

# **An Ideas Paper**

**‘Rethinking Personhood: New Directions in  
Legal Capacity Law & Policy.’**

**Or**

**How to Put the ‘Shift’ back into ‘Paradigm  
Shift’.**

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This paper is dedicated to the memory of Terry Stewart, beloved former  
Director at the European Commission and one of the fathers of EU disability  
law and policy.

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## 1. Introduction.

The title of my talk is 'Rethinking Personhood: New Directions in Legal Capacity Law & Policy.' At one level it is about the 'paradigm shift' in article 12 of the UN Convention on the Rights of Persons with Disabilities. In reality its about a war of ideas, a clash of creeds.

I know what you are thinking! If I hear one more person sprouting platitudes about the 'paradigm shift' I might be inclined toward random acts of violence!

In a flight of fancy I often imagine the 'paradigm shift' as a new shiny electric car - with a new gear shift mechanism powered by a patented paradigm ion impulse engine! We all know that the old model of petrol driven cars - and a hydrocarbon based economy - has had its day and must go. We all know that petrol cars are not good for the environment and that the economic base which petrol underpins is just not sustainable. Of course there is an inconvenience in the switch to electric but I think nearly everyone shares a deep intuition that change is not just good but inevitable. We resist in our everyday lives mainly because of convenience - but we know our resistance is futile. So the process of change is inevitable from a hydrocarbon economy to a green one - despite the undertow exerted by powerful vested interests.

Now, the process of change initiated by Article 12 - away from substitute-decision making (even with elaborate safeguards built in) and toward a model of supported decision-making - seems much more fraught than the march toward a green economy. The resistance seems more deeply embedded and the proponents of change - us - are easily boxed in and labelled as idealists, extremists and worse.

Why is this process of change fraught? Why is endemic, socially damaging, personally dangerous, incorrigible decision-making for the rest of us tolerated - and not for persons with disabilities? This is what I want crack open.

By the paradigm shift I mean three things. I mean the shift way from treating people with disabilities as 'objects' to be managed or cared for to honouring and respecting them as 'subjects'. I mean restoring voice, power and authority to the self over him or her self. And I mean respecting this power and authority by forging pathways to independent living and participation.

And so legal capacity to me is a continuum that connects with everything needed to enable the person to flourish - a right to make decisions and have them respected, a place of one's own, a life in the community connected to friends, acquaintances and social capital, whether in public or private settings. Personhood is broader than just capacity - and these broader connections serve to augment capacity in a virtuous circle.

Article 12 is the lightning rod for the paradigm shift. To my mind it supplants easy assumptions about incapacity and replaces them with a qualitatively different way of framing the human condition and of seeing fragility as a universal condition and by demanding supports to enable persons with disabilities chart their own life course - supports that we all actually enjoy and take for granted.

This talk is not another exposition of the legal requirements of Article 12 - there is plenty of that around. This is not an attempt to directly solve some thorny questions like 'how do we make sure supported-decision making does not morph into substitute decision-making.' Rather it explores why this is a thorny question in the first place.

Nor does it directly address the very real concern of parents which is that 'it is all very well to talk of the right to make one's own mistakes and assume the dignity of risk - who will be around to pick up the inevitable pieces' - service providers?' and 'if you want to experiment with the paradigm shift don't do it with my son or daughter- play social engineering somewhere else!'. This is a wholly natural impulse which, as a parent myself, I fully get.

Instead I want to explore why these issues arise and register as issues. Why are they boxed off into disability when in fact they touch on universal experiences. What is it - what blind-spot exists - in the underpinnings of our political discourse that makes these issues appear unique and exaggeratedly so in the context of intellectual disability? Maybe, by identifying where the tension truly lies at the base can we forge a more sustainable pathway for reform and allow more breathing space for the paradigm shift.

#### **(a) The Paradigm Shift and the Counter Revolution.**

So let's start by being honest. 'We' - the converted - see this vision of change in Article 12 as inevitable. Yet others - including important gatekeepers like policy makers, legislators, service providers and families - have their doubts. I suppose these are not so much clearly articulated doubts but more like the undertow applied by accepted ways of doing things. That's the curious thing about old paradigms - like old soldiers - they don't necessarily go away overnight. Even when people commit verbally to a new paradigm they often have mental reservations - reservations that they themselves may not be fully aware of and which have the effect of deflecting progress toward the new paradigm.

There is nothing new here. Some years ago the British Overseas Development Office tried to figure out how £1 billion in development aid in a particular country left no mark whatsoever. A key finding was that, contrary to popular misconceptions, policy-makers actually work to very simple policy narratives that either facilitate, block, skew, distort or deflect change. They are shorthand and even a substitute for deep thinking. That's fine and even normal - we can't all think deeply all the time.

