights

Intersectional Perspectives

Netherlands Institute for Human Rights Research

Annual Conference

Gerard Quinn

United Nations Special Rapporteur on the rights of persons with disabilities.

21 June, 2021.

Thank for the high honour of addressing you today.

Over a hundred years ago, Oliver Wendell Holmes said he used to deduct his butlers’ salary for lack of imagination. No doubt that was a human rights issue then - as it is now! But I’ve often been struck by the power of imagination in law and public policy – or rather the power of re-imagination. Imagination is like a rust solvent – it can free up the joints in an old system and reveal deep understandings about the original gloss underneath a surface.

It is important to emphasise to younger researchers that knowledge does not make the world go around. Innate ideas and imagination count for more.

So I face today’s talk in the spirit of Holmes. I want to touch on three points.

**First of all, I want to use the time to explore the human in human rights.** It turns out that we have a very one dimensional image of the person in human rights. Or, to put this another way, the surface of human rights can and should be mined to find a deeper, fuller, richer understanding of the person – of the human in human rights. Maybe this reveals deep connexions with vulnerability theory – you be the judge.

**Secondly, I want to focus on a theme that is implied by human rights but seldom brought to the surface – namely the centrality of home in our lives.** This is neither fully public nor fully private – and hence not completely captured by contemporary understandings of human rights. The moral and material scaffolding it provides for the self – for the social self (or, if you want, to the vulnerable self) is critical. Home – in this broader, richer sense – is one of the foundational pillars to the UN disability treaty. I will explain why.

**Thirdly, I will try link this up to the debates about a possible new treaty on the rights of older persons.** Imagination is fine – but it has to be connected with a contemporary challenge to be made real.

Let me suggest to you that a social conception of self and a well-rounded theory of home will be crucial in the drafting of the new treaty on the rights of older persons. And let me encourage you to get involved with the UN Open Ended Working Group on the rights of older persons. They need your imagination.

#  The Human in Human Rights.

**But first of all – the human in human rights.** I have often been struck by the fact that we tell all our first years students that we have human rights simply because we are human. But there the matter rests. There is no deeper enquiry about what it means to be a human. It turns out to be quite a complex field of enquiry.

Furthermore, observable reality is plainly at odds. Many humans – or categories of humans – find themselves placed in concentric circles of exclusion – of ‘unbelonging’ if you like. Some humans like those with intellectual disabilities are labelled in the literature ‘persons of lessor moral worth.’ Some non-humans like corporations enjoy at least limited human rights.

So it seems that the ‘person’ – the foundational jural category lurking behind the human in human rights – is just that, a jural idea or a term of art.

Of course, there have been many theories of the person through time – many expansive accounts, and many more limited accounts. And they seem to have fluctuated through history. Many have hotly debated human essentialism – or quest for the *essential* ingredients of being a person recognisable in law.

Many dwell on *interior-facing criteria* like having a mind, possessing consciousness, being able to rationally form preferences and communicate the same. But this was not always so – the Renaissance conception of the person was quite different to that of the Enlightenment. Leaving to one side that there is still no consensus as to what ‘consciousness’ is, it is strange to observe the strong hold that this view still has over us. Even the Universal Declaration [of human rights] hints that it is because we possess rationality that we are humans worthy of protection.

At play here is some vision of moral agent – someone worthy of liberty (and the right to do wrong), someone accountable for their acts, and someone whose freedom should be protected (if not supported). Implicit is the distinction between a ‘thing’ or an object and a ‘subject’ or a person. Siedentop’s ‘The Invention of the Individual’ is worth reading in this regard.

I have often wondered whether the historical switch to these interior-facing criteria from the Enlightenment onwards have less to do with philosophy and more to do with economics and the shifting bases of our economic and social structures. In point of time at least, the shift to these interior-facing criteria seems to have coincided with the emergence of market based economics (and societies?). I wonder how valid this will be in the Post-COVID economy.

