CONCEPT PAPER

'Personhood & Legal Capacity

Perspectives on the Paradigm Shift of Article 12 CRPD.'

By

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1. Introduction.

Thank you for the high honour of addressing you this morning and thank you Michael and your team for organizing this important event.

Let me begin by paraphrasing a quote from Holmes: 'Whenever you approach a principle pour some cynical acid over it to see what remains.'

Now I'm not cynical – but when you do pour cynical aid over Article 12 of the CRPD you find many layers and many puzzles. This is the hallmark of a norm that is likely to become a very powerful driver of change.

I don't think I exaggerate when I say that the issue of legal capacity reform is probably the most important issue facing the international legal community at the moment. It potentially affects everyone in their own lives – and indeed everyone has a stake in the debate. This is because the issues at stake actually transcend disability and cut to the heart of what we mean to be human.

My task today is to introduce the field and frame the issues. In fact I will make an effort at **re-framing** the issues since I firmly believe the old vocabulary is distinctly unhelpful, often degrading and needlessly divisive. The old vocabulary of guardianship, substitute-decision making, keeps us going in circles. We need a way to break out of those circles to maximize the liberating potential of Article 12.

It is frequently said that Article 12 of the CRPD is emblematic of the paradigm shift of the convention. I agree. And it is worth stating what that is before we proceed. It is the deceptively simple proposition that persons with disabilities are 'subjects' and

not "objects' – sentient beings like all others deserving equal respect and equal enjoyment of their rights.

In unpacking the paradigm shift of Article I do not want to descend into the text - at least not initially. I resist this approach for three reasons.

First of all, we need to first zoom out rather than in to perceive the deep structure of the text. I believe the issues, the tensions, the fractures run deep. It used to be said in these very halls that all 'law is but applied political philosophy'. I would not totally agree with that but I do think there is merit in retracing our steps to retrieve ideas that help provide an ethical compass to the new law of Article 12 – a non-conclusory navigational tool that helps us clarify its moral and normative thrust.

Secondly, a single formula of words can often mask deep ambiguity. The tactic of negotiating through 'constructive ambiguity' has long been used to enable Governments agree a formula of words but disagree totally on what those words signify. Otherwise we would not get agreement. But sometimes this postpones a reckoning. Justice Scalia's famous quest for an 'original meaning' of the text – if not an 'original understanding of the framers – might, if left unaided, prove to be of limited worth. It could of course galvanize the persuaded but fail to move those States which need to move. And we need them to move.

Thirdly, it is palpably not true to say that there is always one right answer embedded in text – even in a unanimously agreed text. More often that not, a certain formula of words will be used to re-frame an issue in a principled manner – thus enabling a principled process of deliberative reasoning to bring us closer to the truth. Reframing the issues as issues of principle might look like a meek advance. But it is not such a bad thing as it enables us to cleanse the debate of the distorting miasma of paternalism and charity. And it enables to see the debate as it is – a debate about very profound moral questions and not a delightful desert island frequented only by the technicians of the law. Those of a critical persuasion among

you will be tempted to say that the text harbours two paradigms in the sense that just as it distinguishes itself from on old framework of reference it also draws on it for its own integrity.

To slay a dragon -like anachronistic conceptions of legal capacity- it must be tempted into the open. As Keynes said:

Practical men, who believe themselves to be quite exempt from any intellectual influences, are usually the slaves of some defunct theorist...Madmen in authority, who hear voices in the air, are distilling their frenzy from some academic scribbler of a few years back.

I don't read this to mean an endorsement of insanity as a legitimate category of thought – merely that it behooves us to become self-aware as to the ideas that are woven into narrative so that they can be disaggregated, interrogated and ditched if found wanting. This, at least, is my way of slaying the dragon of anachronistic laws on legal capacity.

Having said that, - having expressed caution as to the text as controlling and excluding any room for differing views - I do however present a radical view on Article 12. But the key to this does not lie in a textual exegesis on Article 12 alone. I think – I hope – that my approach offers a bridge that many can cross. I feel strongly that we need a **new vocabulary.** The process of radically re-framing the debate has only begun. It will take time.