In our context the relevant policy narrative could be as simple as 'disability costs therefore' or 'we have an elaborate system already in place so why experiment especially when there are known risks and no clear way of mitigating them or there are unknowable risks that could arise and we have no clue how to deal with them'. The first is willingly blind to a more sophisticated cost-benefit analysis that may well show that change is both desirable and achievable. The second panders to the inherently risk-averse nature of the policy apparatus. After all the fewer mistakes you make as a civil servant the higher you go (at least in my country and I suspect elsewhere)!

The conclusion in the British study was that unless those often irrational policy narratives are dissolved and broadened then little change of a lasting nature is possible. No amount of money will make a lasting difference unless new ways of looking at things become accepted as 'common sense' and worth the risk. But 'common sense' turns out to be not so common. By the way, the British Study impliedly pours cold water over the so-called evidence-based approach to policy making. Evidence counts but certainly not in the unilinear ways imagined by the white-coated social scientist! The policy world is just too messy for that.

So 'we' - the converted - like to think that the logic of Article 12 is incontrovertible. How could you not agree that all persons with disabilities should control their own lives and make decisions for themselves - just like everyone else in society? Very few States would actually deny this - or at least deny it to your face. Many would effectively deny it by building larger and larger exceptions on supposedly narrow exceptions. And remember the big lesson from Karl Schmitt - he who controls the exceptions controls the rules! Those States are not really interested in the exceptions - they are interested in retoring old rules through new exceptions.

Ok - so the logic of Article 12 points in a completely new direction - one which makes perfect sense to us within an admittedly narrow community of advocates and maybe within an admittedly self-referencing theoretical framework - one that has yet to break out to connect into more general political and legal debate about the nature of the human condition, its inherent fragility and the extent to which, in truth, we all depend on each other's support for identity, a sense of self and for the myriad of cues - formal and informal - that help us plot a course through life's many travails. I say plot a course when in reality most of us stumble on from one life event to the next. A wise man once said that a career is not something you create - it's something you look back on. Kant saw us as being in hyper self control. The Greeks, on the other hand, saw Delos - our personal destiny - as lying totally beyond our personal control. Although I hate it when students say this - the truth is probably somewhere in between.

So much for logic. We would do well to remind ourselves that, as Holmes once pointed out, 'the life of the law is not logic but experience'. In other words the beauty and symmetry of the new paradigm will not in itself shift

these stubborn policy narratives. I wish it did. I have spoken before about the 'temptation of elegance' - the idea that the inner beauty of our constructs is itself enough to move others. Ambassador Don Mackay - the exceptionally able and wise chair of the drafting process that led to the convention - surely qualifies as a 21st century Cicero - but even Cicero met a sticky end! I am not suggesting that Don is going to meet a sticky end - only that eloquence alone won't do. No. Something else is needed. In the past I have called this the need for new politics of disability - and the need to build bridges between disability politics and ordinary politics - of which more anon.

So there seems to be a communicative gap, a failure of politics as normal, to grasp, embrace and, consequently, create breathing space for the new paradigm.

**(b) Reasons to be a Counterrevolutionary.**

What are the wellsprings of this resistance? Some superficial reasons can be quickly dispatched before reaching the deeper ones.

First, one could put this resistance down to ignorance and prejudice - and there certainly is a lot of that out there. But it never helps one's cause to call those who oppose us or go too slow for comfort as ignorant. So even if ignorance is at play it is probably better to remove the causes of the ignorance rather than personalise the opposition and risk polarisation in the debate.

Prejudice is harder. It often lurks menacingly underneath the surface of discourse. What makes it hard to confront and eradicate is that it feeds off a common intuition or supposition about the profound difference between 'us' and persons with intellectual disabilities. Differences do exist but it is the accretion of layer upon layer of supposition on top of them that ultimately distorts them. And in any event, difference should not provide an added impulse to marginalise but should cause a deeper conversation about how to positively accommodate it.

By the way, if you want to see deep unreflective - even unselfconscious - prejudice in action look to the recent analysis of the Council of Europe's Venice Commission in how it treats the issue of the right to vote for persons with intellectual disabilities.

Secondly, one could put resistance down to vested interests vying to arrest developments that might entail a loss of legitimacy and ultimately a transfer of power. I may be an academic - but I am not naive. Of course there are vested interests opposed. Of course they might on occasion indecently conceal this opposition behind a veil of co-opting the language in order to continue as before.

Again, there is nothing new here. We all do this to some extent even in our own lives. And notice the peculiarly modern phenomenon of 'boxitis' - lets capture the new paradigm in a set of values so that our organisation

becomes a 'values led' organisation. And how do we know its values led - why we tick the important boxes of course! I call this the bureaucratisation of ethics! To my mind there is no inevitable correlation between a 'values led' organisation and one that actually anchors itself on a sense of the centrality of the person.