Extrapolating from the above we can derive a conception of the atomistic, autonomous, self-contained self. Now, of course, none of us actually live our lives like that! To put it bluntly, our personhood is primarily a shared or distributed phenomenon. That does not lessen the importance of individual liberty - it just contextualises it.

I digress momentarily. You will have noticed that if rationality is considered the key criterion of who counts as a person then indisputably some animals poses sufficient rationality to be considered a person. Indeed, this is the argument of many animal rights activities – that some animals are persons simply because they possess the essentialist criterion of rationality. This always struck me as a highly conservative theory under-pinning animal rights. End of digression. Contrariwise, many humans do not possess the requisite degree of rationality. Does this make them any less deserving? – the ethicists seem to think so – hence the label ’persons of lessor moral worth.’

What about *exterior-facing criteria*? Empathy, a capacity to communicate and connect (whether through formal communication or otherwise), a capacity and willingness to reach out to the other? It seems even our brain is hardwired to connect – and cannot grow without human connections.

The point about the exterior-facing criteria is that they focus on relationships, on embodied reality, on the life journey or personal biography of the self. In a way, the person is the sum total of his/her formative experiences and relationships – with an accompanying worldview (whether narrow or expansive).

Don’t get me wrong. I’m not advocating for ‘socialist man’ beloved of Erich Honeker. I’m not arguing for the demolition of the public/private divide. But I do think we need a much richer conception of the person than emanates from much human rights doctrine.

It has often seemed to me that much contemporary human rights doctrine is about the relationship between the person and power - and the need to tame and regularise power. Nothing wrong with that. But surely there is more – if we are really interested in the human behind human rights that we need to take account of the lived reality of the human regardless of his/her relationship with power.

# The Centrality of ‘Home’ in the UN CRPD.

This brings me to me second point – the centrality of home.

Put to one side doctrinal understandings of private life and private home (e.g., Article 8 of the ECHR). We are apt to be led into a wild goose chase if we simply follow the logical entailments of the doctrine without probing what lies underneath.

I put forward the UN disability treaty as exhibit A.

We all thought – myself included – that this treaty would be yet another thematic treaty on equality or equal opportunities – a sort of Americans with Disability Act or an EU Directive – only this time projected onto the international stage. And of course, most of it is referable back to equality theory – the stated purpose of the treaty being to secure the equal and full enjoyment of all human rights of persons with disabilities.

But something interesting happened on the way to the Forum. First of all, disability NGOs began to question the value of an equality approach *without first dealing with the reasons* why unequal treatment had come about. Repealing the odd bad law was not enough. It was felt that the underlying reason why so much inequality had accumulated had to do with the invisibility of the person. So probably the most essential pillar of the treaty has to do with personhood. The flashpoint was autonomy and the need to invert power relationships by restoring power to the person.

But – and here is the important but – the conception of person in the disability treaty is both individual *and* social. Most of you will know that the disability treaty innovated by providing for a right to make one’s own decisions regardless of disability with supports if needed and asked for. This *not* about supports in terms of services provided for by the State. This is actually a tilt toward the social conception of the self. It points to the rich texture of social supports most of us enjoy in exercising our moral agency and autonomy in our own lives – so much so that we hardly even notice it. Of course, these ancillary supports – social capital – is exactly what is lacking in the context of persons with disabilities.

Interestingly, the UN CRPD Committee adopted a General Comment on equality about 3 years ago that emphases *recognition of personhood as its foundational p*illar. Definitely not equality in a traditional sense! So the dialectic between the individual and social conception of the person is immanent in Article 12 (autonomy and legal capacity).

I would hold that it is even more self-evident in Article 19 – on a right to live independently and be connected to the community. Textually speaking, this right is found only in the UN disability treaty (ok – it is also in the Council of Europes’ Revised European Social Charter also). It brings to the surface what is implicit in many of the international and regional human rights treaties.