<u>I want to proceed by laying out what I believe lies at the bottom of the debate – namely conceptions – sometimes competing conceptions - of personhood.</u>

These conceptions are largely unstated but exert a powerful undertow. I want to work outwards from this notion (or notions) of personhood and onwards to the legal tool of capacity that help to secure notions of personhood in the lifeworld. I see legal capacity as instrumental to personhood. I want to use this vantage point as a rust solvent to clear away some easy or formulaic understandings of Article 12 and

to arrive at a conceptual frame that helps us to truly grasp the profound paradigm shift of Article 12.

2. Personhood - Conflicting Impulses & the Enthronement of Rationality.

I start with personhood because I believe it is truly foundational to the debate about the paradigm shift of Article 12. I leave to one side the debate about when a person becomes a person and when a person ceases to be a person. The real debate concerns what are the essential *indicia* of personhood – the criteria by which we can ascribe personhood. Are there such criteria? What are they? Indeed does essentialism apply to humanity?

One might have thought that this is a question of first moment to be treated separately on its own. However there is a complicating and distorting element in the debate. Lets get it into the open. Embedded in any conception of personhood are certain **political** assumptions about the right relations between persons – and then between person and political authority. Even rights-talk in a curious way contain embedded assumptions about the terms of social co-existence. The way a right is calibrated in one country tells us as much as about these political and social terms of co-existence as they do about the centrality or otherwise of the person. So to a certain extent the concept of personhood is not entirely deontological – **it is always relative to the kind of society we value.**

Now heres the initial complication. Most legitimation strategies in political philosophy begin with a **foundational** premise. Usually that premise is centered on a certain view of human nature. They run like this – 'man is inherently evil...therefore the right kind of political system would that channel energies in a positive direction and constrain the innate tendency to evil'.

Now – certainly in liberal democracies – that foundational premise sees personhood in a peculiar way and for its own reasons. All of which is tied to the priority placed

on the private sphere over the public sphere. This implies a certain image of civil society – an uncoerced space where individuals seek individual fulfillment often alone but often with others acting together in concert. The legal universe is not populated with moral absolutes – but it facilities persons to identify their own 'good' and then create their own legal universes with reciprocal rights and obligations freely entered into with others.

Now, this system of governance facilitates, is founded on and highly prizes individual 'auto-nomy'. Our Enlightenment past compels us to assume that this person – **this masterless man – this atom colliding in beneficial ways with other atoms - is rational**. How could you expect anything else from the age of Rationality? If we value freedom in civil society –as we should – this draws us to willingly suspend disbelief and to assume that rationality is at least one of the more important features of human essentialism – of personhood.

Spell it out a bit more, liberal-democratic foundationalism assumes a capacity to rationally process information, to rationally chose among several options, to rationally apprehend the consequences of choices and to weigh them up so as to arrive at a rational outcome, and it assumes a capacity to express our choices in the shape of informed decisions. Indeed, it assumes the 'unencumbered self' – the deracinated person shorn of all cultural and social bonds.

Whats wrong with this? Our choices are nearly always a mix of raw preferences with rationality. Indeed, our rationality is often shaped by our preferences and not the other way around. And so the legitimate – and indeed inescapable - role of preferences is screened out by this liberal-democratic worldview. And of course, we are not deracinated cyborgs – we are a product of our culture just as we occasionally exert choice to separate ourselves from it.

The social dimension to personhood is also screened from view by liberal foundationalism. It is this dimension that provides the parameters for the self – that

supports the self – that valorizes our sense of self – just as it creates enough space to exercise voice or exit when the social fabric no longer proves conducive.

The interesting thing is that these foundational assumptions are demonstrably counterfactual. Most of us, most of the time, both think and act irrationally. We often cloak our reasoning in the garb of rationality but the wellsprings of both thought and action often run much deeper. As Jane Austen once said 'how quick come the reasons for approving what we like.' And we constantly make the same mistakes and never learn. At one level this is what alienates others from us – but at another level it is constitutive of who we are and are valued by

some (ok – a very narrow range of loved ones).