I digress. Over half the Fortune 500 most successful companies in the world do not have a Strategic Plan. And yet they are among the most successful in the world. They are successful because every sinew of the organisation has internalised an ethic of innovation, a hunger for change, an eye on the prize (which is larger than oneself or one's own interests) and an ability to turn on a dime to achieve it. The British Study I previously mentioned actually points to this. Although higher level policy narratives have to change - every member of the organisation also has to willingly consent to the change and to act on it not just because targets must be met, forms must be filled and auditors satisfied but because it represents the very lifeline of the organisation. I have my doubts that traditional service provider organisations - even those that purport to be 'values led' - are up to the job. A lot more is needed than an inspiring mission statement.

Ultimately we have to persuade vested interests that managing people - dare I use the antiseptic managerial language of 'managing risk' - is not really in their own interests. We have to persuade them that their interests are subordinate to the interests - and rights - of the people they serve.

This may sound strange but I believe we ultimately need to get beyond the language (and the institutions) of need and services. I may be alone but I find this language subtly patronising. Ultimately we need to move to the idea that all persons have life-plans (big and small and maybe even tiny), all persons rely on each others' support and affirmation, all persons are embedded in social networks (or ought to be) that provide spontaneous support and that ancillary services (which required mainly because of the lack of this social capital) only truly serve if they enable life-plans to be fulfilled.

Thirdly, one might account for resistance by reference to certain fears - principally a fear of the unknown. It may turn out that some of those fears are well grounded - in which case the ideological beauty of the new paradigm alone is not enough to win over others. We are not all moved by the Mona Lisa. When I saw it I was inclined to think 'what's the big deal'. As a legal formalist we can easily answer these fears by saying 'hey, the law says so, so get out of the way'.

I am more a Legal Realist. One should not rely too much on the formal law to 'trump' perceptions or misperceptions of change and risk. To the sceptic that often sounds like 'I win because the law says so and you lose.' This is like a gunslinger relying on wits alone and a fast draw. And beware, if you want to play the law game you can lose as well as win.

Of course we must respect the law - but the chances of long term change depend in no small part in drawing a connection between the law and deeper legacy values that all people can relate to - and not just the converted. That's the trick.

Is change really good! Now if I were Edmund Burke - which I am not - I would say "and isn't this opposition a darn good thing. We need a natural brake against sudden change in order to temper our zeal and produce more sustainable change." I wouldn't go that far. I am much more a Jeffersonian - 'a little bit of revolution is a good thing now and again'! But you have to bring the people with you and - so far - this is proving complicated.

### **(c) Taking the Counter Revolution Seriously.**

What to do?

Well I think you will surmise that I think there is a lot going on here that doesn't quite meet the eye. The little wars or skirmishes around Article 12 are in an important sense proxies for deeper tensions at the base of our political and legal systems.

Very often we find these wars become a war of attrition with no way out. We don't even know victory when we see it.

I remember playing cowboys with my brothers. We used to spend 5 minutes shooting our toy guns and another hour in intense Jusuitical debate about who shot who first and who was really dead! The impasse would only end when my mother called us in for dinner (it would resume over desert!).

I suggest that the power of the objections - or fears - to the process of change under Article 12 is best explained by relating them back to underlying tensions and even contradictions in our inherited legal and political cultures. Well, I want to use the time and space to dig into those underlying tensions. I think this reveals why it is so hard to give more concrete expression to the paradigm shift of Article 12. In the process it might point the way towards a better communicative strategy to allay fears and create a much more welcoming space for experimentation, innovation, and yes, mistakes.

Theory? Well yes. But remember it was John Maynard Keynes who once said that 'all men who consider themselves wholly practical and free from theory are probably themselves the slaves to some defunct theory' without even acknowledging that to themselves. I am very much of his mind although I have to admit it was a former Prime Minister of Ireland (a very bookish chap) who once quipped that 'this is all very well in practice, but will it work in theory'. No, the point of a temporary excursion into theory is always to return to practice and to change it.

So where are the deeper fault lines and where might the breakthroughs occur? Really, the debate at the heart of Article 12 exposes some deep

fault-lines which, like the proverbial dragon, should be brought out into the open before slain. To do that we need to dig deeper to explore the reasons for the counterrevolution - and expose some of the myths upon which they rest.

## **2. Myths of the Counterrevolution.**

I was once walking in New York with my wife and we overheard a lady yelling into her cellphone (which is unavoidable in New York) saying “the problem with my moisturiser is that it just doesn’t moisturise anymore.” We gave each other a knowing look which said “only in New York”. Now, like the moisturiser that doesn’t moisturise, why doesn’t the paradigm shift, shift?

I think the key to this is a somewhat counterintuitive point. We are all naturally delighted we have a convention on disability. This may be surprising to say but I don’t think the disability convention is primarily about disability!!!! It is really the latest iteration of a long extended essay at the international level about a theory of justice - a theory that is applied to disability to be sure, but one that is woven from much deeper cloth and has universal reach. I think the best way to approach the disability convention is to treat it as an expression of that deeper theory of of justice.

