**‘Liberation, Cloaking Devices and the Law.’**

**Or a Personal Reflection on the Law and Theology of Article 12 of the UN CRPD.**

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**Rights & Enforcement – The Next Steps**

**UN CRPD Article 12 standards and their implementation in legal frameworks.**

**BCNL Conference.**

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**“**Well I came by your house the other day, your mother said you went away

She said there was nothing that I could have done

There was nothing nobody could say

Me and you we’ve known each other ever since we were sixteen

I wished I would have known I wished I could have called you

Just to say goodbye bobby jean”

 **Bruce Springstein, Bobby Jean.**

**1. Backdrop – Cloaking Devices & Personhood.**

We have come here to the beautiful city of Sofia in friendship and in solidarity. You have to know that your struggle to end guardianship is our struggle. You have to take comfort from the many reform processes underway around the world shows that it is possible to imagine and then create in law a post guardianship world. This is an age of remarkable discoveries. We have discovered the Higgs boson in the Large Hadron Collider– we have reached the outer galaxy with Voyager 1. Now it is time to ‘discover’ our own fellow citizens who have lived too long in the darkness.

I was asked to talk to you about international law and the right to legal capacity. More particularly I was asked to talk to you about the pivot – the decisive pivot taken in international law away from guardianship systems – all guardianship systems - and toward a more expansive concept of human autonomy, human discovery and supported decision-making. The law can be described in two minutes – even two words - eliminate guardianship. Explaining it and making it accessible takes a bit more effort. It entails taking seriously some of our systems underlying commitments. But it also entails a huge leap from the present – something that makes the communicative challenge difficult. I speak today as someone who ties to bridge that communicative gap – and not as a litigator – that requires a different hat – a different mindset.

When lost for tools in trying to bridge the communicative divide I often find myself drifting back to the wisdom (and sometimes the prejudice) of Oliver Wendell Holms. He once observed that:

 “law is the witness and external deposit of our moral life. Its history is the history of the development of our {people}…

These moral commitments – even if once pure – become distorted by culture, tradition and yes, bias. Out another way, as Dean Roscoe Pound never tired of reminding us - the law – all law –tends toward decay. It is no surprise then that our law on legal capacity – a law that has basically remained the same for decades if not centuries- is in need of refreshment – with new postulates (maybe more fidelity to old postulates), new contours (leaving a deficits fixation in the dustbin of legal history) and new ambitions (based on a faith in human possibilities).

As is usual with any moment of profound change, the pivot in Article 12 has deep roots which spread much, much farther than the law itself. And its implications are profound for policy-makers and legislators alike. It is fair to say that we are only at the beginning. It is also fair to say that it is a work in progress – and that we all have a role to play on the construction site. Its not simply a matter for the State to legislate – we all have to find new ways of discovery – new ways to find and release the will and preference of human beings long forgotten except to those who love them. This is why the pilot projects taking place here in Bulgaria and indeed throughout the world. This calls for a new art and science of human discovery which is also only at the beginning – but it is full of promise and brings out the best in human beings – a belief in each other and in human possibilities against the odds.

This is a story with many layers – even many lawyers! Perhaps the simplest is the legal layer. From a legal point of view the main inflection point came with the drafting of Article 12 in the UN CRPD. First of all, it doesn’t look like the traditional – and rather turgid – legalese on legal capacity. It sparkles with fresh ideas – unfamiliar ideas especially in the context of disability.

Frankly, I don't think we fully saw its implications at the time. We were primarily concerned with ‘civil death’ – the almost complete shrouding of the person behind the legal form of plenary guardianship – the surrender of personhood into the hands of guardians often with motivations that were not so laudable. We saw plenary guardianship almost as an evil cloaking device – something that had to be dissolved to let people breath and take charge of their own lives. If only we could roll back the curtain that would be enough.

The interesting thing is that many of us – myself included – accepted at the time that there would be some for whom this uncloaking would never be enough. There would be some who would remain in a state of ‘civil death.’ The uncloaking would reveal, if anything, a dead ship - or a long abandoned ship. There was nothing to uncloak. There would be some requiring protection and sometimes protection could take the form of removing their right to make decisions for themselves. There was no other option. Anything else was grossly unrealistic and impossibly utopian.