Even the much vaunted notion of 'dignity of risk' cannot escape the gravitational pull of foundationalism. It is predicated on a spatial image of the person as a *learning organization* – constantly adapting behaviour to avoid learned pitfalls. Let me suggest to you that this image needs to be deepened to reflect the reality that we seldom alter our bahaviour even when we know that coffee is bad for us! Dignity of risk, I suggest, doesn't just mean allowing freedom in order to enable people to *learn* and alter behaviour – it is valuable in itself because it allows for dignity in taking risk.

Why can't we get away from liberal foundationalism – why do these counterfactual premises continue to exert a powerful gravitational pull despite the fact that most of us base our decisions on preferences - and most of us depend on family and friends to give context to our choices even as we differ.

I think there are two reasons. One is an unstated fear that if rationality is dethroned then chaos follows (Cartesian anxiety). That is to say, there are sound reasons to cling to the fiction in order to preserve a system that is fairly good at opening space for freedom.

The other reason has to do with the nature of that space for freedom – for civil society. If the truth be told, the most powerful impulse behind this image of a rationally functioning civil society comes from commerce. And commerce needs stability, predictability, reliability. Actions and inactions generate 'reliance interests'. It is these needs – the needs of third parties – that cements in place our grudging commitment to rationality as a touchstone of personhood.

Now of course the interesting thing to me is that even business doesn't necessarily work rationally (just take a look at Lehman Brothers). There is always a social context to business and individuals do not always act purely on a rational basis.

Let me wrap one or two more elements into the mix explaining the undertow of rationality. Eccentricity is all very well if you can pay for it. But what if you have diminishing assets – or none. What if you are dependent on the welfare state for your existence. I suppose the natural default of the State is to see to it that you preserve your asset base as long as possible so as not to be dependent on the welfare rolls. There is also sense that the State has a vested interest in insisting on rationality to protect property interests and so relieve itself of ultimate responsibility.

So what do I get from the above. First of all, there is no necessary reason why rationality should be given such pride of place in describing personhood. The wholly irrational is no less a person. We see this irrationality in everyday life and mostly it is a cause of comment like 'he is such a character'. And practically none of us make decision – from the most minor to the most important without support. Like most of the guys here, when I visit the supermarket I always have my cellphone to make sure I am getting the right product at the right size at the right price – as well as tame my wholly irrational tendency to impulse shop.

3. Legal Capacity - Generating Space in the Lifeworld.

I say all this in order to give some context on where we have gone wrong.

Let me suggest that legal capacity is the epiphenomenon. It provides the legal shell through which to advance personhood in the lifeworld. Primarily, it enables persons to sculpt their own legal universe – a web of mutual rights and obligations voluntarily entered into with others. So it allows for an expression of the will in the lifeworld. That is the primary positive role of legal capacity. Let me emphasise this. Legal capacity opens up zones of personal freedom. It facilitates uncoerced interactions. It does so primarily through contract law. Michael Bach is entirely right to focus on issues like opening and maintaining a bank account, going to the doctor without hassle, buying and selling in the open market, renting accommodation, etc. This is how we positively express our freedom. This is how we can see legal capacity as a sword to forge our own way. And this has been largely denied to persons with disabilities throughout the world. It follows to me that this is the primary added value of Article 12 – to bulldoze away barriers to the lifeworld in the form of outdated legal incapacity laws.

There is another side to the concept of legal capacity. Viewed as a shield, it also helps persons fend off decision made against them or otherwise 'for' them by third parties. This is an important element of legal capacity. But it doesn't do all the heavy lifting with respect to coercive intrusions. Certain intrusions are put beyond the pale as being not subject to negotiation or even consent. We do not, and cannot, be allowed to consent to torture, inhuman or degrading treatment. That's why there is an Article on violence, exploitation and abuse.

Now the universe of what could be enforced against the will of persons with disabilities in the past was too large – probably on an assumption that such persons were not true subjects but objects with correspondingly more leeway for intervention. This is no longer possible because of the CRPD. But my larger point

is that the liberating potential of Article 12 lies in its promise to open up zones of affirmative choice for persons with disabilities and not just to foreclose the depradations of third parties or of the State itself.

