

**'From Civil Death to Civil Life
Perspectives on Supported Decision-Making for
Persons with Disabilities'**

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“To know oneself, one should assert oneself”

Albert Camus.

Thank you for the high honour of addressing you this afternoon.

I come to you from the far end of Europe and love the fact that we can unite across our common European home to address common issues that directly affect our citizens.

I am impressed with your universities’ deep involvement in important EU research funding programmes – another thing we share. And I note you had the wonderful opportunity listen to Yotam Tolum of BIZCHUT a few weeks ago on the journey to full personhood in Georgia. I’m sure my words will only add to his in encouraging you in your reforms.

I acknowledge and warmly welcome the decision of your Constitutional Court to end guardianship and take note of the vibrant debate here about how best that can be done. Our own Parliament is about to enact Europe’s first Assisted Decision-Making Act. The law reform process in both countries raise some common issues, like the role of courts and experts.

The topic of this afternoon’s talk is ‘From Civil Death to Civil Life – perspectives on supported decision-making for persons with intellectual disabilities.’ This title has been chosen deliberately. The term ‘civil death’ comes to us from Sir William Blackstone – the great English legal historian in the 17th century. He famously observed that upon marriage women suffers civil death in the sense that all of the dimensions of her legal personhood were transferred into the hands of her husband – her right to sue, her right to hold and manage property, her right to make decisions for herself, her right to vote. It has taken a long time for full legal personhood to be restored to women in many cultures – and in some cultures today she still suffers civil death.

I – and others – have often said that something similar happened to persons with disabilities through legal incapacity laws and guardianship throughout the centuries. Yet we are now at an interesting turning point with the abolition of guardian regimes in sight in many places throughout the world. This turning point is not yet fully understood. And its implications have not yet been fully appreciated. But it looks unstoppable.

I want to spend my limited time doing three things.

First of all, I want to stand back from the field of intellectual disability to paint a broader picture of civil death as it has affected many different groups. This is important as it gives a broader context and helps you see the reform of legal capacity laws as part of a historical continuum affecting women, people of colour, prisoners and children.

Secondly, I want to reflect on why the reforms that benefited these groups did not automatically cross-over to the benefit of persons with intellectual disabilities. There were many blockages. But permit me to suggest that the main blockage was the assertion that persons with intellectual disabilities were (and are) indeed ‘different’ – in that their difference of cognitive or communicative capacity meant that civil death was not only appropriate but indeed the only way of properly taking care of their interests – a sort of hyper paternalism.

There are two responses which I will develop. One is to rely on the imperative nature of international law (specifically the UN convention on the rights of persons with disabilities) to demand the roll-back of guardianship – of civil death. I agree. However, there is a deeper reason why a roll-back of guardianship is required and I want to unfold it for you. Guardianship regimes rely on a standard account of what it means to be human, to exercise moral agency in one’s own life, to be present and active in the world. It rests on an exaggerated centrality of cognition and communicative ability in decision-making. However, the reality is that the standard account is no longer standard today. Recent scientific advances reveal the human being to be far more complex – much less

individualistic and more social in his/her decision-making. I will assert that these scientific advances alone demand the roll back of guardianship systems.

Thirdly, I want to say a few things about the new support paradigm. What do we really mean by support? What are the deep connections between supported decision-making and the desire and the right to community living? What does the rejection of a functionalist approach in the support paradigm (to be explained) mean for expert inputs in the process? What is the deeper image of autonomy and human flourishing at play and how should Governments respond?

1. Civil Death.

First, the curious life of 'civil death.

Sadly, legal history is replete with examples of the imposition of 'civil death' on many different individuals and groups of individuals.

The most obvious example is the institution of slavery which converts persons into 'non-persons' in law. If they are not persons they can be considered a species of property which (who) can be traded in an open market and whose lives are controlled at the behest of third parties without much let or hindrance from the law.

Generally speaking, this was imposed on persons of certain races – but not always. It was fueled by a sense of superiority and a corresponding attribution of moral inferiority. And it was fueled simply by naked self-interest. It could be – and was - imposed on the losers (and their families) after wars. Indeed, being sold into slavery was for a long time considered one of the natural consequences of war – the spoils of conquest. Closing down the market - ending the international trade in persons (the slave trade) in the 19th century - was the beginning of the end of the institution of slavery itself. However its abandonment in the 19th century as a distinct and valid legal category has not stopped contemporary forms of slavery in our globalized world.