Others – especially those with first hand experience of what it is to live in complete darkness and experience ‘civil death’ and what that allows to happen to them – pushed back. They felt the dead hand of history on their shoulder. To allow even a small exception – to accept that someone might require guardianship – was to open up a dangerous slippery slope – one that would ‘normalize’ the exception and reinforce deeply etched prejudices about many people with intellectual disabilities. At times I and others were impatient with this view – thinking that those who put it forward put ideological purity over reality and thus ignoring the real rights and interests of those in extreme situations. And, by so doing they might even damage their own self-professed cause by making it appear impossibly utopian. They were right of course. And the text – which to a certain extent speaks with a forked tongue - bears their stamp – a new beginning. Of course, the text must be read in light of other deeper wells of thought in the convention. That rescues it from the circular debate that swirled around the text of Article 12 for a few years. In a way the new beginnigns anchored in Article 12 alongside other departure points as in Article 19 on the right t be connected to the community on one’s own terms, it is testament to people power instead of leaving the drafting of such instruments to the technicians of the law.

What no one understood at the time of drafting the convention was that all sides were all in fact stumbling on some profound truths that were long forgotten – some profound promises etched deep into our legal and political orders but which were never taken seriously – at least for many people with disabilities. Its funny how universal does not mean all – how ‘all’ does not mean ‘all.’ Culture, history and tradition operate in mysterious ways to carve out exceptions at the level of sub-conscious. How else could be profess to universal human rights and yet deny them systematically to whole categories of the human race? It is those ghettos of thought that the convention helps to dissolve.

Article 12 to me is not so much a huge leap forward as it is a mirror that enables us to see more clearly what went wrong, why it is ‘wrong’ and how to put it back together. The decisive pivot of Article 12 is as much back to the fundamental values of our democratic societies which were often distorted for a variety of reasons as it is forward to a very different kind of world.

In the short space of 5 years since the conclusion of the convention this pivot has slowly but inexorably crystallized. We now have a draft General Comment of the UN Committee on Article 12 that is unambiguous – unambiguous - in its pivot away from the past of guardianship and toward a very different future. It points suggestively to a very different future – one that we have yet to grasp with clarity. The draft General Comment says;

1. In order to recognise ‘universal legal capacity,’ whereby all individuals (regardless of disability or decision-making skills) inherently possess legal capacity, states must abolish denials of legal capacity that are discriminatory on the basis of disability in their purpose *or* effect (CRPD Article 2, in conjunction with Article 5). Status-based systems for the denial of legal capacity violate Article 12 because they are facially discriminatory, as they permit the imposition of a substituted decision-maker solely on the basis of the individual having a particular diagnosis. Similarly, functional tests of mental capacity, or outcome-based approaches that lead to denials of legal capacity violate Article 12 if they are either-discriminatory or disproportionately affect the right of persons with disabilities to equality before the law.

This does no more than build on the jurisprudence that had been building in the Committee with its various Conclusions on State Reports. For example the Committee said with respect to Australia (2013):

 25. The Committee recommends that the State Party….take immediate steps to replace substitute decision-making with supported decision making and provide a wide range of measures with respect to the persons autonomy, will and preferences…

So we know the road we must take but we are not sure what we will find when we get there. It sometimes seems like a mirage rather than a distant oasis – especially to those still in thrall to the way culture and tradition have distorted the application of universal values. The new road invites a new framing of old ‘problems’ – and people ***were*** seen as ‘problems’ – and it invites us into new territory and to grow that territory with our own toil. To a certain extent we will only know it is an oasis through our own labour.

So, we now have clear jurisprudence from the UN Committee that demands that States take tangible and immediate steps toward a new system. By the way, to me immediate steps means exactly that. The world will not change overnight. Some element of progressive movement must be present. Plainly put, this new system basically emphasizes a discovery process to reveal the self and enable the self to be in the world on its own terms. And it entails trust in human possibilities and in the efficacy of a discovery process – something culture has shrouded for decades if not centuries when it comes to disability.

We even have the European Court of Human Rights edging closer to the new paradigm – albeit within a civil rights frame that primes it to tolerate legal incapacity if it is the ‘least restrictive option.’ The Court is doing a good job at ‘chipping away’ at the edifice of ‘civil death’ as Oliver Lewis would put it. Its caselaw is now insistent on having in place a reflective – as against a reflexive – process for determining legal incapacity. It is steadily de-linking legal incapacity with the exercise of ancillary rights such as the right to vote. It is breaking own any sense of an automatic link between mental incapacity and legal incapacity. And is becoming very conscious of the darkness represented by institutionalization and the shadow it casts over legal capacity laws throughout Europe. This is all to the credit of the court – and the litigators like MDAC before it.