At one level it wasn’t necessary. If (an big if) one were faithful to the logic behind the provision on non-discrimination them segregation in its most extreme form (institutionalisation) would be unthinkable. However, no European Court has ever reached that conclusion - although the US Supreme Court did over 20 years ago. A sidebar discussion has to do with why the US and not Europe? That’s for another day. So plainly, reliance on general equality and non-discrimination provisions was not enough.

Hence Article 19. I am not going to dive into the details of Article 19. I just want to bring to the surface three general points.

First of all, it implies a rich philosophy of self-realisation in the community – in a web of human relations – immersed in social capital. It speaks mainly to the social self. In as much as it relates to bricks and mortar it really has to do with the scaffolding of the self – seeing oneself reflected in our material surroundings – using those surroundings to maintain a healthy sense of self. Hegel – but not as we know Hegel.

Secondly, it honours individual choice and autonomy - but these individual choices are about *‘how’* to live in the community and not whether to live in the community.

Third, all this implies a radical transformation in services – personalising them, devolving budgets, breaking up large providers, introducing new platform-based services. This is probably a major human rights agenda in the early 21st century – breaking free of the traditional welfare approach of the 20th century.

The old spatial image of public/private doesn’t quite do justice to Article 19.

Home is intensely private – a place for repose where the self can emerge – define and redefine itself – in free association with others. It is hard to do that if one is institutionalised. And home is intensely public in that it affords us opportunities to immerse ourselves in and within social capital. Our front door and our garden (if we lucky enough to have one) announces us to the world and beckons others to enter. What others see in a congregated setting – just a fancy word for an institution – is just the trait the unites us like old age or disability – not the person behind the trait.

The future of social rights is not a direct transfer of resources or wealth. That was a mid-20th century agenda. The future really has to do with how we can intentionally build up social capital and build bridges between those left behind and the community.

This begs a lot questions about the community – which conception of the community. Is community now something we purchase in and out of – or is it capable of meaning something more substantive (gemeinschaft)? Remember, freedom in ancient Greece meant the right to belong – and not to the right to squat anxiously at the edge of society with a well-endowed pension.

This is not without its dangers. Despite our best intentions – we may in fact be moulding or contriving the person rather than giving him/her breathing space – shades of Erick Honecker again. But these are the new fault lines of the 21st century.

# Imagining what a new Treaty on the rights of older persons might look like

All well and good – but what does this have to do with the drafting of a new treaty on the rights of older persons? A lot, I think.

It seems we are getting closer to the formal drafting of a new treaty after 10 years of the UN OEWG. In the last few months the UN OHCHR has published a major Study by Andrew Byrnes outlining the case for a treaty and the WHO has adopted a Global Report on ageism.

If the UN disability treaty was the first adventure of a social conception of the self – the much anticipated treaty on the rights of older persons will likely be the next.

Disability – really ableism – had to do with the discounting of personhood upon a disability. This was usually from birth or maybe later in life. Age, or really ageism – has to do with the gradual onset of invisibility as a person as one grow’s old.

There was (at least in the past) a social acceptance that one’s capacities gradually declined in old age to the point where other’s managed our personhood for us or we withdrew from networks of social capital. Those networked frayed in any event as friends and family passed.

So the main human right issue (in the recent past) has to do with *protective mechanisms* – how to protect older persons whose vulnerabilities left them exposed to the depredations of others or how to ensure protection while living in congregated or institutionalised settings. There was (until recently) a widespread acceptance that ‘long term care’ meant only one thing – institutionalisation. Note how this approach subtly problematised the person.

But look what happens when you invert some of the foundational ideas! Does autonomy really have to decline to a vanishing point as one gets old? If a healthy sense of autonomy depends on the depth and spread of social capital then why not put as much energy into preserving this or rebuilding it than in the traditional protection agenda? After all, much neuroscience is telling us that most if not all people are reachable despite their advanced years.

And what about independent living and community engagement? In a recent conference the European Commission estimated that 2 million older Europeans still live in institutionalised settings. You would have thought that COVID-19 makes this not just a human rights issue but also a public health issue!

I see three distinct sets of losses.