Now that theory of justice has its flaws and its blind-spots. The disability convention and Article 12 in particular - whether by accident or design - addresses these flaws and, in the process, expands the underlying theory of justice. This expansion benefits persons with disabilities. But it has repercussions for all. This may become ever more obvious as progress is made in drafting another thematic convention on the rights of the elderly.

What are the flaws or blind-spots I speak of and how does the disability convention point to a new way?

**(a) Personhood - a soft Political Premise, not a Hard Commitment.**  
First, personhood.

Let me remind you of some of the essential predicates in our legal & political orders - essentials which are woven so deep that we are hardly ever conscious of them. Our systems are committed to a theory of the ‘right’ - which is a fancy way of saying that the most legitimate political order is the one that creates an uncoerced space in civil society for the individual to flourish. We don’t tell you what to think or how to behave. If you harm others you will be held to account - but otherwise feel free to shape your destiny in accordance with your wishes and preferences - however odd we may feel them to be.

The spatial image at play is one of atomized moral agents realising their selves in civil society - planning, plotting, weaving, ducking - and constantly changing course. The spatial image of the State at play is one that intervenes least or that (possibly) provides a welfare floor to optimise the chances of all at this planning, plotting and weaving - otherwise called freedom. I have always felt the line between Lexington and Concord with Woodstock is fairly direct! The allure of this is that it allows maximum space for personhood.

Now, although personhood rests on a web of philosophical theories - it has an essentially political character. We know what it is to be human - to belong to the species. We can distinguish humans from other animals. Personhood is different. It marks one's recognition as a person - and therefore as a 'subject' of the law and the political order - as a beneficiary of the system of justice. It is laden with political overtones. Now personhood in this sense was confined by the Romans to male citizens. And Blackstone famously quipped that upon marriage woman suffered a civil death in the sense that her personhood was merged (i.e., subservient to) with that of her husband.

I have said before that a similar stripping of personhood took place in the past with respect to persons with disabilities. Some would say that the very term personhood implies its own negation - i.e., there are some human beings who, whilst being human, are not persons. So where is the line between those humans that are persons and those who are not? In a way substitute-decision making is a symptom of civil death - of the surrender of the personhood of one person to another.

Now Article 12.1 puts paid to outright civil death on the grounds of disability. It says simply that States reaffirm that persons with disabilities have a right to recognition everywhere as a person before the law. I think that's profound. It draws a line. Like emancipation of the slaves it leaves no room for equivocation or doubt about the moral status of persons with intellectual disabilities. That should be the end of it. But it isn't because it still arguably leaves space for a Functional approach - one that identifies specific incapacities and responds with substitute decision-making - albeit of a more narrowly tailored kind. And it leaves space for those who would say recognition as a person (identity) - does not confer moral and legal agency - the right to act as a person in the lifeworld.

The true war concerns the notion of personhood. Legal capacity is only the tool by which the 'person' asserts him or herself in the lifeworld - in the myriad of tiny daily transactions that make up who we are. It can be used as a sword to enable us make decisions and have them respected by others. It can be used as a shield to fend off others who know better. It protects the 'forum internum' or the integrity of the space in which the person conceives of the good for themselves and its expression in the 'forum externum' - in the lifeworld where we express ourselves. The war over legal capacity is a proxy war over personhood.

So lets say- arguendo - that there is something to the functional approach - that some persons in some areas of their lives lack functional capacity and that substitute decision-making can be made acceptable. Now there are plenty who would say this is wrong and an intrinsic violation of Article 12. I come at it a bit differently. Lets take the underlying notion of personhood in the Functional approach at face value.

Heres my suspicion. The concept of personhood that underpins the Functional approach is really a rhetorical device - part of a syllogism setting up, explaining and justifying a certain kind of political order. It is not, by a long way, part of a hard political and social commitment.

Now, if the commitment to personhood is only a rhetorical flourish then is it any wonder to see the essential ingredients of personhood populated by things that themselves point to, reflect and justify the liberal-democratic political order. In other words, its no surprise from this political angle to see personhood defined narrowly around notions of human cognition and an ability to manage one's own affairs.

The whole point of our political & legal order is to create an uncoerced space for the self, for the masterless man, to assume plenary power over their own destinies. The legal order is there to protect this space - to allow individuals create their own mini-legal universes in free association with others. This can only be done if one is 'self'-possessed and 'self'-driven. From this angle there is internal pressure to define the 'self' - the person - as being rational and capable of plotting one's own course which implies weighing options and risks and deciding accordingly.

We can question 'essentialism' all we like - the tendency to separate out the essential criteria of personhood. But political imperatives point to some form of essentialism - which largely pivots around cognition and rationality.