A question mark remains about how useful the Court is (and whether we have reached its limits) in pushing forward the conception of autonomy and capacity as represented by Article 12 of the UN CRPD. Certainly the Court has the conceptual tools to get beyond the fairly narrow focus on ‘least restrictive alternatives’ – a phrase that in a roundabout way reinforces the deprivation of capacity if sanitized by a consolation prize that it is at least the ‘least restrictive alternative.’ After all, this is what the human personality doctrine in Article 8 is supposed to be about. It often seems to me – and I know I am generalizing here - as if the Court is working out the entailments of the famous Recommendation (99)4 in its case law. Ehen you burn away the legalese it seems to me that Recommendation (99)4 provides for an ever more perfect and safeguarded process of loss. I used to be one of its more enthusiastic supporters. But if you look closely at the underlying logic beneath the impressively elegant language of Recommendation (99)4 you still see loss (albeit at the end of a sophisticated process) and you still see the need for protection morphing into a loss of capacity. There has to be better ways of protecting people than taking away their decision-making capacity.

Working through the entailments of Recommendation (99)4 in its caselaw is not a bad thing given where many European countries are at. But, because of its own perception of its own institutional constraints, it is hard to see the Court play the kind of catalytic ole one would like it to play to fill out the new paradigm, and to require States to move toward it. It is not impossible but there is still some way to go. Meantime most of the ECHR caselaw focuses – rightly – on highly reflexive regimes that embed the very worst of culture and tradition distorting our commitment to due process.

Clearly a bridge is needed until the Court can feel comfortable embracing a qualitatively different future. I suggest using the Collective Complaints mechanism of the Revised European Social Charter. It is considerably under-utilized in this regard. I don’t suggest that it could play a role in forcing the hand of Governments – that would overplay the role of the Social Charter. But it could play a useful role in filling in some colour in the black and white picture we have so far about supported decision making. The Charter Committee has more conceptual tools at its disposal than the Court and can more easily get at the link between decision-making and social connectedness.

So, how can we make sense of this pivot away from guardianship – what does it all mean and how are States expected to go about putting in place laws, public policies and programmes that will aid the process of discovery once the cloaking device of guardian ship has been lifted? More importantly, how do we build an effective communicative strategy – one that can make champions of those currently opposed?

**2. Law as a force for change - a Categorical Imperative or a Socializing Force.**

Law – especially international law – can be quite crude. It often comes in the shape of a categorical imperative – States must do this, States must do that. But, again, as Oliver Wendell Holmes once said ‘the life of the law is not logic, it is experience.’ Saying it should be so won’t, in itself, make it so. Willing into being is not the same as making it a reality.

We need something more to enable the new model gain traction in the hardest places – in the hearts and minds of the policy makers as well as legislators. They have to own it – they have to be socialized away from traditional mindsets. If they aren’t then the new model will be half-absorbed, co-opted, deflected and fatally compromised. This is a process – not an event. It will be a bumpy road where a lot of trade-offs will be needed. Rome was not build in a day and way stations will be needed to give materiality to the new vision. What is important is that the compass is set in the right direction and there is no going back. Legislators have legitimate concerns that wont be allayed by simply holding up Article 12 as a categorical imperative. That is a sure-fired way of postponing change. These concerns will have to be squarely addressed, dissolved and securely handled. That's why the pilot projects are so important in every corner of the world.

And States aren’t the only inhibiting factor to change. Look into your own souls as parents – we are instinctively primed to care, to steer our charges in the right direction and to let go – with difficulty – once we have confidence in our off-springs’ capacity to make it in the world. We are in a perpetual state of protection/confinement and discovery/release when it comes to our children. There is nothing inherently wrong with these instincts. A friend of mine said recently ‘I love my children – its just their life choices I have a problem with.’ Well, at least they were allowed to make some life choices.

When it comes to disability it seems that our protectiveness smoothers our instinct to aid the process of discovery – two equally valid instincts - one now dominating the other. This has nothing to do with parents as enemies of Article 12. Far from it. But it has to do with a natural reflex of protection given that the world, by and large, is not interested in discovery, is not committed to the view that there is a person behind the form, and won’t adjust or respect people even when we can detect the will and reference of the person. In other words – don’t problematize the parents – problematize the ambient environment that has conspicuously failed to give them the confidence they need and have a right to expect in order to ‘let go’ and trust that their disabled ‘child’ can be themselves in the word and that the world will support them in their endeavours. Parent power is a force for good – but their concerns have deep roots born out of decades of experience of official indifference. They too need to be in the frame of the pilots everywhere.