Women too have often suffered a form of 'civil death' – and still do in some parts of the world. In a sense, women became their husband's property who could then direct them (and especially their financial affairs) and sue when his 'property' rights in her might be damaged by third parties. A sense of moral inferiority was ascribed to women disguised in the language of difference and of respecting difference. Women might be considered people (unlike racial minorities) – just less so. This was not quite slavery – but it must have felt like it.

Children too suffer a form of civil death in the sense that responsibility for the direction and care are handed to their parents as natural guardians. This has not generally been rationalized on a theory of their inherent moral inferiority or by naked self interest – although in poorer societies the power to control the labour of children must function as one reason keeping them under the control (disposition) of their parents. Society and the law in most cultures now see children as moral persons with lesser legal personhood on account of their greater than normal need for protection, gradual empowerment and eventual release into the world as responsible adults. It was this 'natural' difference in capacities and the potential for enhanced capacity that justified holding them to the will of another (their parents).

And of course prisoners still suffer a form of civil death in the sense that at least some of their civil and political rights were (and are) taken away upon incarceration. Penal reform movements are quick to remind people that prisoners remain persons – and then seek to ameliorate any consequent loss of legal personhood. Few societies would deny the right of the State to withdraw certain liberties against those who have violated the criminal law that embodies the very basis for peaceful social co-existence. Of course, societies differ as to where to draw the line.

Sometimes, civil death has even been imposed for reasons of political loyalty or trustworthiness. For example, during the American Revolution, various 'tests' were imposed to force people to demonstrate a show of loyalty to the emerging

regime. If the test were failed then certain civil and political rights were routinely withdrawn.

Civil death in law could mean that the person (the human 'subject') was always treated as an 'object.' Its not for nothing that we often say that the purpose of the UN disability treaty is to treat people with disabilities as 'subjects and not as 'objects.' Civil death in law could lead to third parties directing one's personal destiny as was the case with 'ownership' by a husband over 'his' wife or the control exerted by prison authorities over a prisoner. After all, if the entity were biologically alive but legally dead then someone or some way had to be found to manage its destiny.

The history of law reform – especially in the 20th century – has been about the slow and gradual imposition of, first of all, 'objective' and humane standards of behavior on those who exerted control or the rights of 'ownership' over others. In disability we call this the 'best interests' standard. Even if prisoners are denied the right to vote they must nevertheless be treated humanely. Only later came the slow and gradual restoration of the full *indicia* of legal personhood to those affected.

Even form this brief survey it should be clear that the imposition of civil death throughout history and today was and is very much a matter of social and political choice. We (or someone in power) imposed it on racial minorities, on the losers of wars, on women, on prisoners, on putative traitors – and on persons with disabilities. Again, more often than not this imposition does not have its roots in doubts about the moral status of the affected persons as 'persons.' It was done against vulnerable groups by those in power for very specific advantages.

Of course, and very much after the fact, the resulting loss of civil life could be rationalized along the lines that the person was not actually a 'person.' This was how slavery was rationalized in the US South before the Civil War (it was called 'that peculiar institution' of slavery). Somehow (at least in the self-interested

imagination of some) people of colour could be considered to be so radically different and unfit for freedom that slavery was the only option. And of course, the more their behavior was constrained and shaped by circumstances beyond their control, the more they exhibited negative characteristics that were said to justify negative views about them – a pernicious self-fulfilling prophecy.

Recall the way Heinrich Himmler justified the Nazi treatment of the Jews as well as people with disabilities (labeling them as ‘human animals’). What Himmler was driving at was the implicit boundary between humans and animals – trying to depict people with disabilities as animals against whom anything could be done and was done.

2. Why the Resistance to ending Civil Death for Persons with Disabilities?

Civil death has been ended for most groups. So why has the restoration of legal capacity – of full legal personhood – to persons with disabilities come last?

They too (or at least some of them) have suffered a form of ‘civil death.’

More visibly, they have suffered extensive civil death in law especially through the imposition of legal guardianship. Effectively, this meant a transfer of the legal rights of their personhood to someone else, to a public authority, a court or a third party (whether related or unrelated).

And, even if legal rights were not formally transferred by law, they (adults with intellectual disabilities) were often treated ‘as if’ they were civilly dead in that others (families, institutions) assumed the right to make decisions for or about them without any legal authority.

Civil death has had the effect of taking away their autonomy and decision-making powers in areas such as the freedom to marry, the right to vote, the right to manage their own financial affairs, the right to make their own decisions with

regard to medical treatment, the right to refuse treatment such as sterilization, the right to exercise civil duties such as to sit on a jury, the right to choose where to live and with whom, the right to choose how to live (e.g., minor matters such as the right to determine when to sleep), the right of privacy, etc. This panoply of rights go to the dignity of personhood as well as the right of persons to be in the world on their own terms with others.