This brings me to another unseen element in the debate. Lets get it into the open. There is of course a fundamental contradiction in rights talk. Just as rights negate State power they also call upon State power to intervene and structure civil society as well as forestall the actions of 3rd parties that would deny us our freedom. Even the First Amendment which is cast in absolutes allows for some intrusions. This is not considered to be a denial of freedom – but rather prudent interventions to augment freedom. As Locke would put it these are the 'wise constraints that set us free'. Its not a side constraint on freedom – its actually an entailment of the prime directive of freedom.

We all know that the protective embrace of the State in the past was grossly exaggerated. Interventions were done to handle people as if they were problems rather than to genuinely protect their rights. However, this does not mean that the protective embrace lacks legitimacy. It means a drastic re-balancing needs to take place to ensure that the protective embrace is corralled within its proper sphere. But it does have a sphere.

Lets pause. What have I said so far? I have said that personhood draws us in different directions. On the one hand it values rationality. Its seems hard to drift too far from that since rationality seems to be foundational premise of our political order. In other words there are 'systems reasons' that seem to explain why we are so reluctant to admit the obvious – which is that most of us most of the time fail to conform to this stricture of rationality. Even business relationships seem to depend as much on trust and ephemeral bonds as distinct from pure profit maximization and rationality.

And I have said that legal capacity is the tool for advancing personhood in the lifeworld – primarily by allowing us to construct our own legal universes and secondarily to fend off others who think they know better.

4. The Paradigm Shift - why we need a New Vocabulary.

OK - now we come to the paradigm shift. Where did it come from, where is it now and where is it going.

The past reveals a number of approaches that paid scant respect to personhood and that engineered ways to deny legal capacity. One traditional approach was the so-called **status approach**. That is to say, if you were labeled as disabled or had a particular intellectual disability it was simply assumed – often by simple operation of law – that you lacked legal capacity. This status then was sufficient to strip you of legal capacity – of human personhood. Someone else – or some other entity – made decisions 'for you' – substituted decision making.

Now - at one very abstract level there is nothing inherently wrong with 'substitute decision making – provided I pick the substitute and the substitute simply mimics my will and preferences. But we all know this was not the case. Instead of mimicking the will and preferences of the person there was almost a conscious disregard of the will and preferences - even where it was clearly detectable.

The status-based assumptions rested on a binary view of capacity – you either had it *in toto* or you lacked it *in toto*. It doesn't take much to see how this rested on stereotypes about disability which, by definition, lacked the finesse to be able to assess each individuals circumstances. And it doesn't take much to understand that capacity is **not a binary concept** – I can have variable levels of capacity to make different kinds of decisions. And of course, with respect to areas in which I have reduced capacity, why should the first interventionist impulse on the part of the State be to take my capacity away and allow others to make decisions for me even when they are corralled to make those decisions in 'my best interests' – a concept

that actually finds a better home in the context of children. No, if the underlying value of 'auto-nomy' is taken seriously, then the first impulse of the State should be to shore up my capacity, to enhance residual capacity even in (or perhaps especially in) old age and to assist me to make and express decisions for myself. Further, the status-based approach seems obviously over-influenced by the emphasis placed on rationality by liberal foundationalism. And indeed, it pays scant regard to the natural social supports already there and which can be engineered into place to augment personhood.

A second traditional approach to capacity in the past was – is- the co-called **outcomes approach**. That is to say, while we may not make assumption about the lack of capacity based on one's status as, say, a person with an intellectual disability, we can certainly make them by inference from bad decisions or a pattern of bad decisions or a flawed process of decision-making. But lets remind ourselves! We all make bad decisions. Indeed, we all probably make bad decisions all the time in certain aspects of our lives. It actually helps define who we are! As for a bad process of decision-making, one is tempted to ask shouldn't a large sector of the electorate be deemed incapable of voting just because they keep returning 'bad' political parties (whatever that is) to power. Don't laugh - Joseph Schumpeter actually called for this in the 1930s!

Nobody seriously suggests an **outcomes** approach now. And the reason is simple. We all have the right to make our own mistakes. All life is an experiment – and sometimes we never learn. Sometimes we suffer the consequences. And generally speaking, the loss is allowed to lie where it falls. We – as individuals – are not learning organisations. We are all flawed and this helps make us who we are.