And what about service providers? These are the people or entities that provide for needs – and potentially mediate between the individual and the community. For success in kaing Article 12 real depends in no small measure on success in making Article 19 real – that right to choose one’s own path in life and be connected in the community. Can service provides play a leading role? I think so and they are a ital. part of the overall architecture of change. But first, let me distinguish between three types

First, the institutions – the ultimate cloaking device – dark satanic places where anything can happen and has! It is remarkable how institutions share a deep pathology in every corner of the world. Even if born from a misplaced sense of altruism they quickly degenerate into warehouses. I often wonder what is worse about such places – it is the impunity they seem to attract concerning the things done to people behind closed doors and high walls? Or is it the loss and degradation of self that the institution represents – a loss that is internalized and, to use a fancy Americanism, a loss that breeds ‘spoilt identity.’ Article 19 of the convention spells the end for institutions. Even if it didn’t, there is no question about the power of an expansive notion of legal capacity to erase these Berlin walls and restore social connectedness. Clearly such service providers have no positive role to play in either making Article 12 or Article 19 real – not to mention he right to be protected against violence, exploitation and abuse. There is an intimate link between the darkness of such institutions and the darkness experience while under legal incapacity. Lifting darkness under Article 12 presupposes a process for lifting darkness in institutions. And those who maintain darkness on one side of the ledger have no role to play in lifting darkness on the other.

Second, there are the traditional service providers, guaranteed a set budget from the State (albeit meager), delivering a ‘service’ to meet a ‘need’ (which tend to come pre-packaged) and engaging, for example, in ‘person-centered planning.’ Most service providers today operate the same way they operated 40 years ago – the only difference being that many of them use a new language to rationalize what they do. I have often remarked how the new management-speak especially of ‘person-centered-planning’ is an astute way of avoiding any deep process of discovery of the person – a sophisticated box-ticking exercise that wins over the willing consent of those who should know better. It is relatively easy for such service providers to rationalize what they do and even invoke the UN CRPD. But this is ersatz. Its not really in keeping with the mission of service provision as a process for underpinning human freedom and not undermining it. It is in keeping with traditional vision of the welfare State going back to the 1940s. But that time has long gone. It lives on in another ‘modern’ form which is the myriad of health & safety laws. Don’t get me wrong, I am not of the Tea Party and don’t argue for a wholesale rolling back of useful regulatory measures. But is has often struck me how such measures end up creating vastly over-regulated lives with no breathing space for risk, for experiments, or changes in perception and self-identify. I don’t think this is inherent in the laws and regulations. But maybe you will have noticed too how many service providers in this second category hide behind health & safety regulations to put a chilling effect on innovation. No is not the time or place to dwell on this. Suffice it to say that a job of work needs to be done to health and safety regulation back into its proper orbit and made to subserve the convention and not undermine it.

Third, there is a new wave of service provision beginning to emerge. They offer considerably promise. I am not even sure one could call it service provision anymore. For its not really primarily about providing a service to meet a need. Note how insidious this framing is. You have a need, we provide a service – job done. Again, if that had a place it was at the beginning of the Welfare State in the mid-20th century. It seems the new wave of ‘service providers’ (and I am still struggling with the term) is less interested in this command/control model and more interested in the life goals, life plans and inner self of the person. If services are required they are seem less as meeting needs and more as providing enablers to help a person realize themselves in the world. Probably the most important service they can provide is the building of new bridges to connect people with others – human connectivity workers! It seems to me – and this connects profoundly to Article 12 – that this is the wave of the future. Or maybe it is a way of getting back to roots. The impulse behind the creation of the Welfare State was always humane – its just that its collective means often swamped its ambition to enable people be themselves. Whether a step back or a step forward this new model fits perfectly with the zeitgeist of Article 12 –a deep, process of discovery, a re-connecting of people to the lifeworld, and a deep faith in human possibilities. Europe has many such entities and they are the future – and have a profound role to play in making the convention real.

**3. What the Law Requires.**

So now the easy bit – the law.

One result of the crystallization of the jurisprudence under Article 12 is that the tension between those who say that Article 12 – regrettably – allows some guardianship under certain circumstances and in a tiny minority of cases and those who say guardianship is inherently in violation with Article 12 is gone, finished, over. When you read the jurisprudence of the UN Committee you are struck with its lack of self-doubt. The road points in one direction – universal legal capacity for all - with supports if needed or required. The core obligation of States is to take tangible steps along that road. If they take no steps – and leave varying regimes of civil death intact and immovable over time – they will inevitably attract the censure of the UN Committee. Put more bluntly – all guardian systems whether plenary or partial are inherently suspect.

Zoom out for a moment. That position is easily supported not just by Article 12 but by the very intellectual structure of the entire convention. All our human rights treaties ascribe human rights on the basis of being human. Most of these treaties were actually about the rights and very few were about what it meant to be a human – the rights side of human rights. That was just assumed. And it could be assumed. But it could not be avoided when one of the major problems is a denial of the actual humanity of the persons concerned. Gender comes close at least in some countries in the world today where arguably women still suffer a form of civil death.