I digress momentarily. Maybe an added impulse toward cognition as the essential criterion of personhood is the fact that 'we' will be left with responsibility to tidy up if persons without the requisite intellectual capacity will be given additional breathing space to take charge of their own lives and make mistakes. Well, there is an interesting paradox here. There are plenty of 'walking wrecks' out there - and we all know some - who do create plenty of problems to be tidied up by others which we don't seem to mind so much! I have often wondered why this freedom is tolerated for the many but not for the few. Its a puzzle.

Well this is the 'myth system' of personhood - pivoting on cognition and driven by political considerations. I don't say these political considerations are inherently bad. Far from it. Try living in the old Soviet system. But my point is that when the tail wags the dog - when one's conception of personhood is exclusively or largely based on cognition in order to set up a political theory - then much of significance seems screened away from view.

What is screened out? What's screened out is incredibly important for all of us and not just those with intellectual disabilities. A passing point - the 'myth system' - like any 'myth system' - tends to hold its power regardless of the fact that it does not accord with reality. So it is not enough to point out its discord with reality - that's only a start.

**(b) Essentialism and Personhood - doesn't work in Peoria!**  
So what's screened out by the 'myth system'?

First of all, do we (the people on the street) really think that there is some essence of personhood from which essentialist criteria like cognition can be neutrally derived? I don't think so. Most people's conception of personhood runs a lot deeper and probably defies essentialism. There is something about the dignity of all humans that is left out of the picture by the focus on cognition - something that ordinary people are in fact generally willing to factor back in. We didn't exclude the boy with Down's Syndrome from our games simply because he couldn't count how many bullets he fired from his toy gun!

**(c) Essentialism in Action: The Inadequacy of Contractarian Theories of Justice.**

But our culture's fixation on cognition runs deep. Ponder this? Reading the essays in Eva Feder Kittay's recent (and truly amazing) book on ethics and intellectual disability one is struck by the disability (yes, disability) of political philosophers to accommodate persons with intellectual disabilities within a theory of justice. When I say theory of Justice I mean the broad Rawlsian social contract theory of justice. God bless them and especially their commitment to distributive justice!

Most of them accept that the theory of justice cannot embrace - i.e., does not cover - persons whose cognitive ability does not allow them to participate in negotiating the social contract or, if it does, it only does so by way of an exception which cannot itself be explained from within the theory of justice. Now forgive me, but this sounds like the cowboy and Indian arguments I used to have with my brother!

The easy point here is that a theory of justice that does not cover all humans can hardly count as a theory of justice at all!

The deeper point is that the syllogism needed to produce the liberal conception of justice forces one to define the 'self' rationally, forces one toward essentialism - an essentialism that prizes cognition in the masterless man.

**(d) The Myth of the Masterless Man - Who is He?**

So this reductionist and essentialist picture plays to the notion of the masterless man - wandering purposively through life. Although we all aspire to be masterless man (and women) we all acknowledge that we (our sense of self) is a relational concept. It comes about - it individualizes - as a

result of socialisation. Don't trust me - look to the recent work of neuroscientist Antonio Damasio. The Mind does not exist in some atomistic desert beloved by Thomas Hobbes. It is an intensely social artifact, melding as it individuates.

Maybe a story brings this point home. I once did a very naughty thing when playing cowboys with my younger brother. I pointed a loaded potato gun (loaded with tiny pebbles) directly at my brother. Wham! I got him first time! No need to reload. I felt like Atilla the Hun at the gates of Constantinople - final victory was in sight. The problem of sibling rivalry is solved once and for all. He screams. Out runs my mother. There was no use denying I pulled the trigger. What to do? Well, I knew how devout my mother was so I quickly played the Catholic card. When confronted I didn't deny it - I just passed on responsibility by saying 'the devil tempted me!' I didn't suffer from Irish Catholic guilt - I knew the devil was the guilty party. That bought me about 30 minutes peace while my mother struggled with a way to respond! Aha. I knew I had her. Hoist by her own petard! As a 9 year old I had successfully internalized her worldview (while never actually believing it myself) and negotiated a temporary reprieve by playing to her emotional commitments and knocking her off balance. What amazingly social (as well as cunning) animals we are! I became her in order to undo her. By the way, this is when I had the first stirrings to become a lawyer!

So the self in self-determination or the auto in auto-nomy turns out to be a hologram for the community - one in which social capital is reflected just as the self individuates itself free.

Now, hover here for a moment. It is the social capital of our lives - especially intimate social capital in the form of parents, family, friends and community that help define who we are. I am Gerard Quinn the person...but I present as a 'self' having been through a conservative Catholic upbringing (against which I early rebelled). This is the dialectic of our beings. We present our 'selves' differently in different contexts.