Generally speaking, as aforementioned, the first wave of law reform reform in the context of guardianship has been characterized by the superimposition of 'objective' standards of 'best interests' to control the actions of these third parties and a narrowing of the category of persons susceptible to the loss of legal rights to ensure that only those who really need guardianship are admitted to it. Thus the field was 'sansitised' in how it functioned as well as 'telescoped' in terms of its scope of application. But its essence remained unchanged.

Why this hesitation? If civil death can be lifted for other groups then why not for persons with intellectual disabilities? What is the difference between intellectual disability and these other groups that justifies the retention of civil death for the former and not the latter?

We know that racial minorities, women and others are quite capable of looking after themselves – of exercising their autonomy. Its just that they were arbitrarily precluded from doing so in the past. Their moral personhood was never seriously in doubt – although ardent slaveholders and the most fervent follower of patriarchy might have disagreed in the 19th century. Their legal personhood was unjustly impaired and it was only a matter of time before it was restored.

What distinguishes intellectual disability of a certain severity (or so it is said) is that the very existence of the disability goes to the heart of, and impairs, what it means to be a person. When all is said and done this essentially means that certain persons with intellectual disabilities lack the cognitive or intellectual means to responsibly determine their own destiny – to make their own choices

and decisions. Many would question their capacity to exercise the rights that go with recognition as a legal person. Why?

Part of the reason most human societies (not all) value and respect human freedom in the world has to do with a trust in the capacity of persons to choose their actions (and inactions) and to exercise their autonomy responsibly. Of course, they pay a price afterwards if they don't – either in their own personal lives or by triggering the attention of the criminal law. But we generally cut people a lot of slack to 'choose to do wrong' - and face the consequences.

This assumes there is a 'self' somewhere directing one's actions (and inactions). It assumes there is 'human agency' in the world – that the 'self' can emerge from its internal exile to make itself known in the world and exercise choice. It assumes we can 'know' each other, interpret each other and respect each other's known or expressed wishes.

The challenge of intellectual disability is that many people believe that civil death is not an imposition or an arbitrary exercise of power by those in authority. Rather, it is simply a reflection on a sad reality. Either these people are genuinely dead in the sense that the impairment is so severe that we can no longer talk of a 'self' behind the persona of disability. Or, the 'self' may as well be dead because we do not currently have the full means to divine their intentions or to use the argot of our times to understand their 'will and preferences.'

It is no accident that the treatment of persons (especially adults) with intellectual disabilities was equated in the past with infants ('infantilisation' – i.e., treating people with disabilities as if they were infant children). The big difference, of course, was the expectation that children would eventually emerge from the cocoon of parental control – emerge into full legal personhood in their own right with the right to control their own lives including the 'right to do wrong' (provided they could be trusted to take responsibility for their actions). Indeed, emerge even to disrupt their parents intentions for them. No such

expectation attached to persons with intellectual disabilities as their incapacities were not temporary but lifelong.

Every imposition of civil death on any group poses profound questions on the essence of what it means to be human. But these questions are thrown into sharp relief by intellectual disability. These questions could be side-stepped or avoided in the context, e.g., of gender, because it is self-evidently (to most people) true that women are persons worthy of moral considerability and legal rights. But they can't be side-stepped in the context of intellectual disability.

One will be hard pressed today to find someone like Himmler who will openly say that persons with intellectual disabilities are 'human animals.' True, some (especially institutions) will act 'as if' they were 'human animals' – but very few will rationalize their actions along these lines. On the other hand, most people will intuit that persons with intellectual disabilities (at least of a certain severity) do not have the native capacity to safely navigate the lifeworld and the imposition of civil death is just a way of acknowledging that hard reality. This is certainly the view of many States today in the world.

This viewpoint does not say that we cannot and should not liberalize existing laws on civil death. Of course there is considerable scope in removing many (most people currently under guardianship are there because of incorrect or exaggerated assumptions about their incapacities). Yet, according to this worldview, even if we can reduce the field of application of guardianship there still remains a field of application since there are still some who cannot make it and who 'need' and deserve civil death. This is the dominant worldview in the world today.

But what is the standard account of personhood – moral and legal? The standard account seems anchored in point of time from the Enlightenment forward. Its component parts are relatively straightforward.