So in a sense the drafters of the convention were forced to face the question what does it mean to be human? They key to Article 12 – and indeed to Article 19 – lies in their answer. Their answer seems – and I emphasise seems like - like a contradiction – an answer that oscillates between an atomistic conception of the self and a social conception of the self.

The first answer is that everybody can grasp some conception of the good for themselves, that everybody should have the right – the autonomy – to steer their own path through life. That, to paraphrase Locke, individual consent lies at the heart of all relationships of power – that power is illegitimate unless permitted by the un-coerced consent of the person. So the image at play is the classic atomistic conception of the self – navigating a lonely path through the lifeworld. In other words a very expansive conception of autonomy is at play.

But there is another answer at play. On the other hand the drafters knew something that the drafters of other conventions were barely conscious of. They knew of the ruptured social ties that hollowed out the lives of persons with disabilities, they knew the effects on generations of the isolation, segregation, and loneliness in peoples lives. Flipped more positively, they knew that inclusion, embeddness in social networks is part of who we are as humans – it makes us who we are. Lets state the obvious. Quite a lot of the convention is actually geared toward inclusion – participation, accessibility removing barriers etc. This is not simply a mechanical task of barrier removal. This is in fact putting in place the preconditions for people to realize their selves in the lifeworld – in the world of social connectedness.

Now sometimes these two frames – autonomy and social connectedness - are in tension. What, for example, if I exercise my autonomy rights to live in an institution? To me, it is not a complete answer to say I don’t know what I am choosing because of the lack of an alternative in my life. I may still chose to live in an institution. And it is actually somewhat a dangerous answer since it might be used – as Rousseau would put it – to ‘force people to be free’ and to see their own interests as we would essentially see them. Free people – but socially sculpted people.

But mostly these two frames are mutually reinforcing. We value the ‘self’ – our will and preferences as OURs – and yet we see ‘naturally’ how we are at least in part a product of social interaction, social forces – the benign ‘give and take’ that makes us who we are. Of course, it is exactly this ‘give and take’ that is denied to many persons with disabilities and especially those with intellectual disabilities.

Big deal? Well it is a big deal and it helps to make the grand pivot away from guardianship in Article 12 understandable and accessible. Paraphrasing Holmes again, you should pour some cynical acid over the text of Article 12 to see what nuggets lie at its core. To me two nuggets stand out after careful excavation and they both play on the interaction of these two images of the atomistic self and the social self.

The first core nugget of Article 12 is the idea of the ‘will and preferences’ of the person. Now this is intended to – and does – stand in stark contrast to concepts like ‘best interests’ that operated in the past as a Trojan horse to allow massive interventions that were not in the slightest bit interested in the person’s views.

What to we mean about will? I was re-reading – as one does in ones’ spare time – Schopenhauer recently who was writing in the 19th century about the centrality of the will - especially the will to life, the will to live and the will be to be part of the world and connected to others. This is an instinctual dimension to human will which, to Schopenhauer, this is universal in all of us. Note that part of the instinct is the desire for human connectedness. It is in the interaction with the world that we find the self – not in an atomized shell of the body. Our will – our self - is in part of product of healthy interactions. This resonates – strongly – with contemporary insights from neuroscience – and the thesis put forward by DiMasio that ‘all humans are wired to connect.’

But of course will also denotes ‘free will’ and hence its connection to human ‘preferences’ which may remain fairly constant or which may change through time. One can think of our preferences as the exercise of the ‘free will’ to steer us in particular directions in life and in all the choices that we make in life - big and small. By the way the small preferences are just as constitutive of who we are as the big preferences – which is why a large latitude for informal decision making (by third parties) is also suspect.

It is clear that many of our preferences are peculiarly ‘ours.’ For example, I will never willingly share a room with a Leeds United supporter. I would prefer to study history over law – actually true. I strongly prefer Belgian beer to German beer – party because it is stronger! And while ‘my’ preferences are ‘mine’ yet they are clearly shaped by my experience, by how others react to my experience (maybe I was exposed to too many people who had a negative experience in Leeds). This does not make my preferences any less ‘mine.’ But it does give me the freedom to change my mind – to love Leeds. After all Anna Lawson is there – whats not to like! But of course the point is I have had experiences – I have tasted both Belgian beer and German beer. I have become myself in the world – not apart from it.