Is intellectual capacity so different? Well, you might counter it is different precisely because the disability is intellectual which means a reduced capacity to process information and make knowing choices. Yet, just because some of us are assumed to have full capacity doesn't mean that we use this capacity to rationally sift

information and make cold analytic choices. Life just isn't like that for the vast majority – why does it have to be like that for the minority? In other words, there is a profound contradiction between tolerating extremely poor choices and decision-making in non-disabled people on the one hand and then raising the bar exceedingly high for persons with disabilities – so high that most non-disabled people would have difficulty surmounting it!!!

So if a **status-based** approach is objectionable because it rests ultimately on proxies and stereotypes and if a **results-based** approach is objectionable because of the inherent contradiction between allowing the majority to make bad mistakes without intervention and disallowing a minority to make the same mistakes and overplaying the protective role of law, then what is left? Ok – now we are close to the heart of the shadows in the cave.

Lets pause again. In fact, we govern ourselves – 'auto-nomy' – through a mix of the rational with the irrational, of preference comingled with choice. Most of us most of time rely at least implicitly on others to assist us making decisions – whether based on preferences or otherwise. This can take the form of subtle cues like "I don't think this donut will help your waistline' or more practical advice like "I know you abhor Excel spreadsheets so let me take a look and advise'!!! The image of the rational cyborg making lifechoices in a vacuum shorn of a social context just doesn't rhyme with reality.

Well, to me Article 12 accepts and builds on this reality. To me disability makes plain a hard reality which is that the foundationalism premise of rationality doesn't hold for the vast majority – let alone persons with intellectual disabilities. The true revolution lies in its concept of affording persons "the support they may require in exercising their legal capacity.' (12.3). By the way, I see this as broader than just decision-making.

How might this shape up? The first beneficiaries of Article are those who are denied legal capacity and who don't need elaborate supports to make it a reality.

A second group of beneficiaries would be people whose will or preferences can be detected but who are currently ignored. There is no obligation as of yet to even make an effort to retrieve the will.

Assuming that a will or preference can be detected, the first obvious obligation is to put in place supports that can divine this will and express it. Here we are facilitating the expression of the will and enabling persons to decide for themselves.

A third group might be those whose will or preference is well nigh impossible to detect. It is possible to imagine a community of interpretation forming around the individual to ascribe to him/her a will or a preference with respect to a certain action/inaction given the kind of community/culture he/she lives in. That assumes that he/she has been embedded in a culture and living independently. There are some dangers inherent in the idea of a community of interpretation. First of all, the fact that I was born in conservative, Catholic Ireland doesn't necessarily mean that I will turn out conservative and Catholic. The right to be different is somehow smothered here. And indeed, what happens when the community of interpretation cannot agree? Where/who is the tie breaker? The role of law and regulation is vital here.

Now, what about those whose will is undetectable or for whom it is not possible to ascribe a will or preference? Who are we talking about. These would include people who have been institutionalized and for whom the 'mystic cords of memory' that bind them to others, to family, to friends, to community is gone. And these would be people in what is often described as a 'persistent vegetative state' – a form of language that seems to even deny personhood.

Now at some point the supports and assistants will end up making decisions 'for' and not 'decisions with' those individuals. One can try and define this inconvenient reality out of vision by saying that 100% support is required. This doesn't quite work for me. Its obvious that 1 million % support is unlikely (at least in the short term) to hide the reality that decisions are being made 'for' and not 'with'. But far from viewing this as a set-back I think it is exactly at this point that the paradigm shift kicks into high gear.

I think the hard reality which is that sometimes decisions will be made 'for' and not with' does not mean that 'substitute decision making' **as usual** is the correct response. To me, we have to ensure that the paradigm shift means that even in this category it is now necessary on foot of Article 12.3. to take additional steps. You will have noticed recent medical advances that can 'read' a persons brain to detect preferences – so-called 'locked-in syndrome'. To me we should never give up on this possibility – no matter how remote. Secondly, and with respect to those whose social connectedness has been severed due to institutionalization it seems to me to be the correct response to try to create social conditions in the hope of kindling some kernal or preferences. This is of course tied to Article 19 and my reading of it as a mandate for deinstitutionalization.

Now these super-added obligations – which I believe are required by Article 12.3 - do not efface the reality that decisions are being made 'for' as distinct from 'with.' We have to be honest about this.