First of all, it posits the existence of a 'self' – of an 'I' that constitutes the person.

All persons have a body. No two bodies are exactly alike and it is interesting how most of us focus on the face as expressing who the person is. And all (or the vast majority) persons have a brain. The brain is of course part of the body. One of the enduring problematics is the extent to which the idea or concept or reality of the mind is separate from or separable from the brain. The mind/body problematic seems to have consumed those working in the field of the philosophy of mind for centuries since Descartes.

Regardless of where one comes out on this issue it is fairly clear that possessing a mind has been generally held to be one of the pillars of personhood. And the mind doesn't just apprehend the world – it apprehends itself – it is a self-conscious entity. It is conscious of who 'it' is – of its own identity through time. It is conscious of the world around it and of its own understanding and appreciation of the world. It is conscious of its own posture toward the world – and its own preferences. As a 'self,' it possess its own will – and through its will it expresses itself in the world. And it has its own preferences – which are distinguishable from those of others – which helps, cumulatively, to define its 'self.' All of which is informed by its capacity for reason – for rationality. This of course assumes a certain level of cognitive ability – precisely what is damaged through intellectual disability. Reason, in turn, assumes a capacity for reasoned deliberation. Interior deliberation in the abstract is one dimension. But the most important dimension for us is reasoned deliberation concerning the self in the world.

The world constantly confronts us with the need to make choices to respond to, e.g., immediate threats, or imminent events or to strategize about more long-term planning for one's 'self' in the world. This is where human agency fits in. It bridges our interior life with our manifestation in the world whereby we take control of the only thing we can really control (our 'selves') and express that in our behavior toward others and in the world. Acknowledging our human agency is important. It means that we are accorded the freedom to do wrong – and to face the consequences. Its absence means that as un-free human agents we are

not held responsible for our actions where they cause injury to others (the essence of the old insanity defence).

Even if all of the above are present (or detectably present) then one must also be able to connect with and communicate one's 'self' in the world. If one can't (at least in the conventional sense) then it becomes hard to establish that there is indeed a 'self' lurking within the frame of a body or that, if there is, then its will and preference are unknown and unknowable. Communicative inability therefore can cause suspicion that not only is the 'self' unreachable to any by 'others' but there may not actually be a 'self' lurking behind the mask of disability.

Whats my point? My point is that this 'standard account' explains the various 'tests' used in law to determine or confirm the existence of legal capacity to make one's own decisions. They tend to turn on factors such a rational ability to understand the world, a rational ability to appraise options for action, a rational ability to sift through the likely and probably consequences of one's actions or choices, a rational ability to arrive at a choice that expresses our own (un-coerced) preferences and of course, a rational ability to formulate our choices in a language or form of communication that others can understand.

Of course, in a world constructed largely on rational principles (after all, that was the chief goal of the Enlightenment) this emphasis on rationality – on communicative rationality – makes a lot of sense. The rational expression of preferences allows for a rational accumulation of preferences which aid in the design of social, economic and political processes. Maybe another example of rationality working itself pure through generations. Of course, this need for rational expression becomes a self-reinforcing dynamic according as what 'others' need to hear and see is rational. In other words, the 'reliance interest' of third parties (landlords, doctors, bankers, educators) in rationality becomes the driving interest. Our rationally constructed lifeworld demands nothing less.

But is this account really the only one available and does it actually resonate with our own experiences? I think not – and this is the secret behind Article 12 of the UN convention.

Modern science is displaying in brilliant technicolor the true extent to which the self is a social construct. At one extreme is the field of sociobiology or evolutionary psychology. This finds its roots in Darwin's work on natural selection and the role played by our genetic heritage in combination with our environment in moulding our sense of self. At one extreme, it can lead to the view that the 'self' - like the 'mind' - is an illusion. Certainly, if taken to such extremes it places not just an asterisk but also a huge question mark over all decision-making whether by 'normal' people or persons with intellectual disabilities alike. My intent in mentioning sociobiology is not to deny the existence of a 'person' or a will or a mind (although many do). Rather my intent is to place notions like autonomy and mind in context and to show how the standard account is far from monolithic.