Getting back to two different spatial images of the self, the point about ‘will and preferences’ is that they are part an expression of the autonomous self and part a product of the social self. Which begs the obvious question – can I ever really know you – the ‘other.’ Can I ever really approximate you to your inner self –the motor force of your will and preference? Indeed, can I ever really know ‘my’ ‘self?’ Let me confess I’m never sure about that. Yet, the many outward signs of self – the many expressions of will and preference that we all make on a daily basis are enough for others to take them seriously and to act on them. That is. the myriad signals and signifiers – express and implicit - are enough of a solid proxy to be relied upon by others to ‘know’ you. That is so except when it comes to barriers that decrease our confidence in ‘what we see is what we get.’

Now people throw up barriers all the time – and this is seldom used as an occasion to doubt that there is a self. For example, who among us has not gone into a Minister’s office and come out wondering was that a multiple personality I was dealing with? Who was the real Minister? Wasn’t he or she so slippery as to evade tying down. And many people chose barriers – and project different dimensions of the self as the occasion or social context warrants. Generally, we accept this. It is ’normal.’

But if the barrier is such that we are left to doubt that there is any ‘self’ at all lurking behind the façade then any expression of ‘will and preferences,’ no matter how clear, is put down to something other than the authentic self. A clear analogy is mental health – doctors will often say , for example if I ‘prefer’ to remain off medication, that thats the disease talking, not Quinn. Likewise with intellectual disability. What is it that blocks off the person – or appears to block off the person? Why, when confronted with intellectual disability, do we immediately lack confidence that we can approximate the ‘self?’ And why then is no effort really made to try to unpeel the self from the externalities that are not as approachable as with ‘normal’ people?

Of course, here is where we come face to face the prejudice – a prejudice born of the Enlightenment’s enthronement of rationality as the essence of being human. It has a more venerable lineage in Aristotelian thought – but its modern shadow is cast more by the Enlightenment. The prejudice has to do with a linking of notions of ‘self’, of an innate capacity to steer a path in the life world one the one hand with rationality, cognition and intellectual ability on the other. You even see this linkage – this over-conflation of two separate entities – personhood and rationality - it traditional legal capacity Law. The test in such laws of legal capacity is the presence of sufficient mental capacity - some the Un Committee is set against.

When you zoom out, this conflation is strange – and, I would say, a historical accident. Why did it happen? Part of it is due to the re-imagination of Man (yes Man) in the Enlightenment as a rational being. Part of it is due to the emergence of commercial societies in which third party reliance on the bond of another was key to stable and growing market economies (bankers, traders). It is this reliance interest – and the imperatives of third parties for reliable contractual partners - that probably most skewed our understandings of legal capacity. Part of it was due to repressive forces that saw little ‘use-value’ in persons with intellectual disabilities and sought ever cheaper was of warehousing them. Which leads me to think just how enlightened was the Enlightenment? Funnily enough, this commitment to rationality as the essence of man and rationality as the essence of decision-making is most assuredly not supporter by contemporary science. Contemporary theories of decision-making emphasize the complementarity of the irrational with the rational. Indeed, even the integrity of the divide is challenged in clinical psychology today. Yet the fixation on rationality as the touchstone of legal capacity exerts a powerful hold to this day.

Article 12 is an antidote to all that. It is as if it is telling us we have to liberate the conception of ‘will and preferences’ – and indeed the conception of ‘self’ that it presupposes – from one of the sins of the Enlightenment which was a tying of personhood to cognition or cognitive ability. That is why the pivot in Article 12 to the assumption that all persons hold legal capacity is really important.

So the first nugget in Article 12 is ‘will and preferences.’ Which brings me to the second nugget. Again, how do I ever know you – come to think of it how do I ever know myself? Maybe I don’t – maybe I never will! But our lives do have at least an outer if not an inner narrative – a story always worth telling. In a sense, all life is a journey of discovery. To be sure we don’t go around all the time worrying about who we are and where we are going - that might be Woody Allen! But there is an iterative process that is always taking place in our lives concerning essentially the interface between ‘self’ and ‘other’ and the constant re-definition of self. To put it more bluntly and in language that comes form Article 12 – ‘support’ is integral to who we all are. It functions as both a threat and a reaffirmation – but it always impacts on self-conceptions as well as the production of will ad references. Support – the iterative interaction with others – is the key to the journey of discovery. So the second nugget is the necessity and inevitability of discovery – or what Article 12 junkies call the ‘support paradigm.’.

Why do I say this? Well, a new language has arisen with respect to supported decision making – a new paradigm of supported decision making – a new white coated elite designing supported decision making regimes. Allow me to demystify it. First off, pay attention to the language actually used in Article 12. It talks about access to support to enable a person to exercise their legal capacity. Now to me at least that goes deeper and further than supported decision-making. To me this speaks to those who, perhaps through institutionalization, have had their social connectedness and therefore their capacity for ‘self’ understanding and ‘self’ realization shredded. The mystic chords of memory that tie us and enable a stable conception of ‘self’ to emerge is gone.