It might be said we should deny this out of a fear that if we allow some decisions to be made 'for' then this will work backwards to corrode any advances made for the vast bulk of persons with disabilities. Carl Schmitt used to say 'he who controls the exception controls the rules'. I sympathize with this view especially when we realize just how awful the history has been and when we realize that it will take culture (especially legal culture) time to catch up with the paradigm shift of Article

12. It could be said that because the judiciary are so used to the old system that any new exception (decisions' for') will become the norm.

Plainly there is a slippery slope at work here. We are no longer talking about law and rules in the abstract – but are focusing instead on the **psychology of law and rule making**. I don't subscribe to this view myself but see how others can. Why don't I subscribe to this view.

First of all, human rights are meant to be deontological – which is a fancy way of saying counter-consequential. We of all people, should not be in the business of sacrificing 5% for the sake of the 95%.

Secondly, this perspective betrays a lack of trust – a lack of confidence – in our ability to draw lines, to identify toeholds on the slippery slope that will forestall the possibility that the exception (making 'decisions for') becoming the norm. True, there is always the standing possibility the new paradigm will be progressively deradicalized to use the words of Karl Clare especially as an unsensitized judiciary are apt to seize on the exception to inform and maybe swamp the rule.

But whats worse: stretching a fiction (100% support) to the point that it is visibly at odds with reality – a factor that is only likely to be seized on by States acting out of abundant caution and enter declarations or reservations ring-fencing substitute decision-making – or, admitting the obvious and then using our talents to lock in the exception and transform how decisions are 'made for' people? Lon Fuller had a lot to say about the uses and limits of legal fictions – and I think he would have agreed.

Thirdly – ant to me at any rate – most importantly, this perspective actually underplays the power of the paradigm shift for those 5% for whom there should be an added obligation to divine the will if at all possible and create social embeddedness that allows a some flash the will to emerge. Human rights cannot accept social determinism. Because we believe in personhood we must believe that

all have the potential to exert will in the world. Likewise, human rights cannot accept medical determinism. Medicine is not exempt from social determinants – its categories, its diagnoses are also socially bound. We cannot trade-off the reality that decisions will be 'made for' some people under the carpet in the hope of cementing into place the paradigm shift only for the majority.

5. The Text.

So what of the connectedness between the above philosophical wanderings and the text. Well, its no surprise that I find Article 21.1 remarkable. Remarkable because it states the obvious – that persons with disabilities are, well, persons before the law. Now this means something to me. It isn't just about the registration of births. It goes much deeper and it interrogates our sense of what it is to be a person. This recognition is an obligation to be immediately achieved.

I see Article 12.2. – which secures a right to enjoy legal capacity on an equal basis with others in all aspects of life' as advancing personhood both positively and negatively. Positively in the sense that it should be used to open up opportunities for free interaction in the life world through contract. To me this is the most important constructive function of Article 12.2. And of course it plays a role to fend off unwarranted intrusions of third parties and indeed the State itself. This is also achieved by other Articles in the convention.

One problem I see with the phrase 'in all aspects of life' is that a State might want extra time to work out the implications of the paradigm shift in – say - the area of sexuality. To what extent is the phrase 'in all aspects of life' to be viewed as giving rise to an obligation of immediate effect or an obligation of 'progressive achievement.' How do we gauge the interaction of the non-discrimination norm with Article 12.2? I just put this on the table.

And how do we spin the concept of 'on an equal basis with others'. Remember the Aristotelian edict – 'treat equals equally and unequalls unequally.' This allows leeway for courts to characterize the 'difference' of disability as so profound, to slip back into status-based reasoning and to rationalize the non-enjoyment of legal capacity as something that is not only justified under equality thinking but actually warranted by it. The way out of this Gordian knot to me is Article 12.3 in combination with Article 12.1. We are all persons. We all exhibit a mix – often stable sometimes unstable – of the rational and irrational. We are all socially embedded – even as we strive to individuate away from our context. And we all rely on a web of supports that augment our personhood. These supports go beyond decision-making. They prop up and valorize our sense of self. They give us enough confidence to begin auto-nomy – shaping our world in accordance without own lifechoices. This is woven so deep we hardly ever notice it – but it is there. And of course, few of us seldom make important decisions without consulting trusted family, friends and mentors.