Hover some more. This dense social capital at once poses both a threat and an opportunity. We - none of us - cannot safely cabin the threat element away from the opportunity element. Of course this places a question mark over identity - can I be sure that I voted for party X because it is the right thing to do or because I internalised my parent's aversion to party Y?

Whats my point! Well, we tend to agonise over the hidden dangers of supported decision making - the ease with which the 'other' is not just invested in but absorbs the 'self'. Can we draw lines to ensure that supports do not become substitutes? Well, my point is that this affects all of us and not just those for whom a formalised system of support is put in place. Is there something about persons with intellectual disabilities that makes them maybe more prone to this 'capture'? Maybe the threat exists in a stronger form in the context of intellectual disability - but it is actually a threat we we all navigate daily in our lives. Depending on the relationship in question we are all deeply impressionable.

Stay hovering! If deprived of this social capital, of the raw material out of which we emerge individuated and into which we continually affirm our selves as we alter our selves, what chance do we have of constructing a sense of self, a solid identity and the inner resources to face the slings and arrows of life? Now I grew up a few doors away from a boy with Downs Syndrome. His father was a policeman - a very jolly policeman. He was always in our games and ran around with us. We were an adventurist lot - no health & safety for us! He lived among us and not apart from us - and I am sure this helped him to move on in life as his parents passed away.

Where we grew up was not exactly on the right side of the tracks - but we didn't care or even notice. We had a happy youth in relatively modest housing. Ah, a house of your own. Don't forget the material trappings of this social capital - a place we can call home. Home is what one philosopher calls the 'materialisation of identity.' Ok, our houses were nothing to look at - but at least we could pop next door to talk to other youthful gunslingers. Is it any wonder that whatever sliver of self remains quickly becomes deracinated as our surroundings become ever more impersonal, more clinical, more detached from the social capital that gives context and into which we express our selves.

My point! It is not really possible to separate out personhood - to neatly separate out issues of legal capacity - from broader considerations. To me the benefit of the paradigm shift in the convention is that opens up the narrow synchronic enquiry about capacity into a much more diachronic enquiry into the deprivations (in terms of community embeddedness) that have led to this point and a further enquiry into how pillars for the development of a sense of self can be laid down to optimise the chances for self realisation. The way the convention is framed allows us to see cumulative disadvantage and to connect that with seemingly narrow technical issues like legal capacity.

Thus viewed issues like embeddedness in community and participation in life are folded back into to the traditionally narrow legal enquiry in legal capacity. Incidentally, that is why Article 12 should be read alongside Article 19 on the right to live independently and belong to the community as well as Article 29 on the right to participate.

**(e) Cognition and the Masterless Man - Its Just Not Captain Kirks' Style!**  
What then of cognition - rationality - as the *sine qua non* in enabling the masterless man conquer the universe? Cognitive psychologists have - as you might expect - long worked in the field of decision making. And, surprise, surprise, they have come up with some conclusions that are strikingly at odds with this essentially politically driven notion about the centrality of cognition.

To make a long story short they question the very integrity of the divide between cognition and emotion. They depict decision-making as very

complex, very intuitive and - wait for it - very reliant on experience as well as the innumerable cues and supports of others.

Experience!!!! Hymmm. If you are denied experience then how can your decision-making capacities evolve? Cues and supports? I don't know about you but there are very, very few decisions I make on my own as a completely masterless man. My wife is my constant companion in more ways than one. I often unconsciously factor in how she might decide before deciding. I often seek her support and guidance. I play mental games playing scenarios out among my many friends, acquaintances and professional peers. Hey, the most important decision - whom to marry - was certainly not rational (but very worthwhile).

So what is it with the rational masterless man! Indeed, some of the most important battlefield decisions of Captain Kirk - my boyhood idol - could hardly be characterised as rational.

Now lets re-group - where are we? Can we bring the issues out of the ghetto of disability and closer to the people at large?

### **3. Reconstructing the Revolution - Time to Engage with the Peasants!**

By the peasants I mean everyone! Remember I said the convention is not primarily about disability - it is about a theory of justice as applied to disability.

The myth system of our political order pulls in one direction with its commitment to rationality. And the operation system - that which we all observe around us - points in the other direction. Can we bring the two closer?

What difference would it make - for all of us and not just for persons with disabilities - to acknowledge and build on reality - on the operation system and not the myth system? What difference would it make in terms of the role of law - adopting a Legal Realists' take.

#### **(a) Leaving Myths Aside for Realities.**

In reality we do not treat cognition as the essence of personhood - indeed we studiously avoid 'essentialism'. We all have intuitions about personhood - but they are not exhausted by the emphasis placed by moral philosophers (really, political philosophers) on cognition. In my view, most ordinary people would be shocked to learn that contemporary political theory - especially contractarian political theory - cannot accommodate persons with intellectual disabilities. Tapping into that deeper well of justice needs to be done to make the paradigm shift appear natural.