What does this support – or really a discovery process – actually look like? First of all it involves others in our lives. Now this means little to me or you. But it represents a profound change for persons with intellectual disabilities. Remember, Article 12 talks of ‘access’ to support. To me that's an implicit concession that access to others and to the lifeworld was absent and needs to be stitched back together. This is not primary provided by the State – but the State has to stimulate it into being and itself play a supporting role. And it does involve a new dynamic in the community – connecting is a two way street and those who do the supporting will themselves be changed by it.

The easy bit comes when the expressions of ‘self’ – the expressions of ‘will and preference’ – are not immediately accessible to the outside world – the world of doctors, bankers, landlords, etc. But it can become accessible to the outside world *via* the intermediary of persons who know the individual and can accurately parlay his or her will and references to the outside world. No one doubts the presence of a ‘will and reference’ – it is only a mater of translating it for others to access it. Our legal system knows of proxy rights voting on boards – it should not be too difficult to extend proxy rights to confer legal status on the representatives – provided we can have confidence they are accurately projecting the voice of the persons – a risk inherent in all human communications. By the way, to me at least, service providers can never provide this ‘supporting’ role – or should not be allowed.

Here we are imagining the relatively straightforward case of representing a known, knowable and stable set of will and preferences to the outside world. What of situations where we are less sure that we can approximate to the ‘will and preferences’ of the person? Again, lets zoom out a bit. Its not a mechanical task of exposing what ‘is there.’ Its never that with any of us. Its always a process of discovery involving human interaction and many parties. And it's a process fraught with problems and delicacies given that there is often no habit of human interaction especially for those whose family ties are long gone. Set against this is the experience of many – which is that it is remarkable how quickly a spark of the ‘will and preference’ can flicker into life once the human environment changes and once human interaction begins.

This last case also assumes a more or less stable set of ‘will and preferences’ requiring more than simply ‘translation’ to the outside world. It requires a deep and ongoing process of discovery. It assumes that such a process can approximate to the ‘will and preferences’ provided sufficient time and care is taken. In a sense the person is surrounded by a community of interpretation whose task is not to ascribe a ‘will and preference’ but to divine it.

But what about the case where there is, at least to all outward appearances, no ‘will and preference’ and we are left to doubt if there ever will be. Well, first of all, read your neuroscience. Remarkable breakthroughs are being reported almost by the week from around the world on new techniques to communicate even with those in a so-called ‘persistent vegetative state’ – a fairly odious term. We are blessed to have this conversation bout the viability of the pivot in Article 12 in the 21st century.

But lets say you don’t have access to that technology and/or we genuinely have a case of the near impossibility of excavating a ‘will and preference.’ Aren’t you inevitably going to have to make decisions ‘for’ as against ‘with’ a person? And isn’t this guardianship by another name? I would say no for three reasons. First of all, our commitment of discovery should apply to all persons. The obvious inflection of guardianship away from the person and toward the process of making decisions for the person by third parties inevitably misses opportunities where discovery might have made a difference. That process simply isn’t there under guardianship because a transfer has been assumed between your capacity to that of another – the guardian. Secondly, the iterative process of making decisions both for and with a person in that situation focuses just as much on sparking the ‘will and preference’ as it does on giving it voice. In other words, go back to the actual wording of Article 12. It does not just talk about supported decision-making. It talks about support to enable a person to exercise legal capacity. This is especially important with respect to people exiting institutions. It is this dimension of augment capacity – sparking it – that is just absent from any guardianship frame. Thirdly, the lodestar of guardianship is ‘best interests.’ As a concept it is under-ambitious, capable of being moulded to suit others whilst appearing to suit the person and it does not focus on rights – and here the most crucial right is a right to emerge into one’s own – to assume a ‘self.’

**4. Making sense of the Law and Space for Legal Change.**

So to me the question faced now is not whether to get rid of or phase out guardianship – all guardianship. The answer from international law is unambiguous – do it – and start a serious process of doing it. And this question is intimately tied to the right to live independently and be included in the community. For it is only when this right is fully respected that the ambient ingredients will be in place to realize the full potential of Article 12.

It must come as comfort to you to know that others around the world are imagining a post guardianship future. As you begin to think about legislating for it here are some of the things you will probably need to reflect on for ‘next generation’ legislation inspired by Article 12.