To me Article 12.3. builds on this background reality that affects all of us. It assures us the supports necessary to enable us to enjoy our legal capacity. Again, to me at least, this goes deeper than decision-making. And yes it does apply to even those who – to all outward appearances – cannot form or express a preference or exert their will. The purpose of the supports in this instance is to work to retrieve the will – no mater how hidden – or to create conditions of social embeddeness to spark the will. Now if you say to me 'fine, but decisions will still have to be made for' such persons' – I agree. But the difference is – while I agree – I will see a role for the obligations contained I 12.3. That's what I mean by not confining the paradigm shift to the 95%.

Is Article 12.3. subject only to the obligation of 'progressive realization'? At first blush yes. However, there are interesting case studies from around the world about how supports can be harnessed from the community at virtually no cost to the State. These models need to be highlighted and propagated. My sense is that the State

needs to act to put in place a regulatory regime that allows these supports to emerge, to be treated seriously by third parties and policed. To paraphrase the slogan 'we don't want your welfare, we want our rights.'

What to make of Article 12.4? The safeguards in 12.4 seem to have a double life. On the one hand, the seem to imply or legitimate substitute decision-making. It seems to contain trace elements of the old paradigm. If spun this way they would seem to both regularize and rationalize substitute-decision making. The fear would be that if spun this way Article 12.4 could swallow the paradigm shift. Or, we could say that the safeguards are meant to apply to the supports that are put in place.

I do agree that the safeguards are relevant to supported decision-making. Lets be frank how these supports are configured can pose as much risk to the person as traditional substitute-decision making. If the truth be told, we are still in very early days with respect to regimens of supporting decision-making and it may take time to fix on the right regulatory mix with the right safeguards. Now it is also true that the safeguards are relevant to those rare instances where decision will have to made 'for' some persons regardless. Again, however, I would insist that the Article 12.3 supports apply with as much - if not more force - in this instance. So its never just a question of safeguarding against bad decision-making – its also – and now for the first time ever – a case of super-adding supports to divine the will or to spark the will even in extreme cases.

I view Article 12.5 (capacity with respect to financial matters) as implicit in Article 12.1 but nevertheless worth specific treatment since it is the lack of legal capacity with respect to financial matters that truly hiders independent living

6. Conclusions.

What are my conclusions.

First of all, I think there is a need to connect the debate back to philosophy – particularly our ideas about what it means to be human. It may well be the case that recent advances in neuroscience put paid to -or seriously erode - the assumption that persons with severe or multiple disabilities cannot hold a will or express it somehow. Paradoxically, medical advances themselves put paid to the medical model.

Secondly, the enthronement of rationality as the touchstone of humanity needs to be closely interrogated since most of us do not actually function rationally. There is a powerful political undertow holding us back. But if the desideratum of 'evidence-based policy making' ever means anything it should mean taking a practical view of human nature and not condemning the less rational.

Thirdly, there isn't really a difference of substance at play in the most important debate about Article 12.3. We all agree that supports to enable one to exercise legal capacity (which to my mind goes deeper than just decision-making) is at the heart the paradigm shift or is the key to give effect to the paradigm shift under Article 12. We all agree I think that some form of supports – I call this enhanced citizenship – should apply even in extreme circumstances where it is well nigh impossible to detect a will or preference.

The difference – if there really be one – has to do with argumentative tactics. Yes, there is a slippery slope. Yes, the weight of history points one way which is overwhelmingly negative. Yes, we do not yet have a judiciary prepared to grasp the paradigm shift. Long term however, we must have trust on our own capacity to draw lines and to resist stretching fictions beyond the point of credulity. One thing is for sure, incredulity will not exactly motivate Governments to begin the reforms we need.

It may be that our old categories of thinking need re-thinking. It may be that we have to begin thinking of legal capacity as something that goes much deeper that

decision-making. It may be that language like 'substitute decision making' has to be consigned to the dustbin of legal history. I think its obvious that we need a whole new vocabulary. We are at the beginning of that process and certainly not at its end point. And this intervention is just one point of light in the grand discussion. I hope if I'm wrong at least I am clearly wrong.