**In reality**, we all depend on others for our sense of self. The mind evolves as a relational construct. These others always pose a threat as well as an opportunity. This dialectic is essential to personal growth - and absolutely unavoidable. Now some people worry a lot about how supported-decision making models might too easily morph into substitute-decision making and hold back until answers can be found to elucidate and police lines. But wait a minute, this is a universal experience - and not confined to intellectual disability. The difference is one of degree and not kind. When I imbibe the dinner table talk about how Party X is horrible and Party Y represents Nirvana and I vote accordingly, am I not being undermined? Why is my vote not taken away? Doesn't it have something to do with dignity - with the natural impulse in any society to respect the inviolability of the self and its preferences. Doesn't it have something to do with a healthy fear that if we start unraveling our respect for others - as expressed e.g., through the ballot box - that there is no end to this logic! And so we need to tap into this deep ethic of always treating others as ends in themselves (even when we know their electoral preferences are wholly 'irrational') - something that has been conspicuous by its absence in the disability field.

**In reality**, we all assume social capital to provide context, incentivize connectedness and provide the innumerable supports (mostly informal) without which we could not function. Now isn't this the big point about the paradigm shift in the convention! Social processes were not open to persons with disabilities in the past. This message of unbelonging was internalized - with the result that persons with disabilities were hidden away as if out of shame - thus creating 'spoilt identity.'

By the way, Article 12 calls for support to enable persons with disabilities to exercise legal capacity - which includes but stretches beyond supported decision-making. I see supported decision-making as something that happens as a decision is being made. I see supports for legal capacity as encompassing some of the essential building blocks to enable legal capacity to evolve. And so it makes little sense to me to view Article 12 in complete isolation. It necessarily involves putting in place the essential ingredients for enabling capacity to evolve. This requires a place of one's own - stamped with one's own personality even if that is something as simple as a treasured photo. It is this 'materialization of identity' that links Article 12 with Article 19. It isn't just that expanding legal capacity allows one make choices about where to live and with whom. It is that having this choice itself helps augment legal capacity.

Similarly bound up with the full implementation of Article 12 debate is Article 29 on the right to participate in political and public life. The Romans understood freedom as public - the right to be involved and to participate. Out of this evolved civic virtue -a sense of connectedness to the collective. That too is not just an outcome of enhanced legal capacity - it is one of its preconditions.

**In reality**, cognition tends to be a minor element in helping us plot a course through life and make decisions. Strange that we can 'see' this and yet

avoid its implications. We allow ordinary people to vote on the fate of the nation even when we know that most people do not vote rationally. Why can't we build a more realistic picture of ordinary decision-making and then build a legal capacity structure to reflect that rather than the myth of rationality?

**(b) Building on the Realities.**

What if we built a system of law and policy not on the 'myth system' but on the 'operation system'? What would it mean? If it became a commitment to the development of the ingredients of personhood rather than just respecting the outputs of personhood then what might follow? Can the Functional approach become the basis of an enquiry not about when substitute decision-making is needed but on what kinds of supports are necessary for the person? Obviously much hinges on the concept of support. And remember Article 12 talks of support in the exercise of legal capacity - and not just support in decision-making.

Take the person for whom there is no - or at least no obvious - will or preference. Bald substitute-decision making is no longer acceptable. Or put this another way, the necessity for making some decisions 'for' rather than 'with' the person has to be accompanied by a parallel and serious commitment to put in place the necessary ingredients to help spark the will and preference. To me, that means connecting the individual with social capital, with the community. This is especially important with respect to those who have been institutionalised and for whom the 'mystic chords of memory' that connect them with family and acquaintances are shattered. To me this is the essence of the paradigm shift in action.

Take independent living and participation in the processes of life. Its hard for me to see how the revolution in Article 12 can be achieved without movement on independent living and being involved in the community. In other words, I don't just see Article 19 and 29 as the outcome of achieving full legal capacity under Article 12.

Take those who experience profound communicative barriers that block the expression of their will and preference. I see a role here for new technology - even new technology in neuroscience as well as new ICTs- that might open a window on the will and preference.

If the person does have a will and preference then the object of the supports might be to assist him/her in articulating those wishes.

**(c) Building on Realities - what role for the law?**

And what of law? What role should law play?

Let me make an observation in passing. And it speaks to one of the hidden dangers inherent in any social model. My day is not micro-managed by anyone. I change my mind a lot and change my plans a lot. I think we all instinctively repudiate any assertion of power that effectively canalizes our

existence. Now legalism is all about control. These controls attach themselves to the many arms of the State - but they also attach themselves to other entities like service providers when invested with State authority to achieve certain ends. Nothing bad here you might say...power needs a corrective. But, in the context of expanding something as fragile as personhood, legalism - even well intentioned legalism - has its costs. Legalism is good at protecting people against certain things - but what persons with intellectual disabilities need most is to re-engineer services to augment capacities. Legalism likes to mitigate risk. But more space for risk seems needed if capacities are to be augmented. Legalism can contaminate the philosophy of an organization - lead it into losing sight of the underlying goal which is respecting dignity and expanding autonomy. Now don't get me wrong - I am all in favour of protection. But somehow or other the convention calls into question the balance between protection and expanding autonomy. I don't know how the balance can be re-struck but I do know that excessive legalism can be the kiss of death for the kinds of innovation called for in the convention

It seems to me that if we take personhood seriously law is being asked to play three connected sets of roles.