First how can you give legislative expression to the centrality of ‘will & preference.’ Be clear in your own minds about the difference between ‘best interests’ and ‘will and preference’? How can we put in statutory form the right of the individual to request or to refuse supports?

What is the continuum of supports which are really tools in the process of ‘self’ discovery? What legislative form would best suit them?

What supports best reach those with high support needs and enable their ‘will and preference’ to be expressed and respected. Should the legislation be silent as to the extent and degree of disability and support or should the legislation pay particular attention to those with the highest ‘needs’.

If the majority of supports emanate from the community then how does the legislation reflect this/acknowledge this. For example, does/can legislation incentivize/recognize the evolution of circles of support in the community? Are there any precedents? What are the links (?) between support and advocacy systems already in place – can statute law somehow link the two creatively?

How do we imagine and then give statutory expression to safeguards in the context of supports – especially in order to avoid a situation whereby supports cross the (elusive) line to substitute for the will of the person instead of expressing and give effect to their ‘will and preference?’ Which safeguards need to be in the legislation? How/can these safeguards be mainstreamed into general adult protection laws, policies and programmes? Is there a danger that if the safeguards are peculiar to persons with disabilities that they will be inferior and less robust – or enforcement will be less of a priority? Recall, a safeguarded life can easily become an over-regulated life. How do you protect against this happening? What toe-holds are needed in the legislation to temper the protective impulse at the point that it begins to undermine autonomy?

What institutional framework can/should oversee the new architecture of support and discovery? Can it/should it be merged with more traditional protective machinery (e.g., Office of Public Guardian) or will that inevitably overshadow and exert an undertow backwards on otherwise positive legislation?

What tasks should the new oversight body have in the legislation (monitor practice, issue Codes of Best Practice, develop new kinds of supports, register representation agreements…?). Under what Ministerial aegis should any new oversight body it fall? Social Affairs, Justice…? Or should it be directly responsible to Parliament? How can/should it relate to the national framework for a monitoring mechanism under Article 33 of the UN CRPD. How can/should it relate to national human rights institutes (human rights commissions, ombudsman, etc).

What kind of review should be envisaged in the act? Do we want to nudge the review in certain directions? For example, do we want to use the review as a learning opportunity to find out what worked well, what didn’t and why? Do we want to use this knowledge to improve the edifice being built up? Do we want to use it as the basis for making incidental decisions about the further reframing/refining of protective measures including substitute decision-making measures in the future?

How do you delineate between those parts of Article 12 that are to be immediately achieved and those that can be progressively achieved? Which aspects of support has to be immediately achieved and which can be progressively achieved? How would you prioritize?

Can you/should you have a general statute but then leave intact outlying statutes that delimit legal capacity and hope (plan) to reform them one by one? Should the general statute take precedence? How would you plan to reform all the outlying statutes (e.g., right to vote, freedom of contract, marriage rights?). What is the best division of labour between the headline statute and other more subject-specific statutes? In particular, what is the correct interface between a new general statute on support with mental health laws?

if one system (substitute decision-making) is to be phased out in favour of support then how might this transition be reflected in statute? What kinds of triggers would prompt the move? What thresholds need to be reached to give confidence in further refining/removing the ambit of substitute decision-making? How well developed should the support regime be before the triggers are activated? Who pulls the trigger? What is the process of reflection on gathering the evidence to give confidence to move wholesale to supports? Does the converse hold true – the more tightened the fiscal constraints become the more space for substitute decision-making?

Socrates once wrote that ‘the unexamined life is a life not worth living.” But to examine a life, to make sense of its narrative, to get at the soul of the person behind the text of his or her story, is not something that can or should be pursued through logic or rationality. Our own steps and missteps in life can be rendered logically – and usually retrospectively. But we all know that are lives are woven of many strands and that logical is perhaps the least important when it comes to major inflection that go to form ‘our’ story.’

I started with a quite from Bruce Springstein. It expresses deep bonds, almost a mini-world shared by two people and a deep sense of loss – a loss of companionship but also a loss of ‘self’ flowing from separation. It captures well our social selves and the constant and painful process of being in each other’s life and then simply being. Of course ‘we’ at least have the good fortune to experience this and evolve as result.

And I end with a quote from Arthur Koestler from his novel ‘Darkness at Noon,’ (1940 at 204-205):

“He had believed that he had drunk the cup of humiliation to the dregs. Now he was to find that powerlessness had as many grades as power; that defeat could become as vertiginous as victory, and that its depths were bottomless.”

He was writing about totalitarianism. He may as well have been writing about guardianship – about its powerlessness and humiliation. Lets end it and create a new future with Article 12 prodding us forward. Support yes – discovery most assuredly.

Thank you.