Certainly, much neuroscience is yielding new theories of the mind which have been conspicuously absent from debates about the 'self' including decision making and community living. Antonio Damasio, for example, is famous for this thesis that the brain is 'wired to connect.' He does not say that the brain of those with higher cognitive functioning is 'wired to connect.' He says that all brains are wired to connect. In essence the 'self' emerges from these connections. Our 'selves' are inter-subjective and our autonomy is relational. Similarly, Bruce Hood develops the idea of the 'social brain'. The point is that modern neuroscience debunks the standard account of a hermetically sealed and disconnected mind. What it points to instead is the quality of the social connectors in our lives and in the life of the mind. Its probably the normal interplay of support and threat that 'others' pose that identity is formed. This is another way of making sense of the support paradigm in Article 12 and the faith in Article 19 that placement in the community is good for all persons.

And, still in the field of science, contemporary clinical psychology is also relevant since it tends to reveal the complexity of decision-making which is very far from the simple spatial or unilinear image above of consciousness, mind, emotion, rationality and decision. Decision-making is never so straight-forward. Indeed many clinical psychologists question the very existence of the boundary between cognition and emotion. What is reason? Are there any purely reason-driven decisions? If so, who would ever get married? Much of the relevant literature casts doubts on the standard account to say the least. And of course these doubts apply to all of us – not just persons with intellectual disabilities. Added to recent literature in clinical psychology is the burgeoning field of behavioral economics.

The standard account of mind, consciousness and rational decision making underpins much classical economics and animates many econometric models. Yet the explanatory power of these models has been found deficient. Economists have been reassessing the role of rationality in economic decision-making. Indeed, the latest 2015 World Bank World Development Report focuses on exactly this: Mind, Society and Behavior. Clearly the standard account needs substantial revision.

Philosophy whether ancient or modern, has, of course, long pondered the dialectic between 'self' and 'other' – between an atomistic or individualistic account of the self and the inter-subjective reality that we all intuit and experience. This is so whether we are talking ancient Confucian philosophy, Islamic thinking and contemporary theories of human nature. The focus – almost fixation – on cognition was something that happened at a particular moment in time (Descartes) and is more the exception than the rule in philosophy. Furthermore, it was consolidated not so much for philosophical as for political reasons

One might take exception to the introduction of religion into any assessment of the standard account and into any new framing. It certainly has no place in Darwinist accounts and if we are to believe Yuval Harari, it is quintessentially an

‘imagined reality.’ Yet the positions taken by the world’s main religions over time give us an added insight into long-held and enduring views about the nature of man. Most religions opt for a social approach to the self – not an individualist one. Indeed, Islam reputedly does not even see disability as a real difference between people. Of course, religion is parsed from the perspective of the nature of man *vis a vis* an ultimate creator.

The diversity of views is enough in itself to cast doubt on the standard account. Or at least it shows that the standard account has not in fact been standard for a long time.

So what do we have – the standard account is bad enough in itself. But it also underpins much of the law we have inherited. My point is that the law has to change – guardianship has to be removed – not just because the UN treaty says it should but because it is no longer supported by respectable scientific or philosophical understandings of what it means to be human.

3. The Paradigm Shift to Supports.

The above paints a broader context than normal to ‘explain’ the deep logic of Article 12 of the Convention. This deep logic to Article 12 is not apparent on its surface – but making it plain helps explain why Article 12 takes the turns that it does.

We saw how civil death was removed from the other groups above over time. There were actually two waves of reform on legal guardianship – both based on human rights. They overlap to this day. Article 12 is the leading edge of the second wave of human rights reforms of legal capacity regime.

The first wave dates to the 1990s and is encapsulated beautifully in Recommendation 99(4) of the Committee of Ministers of the Council of Europe. The essence of the first wave of reform of guardianship –based on contemporary human rights analysis at the time – was that the instances of the imposition of

legal incapacity should be reduced and only imposed where there was some clear 'functional' deficit with respect to a particular type of decision-making (e.g., in financial affairs).

So, from a substantive point of view legal incapacity was to be narrowed down to these instances of clear functional incapacities. Another feature of this first wave was that the process for imposing guardianship should be transparent, clear, regular, free from conflicts of interest, and, most importantly, mediated through an independent court of law. Note that this 'functionalist' approach concedes the legitimacy of guardianship – it just reduces its instances. Note that this functionalist approach equates mental incapacity with legal incapacity (at least in certain functional areas). Therefore, expert testimony is deemed important in order to accurately gauge the presence and extent of functional deficits. And note the important role of courts.

The engagement of courts from within this functionalist approach makes sense because what is really happening is that rights are being stripped away. Classic 'rule of law' theory demands that courts mediate this process and police it.

In point of fact the European Court of Human Rights has been steadily interpreting the European Convention along the lines of this functionalist approach – demanding for instance the full 'equality of arms' of the individual in the legal process and that s/he should be seen by the court.