First of all, even at a symbolic level, the law must be re-oriented toward a model of supported decision making. I suppose a comprehensive strategy would be one that does not just focus on Article 12 but also builds in tangible movement toward independent living and active participation in the community - in the social capital that envelops all our lives.

Secondly, some of the tensions within supported decision-making will have to be explicitly dealt with. How do we know when the supporters are not actually interposing their own preferences and undermining the person? Can we draw any bright line in law as a safeguard against this and other abuses? Me - I am not sure such a bright line exists. I suppose my general point is that this is something that actually afflicts everybody.

Thirdly, a way will have to be found to ensure that the voice of the person that emerges - whether directly or as mediated through representation agreements - is actually respected. Now, most of us live most of our lives in a web of private market-based transactions - like rental agreements, banking transactions and the like. What of the contacts entered into by representation agreements' - are they somehow worth less. This intrigues me. The pure 'will theory' of contract depicts the contractual relationship as a function of the meeting of minds. The reality - as pointed out long ago by Oliver Wendell Holmes - is that courts impose contractual obligations regardless of the will of the parties if social purposes point in that direction. So the real hesitation here is an objection to a mechanism that advances the social interests of persons with disabilities - hardly a viable objection.

And what of the legal implications of mistakes! And there will be many and some will have lasting consequences. Who picks up the pieces - who is liable and who bears the costs? Its back to legalism again! Clearly a new

social contract with consequential legal changes is needed to create breathing space for the new paradigm. Carl Auerbach once wrote a stunning book on Justice without Law - on how to achieve just results in a community setting without exclusive reliance on the rule of law. It's a bit Utopian and we all need law to protect us. But we still need this re-balancing to take place. Otherwise, we will end up with very restrictive practices that will stifle the growth of supportive decision-making regimens.

All life for all of us is generally a balance between nurture and exposure - a graduated process resting on the hope that capacities will mature and responsibility emerge. When it comes down to it there is a balance of risks at play here - the risk that over-protection will smother whatever chance there is that the will and preference can express itself and the risk that under-protection will lead to bad consequences which no one will take responsibility for. Now this is easy to say - but as a parent you will naturally have your doubts. You wouldn't be human if you didn't.

Tangible steps will be needed to remove egregious overly protective laws. For example, we have a law in Ireland that makes sexual relations with a person with an intellectual disability a crime of strict liability! That means that, out of abundant caution of the law, service providers are not too happy with developing relationships. We can make a good start by repealing all such laws. Through time, with the emergence of a new kind of service provision model that proves that capacities do exist and can be augmented, resistance to these kinds of laws will fade. This re-balancing is not going to be easy - but it has to happen.

#### **4. Conclusions: Its Not about Disability - its about the Human Condition.**

What are my conclusion. It should be obvious by now that I believe the relative inability of the paradigm shift to shift has explanations that lie far beyond or beneath disability.

We have a 'myth system' that places a premium value on the premise of personhood - but doesn't really commit to it or to underpin its main ingredients. By the way, it is questionable whether all of us aspire to be 'masterless' men. Or, at the very least we all vacillate between our need for separateness and control to our equal need for connectedness and support.

We have an 'operations system' that all of us experience (and benefit from) which generally speaking has no problem with irrationality except when it comes to persons with disabilities.

And in truth we are all vulnerable. We all count on innumerable supports just as we brush them off in favour of our own liberty. Its not just that

society has a problem acknowledging this for persons with disabilities. Its that society has a problem acknowledging this - period! It is in this sense that the struggle of others - like the elderly - are our struggles.

So in a sense Article 12 provides an occasion to reveal and expose the partiality of our collective commitment to personhood - good on personhood, not good on the causes of personhood. So I see the debate as a subset of a larger debate about citizenship, about mutual support, about connectedness to social capital, about independent living, about participation. And it needs to be re-positioned there. If it continues to be a disability-specific debate it will be dragged down by decades if not centuries of baggage.

Let me end with one of my favourite quotes from Robert Kennedy:

we can perhaps remember -- even if only for a time -- that those who live with us are our brothers; that they share with us the same short moment of life; that they seek -- as we do -- nothing but the chance to live out their lives in purpose and happiness, winning what satisfaction and fulfillment they can.

Its up to us to make it so.