**First, with respect to home,** **you lose that intimate bond between self and place** – a uniquely human experience, the mystic cords of memory that hold our sense of self together. This is important in itself. But is also important because it is a portal to other things. It is well known that to move people from this kind of environment into a more anonymous congregated setting accelerates medical decline. Mind and body do matter.

Is it possible to replicate home in a congregated setting and thus avoid decline? I doubt it. And even if it was possible – what’s the point. Surely it is better to find ways of supporting people in their natural environment than to try and recreate that environment in an unnatural setting.

**Second, you lose voice, choice and control**. Ok – most of us don’t enjoy complete voice, choice and control in our own lives. It’s all relative I hear you say. Yes, of course it is.

But isn’t it funny (as in funny - strange) how popular culture simply assumes that older people lack autonomy or that their capacity to make choices affecting themselves naturally declines over time to the point of invisibility. There is actually nothing natural or inevitable about this. I have called for a re-consideration of guardianship for older persons. I know the UN SR on the rights of older persons (Claudia Mahler) is thinking along the same lines.

All of us rely on social support and cues to enable us retain confidence and competence in decision-making. As I say, our personhood is fundamentally a shared phenomenon. Curiously enough, it’s the small decisions that count the most like when to have breakfast or turn out the lights. Behind a declining capacity for communication lies a person. No, the answer to decline is not to compound it with further loss.

**Third,** **your relationship with the community fundamentally changes** **in a congregated setting.** As I said, when you see the nice flower patch your mind turns to the kind of person who tended it – no matter how modest it is. Let me put that more bluntly – *you instinctively think of the person behind the façade*. If, on the other hand you pass a nursing home do you think of the person? Let’s be honest - not really. You are more likely to think (and perhaps even recoil) of the trait that unites the persons inside like old age.

Even the architecture broadcasts that this is not a ‘home’ in the traditional sense with all its allure of intimacy, autonomy, personality and the implicit invitation to social connectedness - but a home in terms of confinement and care. The human soul wasn’t meant to be confined. Who loses. The individual loses. But the community loses too – especially the younger generation.

In a word, what you lose is **personhood which is vitally supported by a home of one’s own.**

Yes, but what do you gain? Is there anything on the other side of the ledger in favour of congregated settings?

What about care, frailty, and the ‘benefits’ of congregated settings? Surely care takes precedence, you may say, especially when people are not in a position to take care of themselves?

I want you to experience a fundamental contradiction here. The view that there are some people with such high-dependency needs that institutionalisation is the only realistic option has been decisively and universally rejected in the disability sphere. Yet it continues to be implicitly accepted in the elder sphere? What’s going on here? Why the fundamental disconnect?

Given the high overlap between both groups this makes no sense at all. In any event, is it really clear that the exigencies of care trump the very real personhood losses for older people as outlined above? I don’t think so. And is our policy imagination so crabbed that we cannot see – and build – alternative community based systems of care that tend to the home?

# Conclusions.

Where have I gotten to?

To sum up: it is time to reconsider the human in human rights. It is time to disentangle our conception of the human from power relationships – important though they are. To do so, would treat the human in human rights seriously. This is entirely possible within human rights – but it does require a certain distance form legal formalism that seems to cloud the legal imagination.

Secondly, The UN disability treaty makes a decent stab at this – and in the process embeds a mix of a social and atomistic conception of the self. Through its provisions one can see an image of shared personhood and an image of home that is neither completely public nor private but lingers somewhere in-between.

Thirdly, it is this more social conception of the self that should play a critical role in the drafting of the much anticipated UN treaty on the rights of older persons.

Finally, I recall the famous words of Lon Fuller who once memorably said, that if H.L.A. Hart was wrong, at least his writing had the merit of being *clearly* wrong. I may be completely wrong in my framings above – but in a way that’s not the point. The point is to have the courage to give scope to your own imagination – and hopefully in the process to reinvigorate the field of human rights. We all count on you - especially the younger researchers - to think imaginatively, to respect history but not be bound by it.

[ENDS]