I only say this in order to be crystal clear about the completely new trajectory of Article 12.

One might consider Article 12 to be the second wave of the human rights approach which supercedes even the caselaw of the European Court of Human Rights. Why?

Article 12 is a post-functionalist instrument.

It implicitly rejects the view that mental incapacity ever equates with legal incapacity. This point has been strongly reinforced by the UN Committee on the Rights of Persons with Disabilities.

It implicitly rejects the functionalist approach of simply reducing guardianship to cover one or two areas in a persons' life where there is 'proven' mental incapacity. It denies the imposition of any form of guardianship.

It implicitly rejects highly individualistic accounts of personhood and legal capacity. Instead, it relies on the idea of shared personhood and the natural supports that flow from free human interaction – something that is, by definition, impossible within an institution.

It implicitly rejects a role for courts in policing the denial of rights. Indeed, if legal capacity is presumed then courts do not logically have a role in restoring people to legal capacity since that is something they already have. If courts have a role it is to ensure that the supports that are in place do not themselves smother the person. However, this policing role is very different to saying that the courts have a role in determining what supports should be in place – in truth, the personal choice of the individual lies at the heart of this determination.

It is obvious that the theory of equality that underpins Article 12 is one that sees the difference of intellectual disability positively.

It is also obvious that Article 12 is logically linked to Article 19 on the right to live independently and be included in the life of the community. The image at play between both Articles is that of the person flourishing in his/her social connections with others. It's the social self that comes to the surface in Articles 12 and 19. That means that the supports we talk about in Article 12 are natural supports that occur in any community – but which have been denied to people with disabilities. And it means that the best – indeed the only – way to achieve this is outside institutions and in the community. Indeed, it might be considered

a form of inhuman and degrading treatment to grant people legal capacity in institutions and then keep them in there – a Kafkaesque nightmare.

One important implication of the rejection of the equation of mental incapacity or communicative incapacity with legal incapacity is that the supports we put into place are not connected with human deficits. Its not as if we concede legal capacity, identify deficits and then put in place supports to get over these deficits.

Its actually the other way around. We put in supports to spark the will and preference of the person. We put in supports to assist in the exercise of autonomy – not to subtly impose our view of the ‘right’ decision. We put in supports to enable the person be understood or communicate – and maybe not in the way that ‘we’ communicate. In short, we shift focus entirely from human deficits to place the emphasis on a search for new techniques of discovery – new ways of understanding the person behind the disability. Importantly, no one can impose supports on another. That is a core principle of Article 12.

I think it is clear that Article 12 reaches out to communities – to social inclusion within communities – to the expansion of social circles – provide natural supports for persons with disabilities. The most useful role the State can do is to issue Codes of Good Practice to ensure that supports do not undermine instead of underpinning the person. Its obvious that this works best alongside a community living strategy – not just for those currently in an institution but also for those with few options at home.

A more robust role for the State might be imagined with respect to a minority whose persona has turned unnaturally inward due to no meaningful social connections over a lifetime. But even then, one should be wary about direct State provision of the support. It should kick-start a process and not take it over.

4. Conclusions.

What can we see from the above analysis?

First of all persons with intellectual disabilities were not alone in suffering civil death. We can see a pattern here – of gradually restoring legal personhood to many different groups over time. Intellectual disability is simply the last outpost of civil death.

Secondly, the alleged differences between persons with disabilities and others are not enough to preserve guardianship. It turns out that the standard account of what it means to be a person and to make your own decisions rationally is no longer standard. Even if it were, look at how accusations of irrationality also held women in bondage over the years. Science points to an interesting mix of emotion, irrationality, impulse and rationalization in all of us.

Thirdly, the switch to the support paradigm points a light in a long neglected dark corner – how can we develop tools of discovery to reveal the person behind the disability. The reason they are not immediately apparent is because we have not invested time in them and relied excessively on the convenient option which was to take a person’s voice away and simply ‘manage’ them.

Fourthly, this voyage of discovery can best take place in the community with naturally occurring supports. The prime directive of social services needs to change – its not just about meeting basic needs – its also about building bridges for people into their own communities. That is why there is an intimate relationship between the right to legal capacity and the right to live in the community.

Fifthly, what about our natural human impulse to protect people against damaging choices? My own personal view is that this is a wholly natural human response. The problem in the past was that the device we used to protect people – guardianship – ended up doing exactly the opposite. Notions like ‘best interests’ did not work well in protecting people. And in any event, it is a strange form of protection that removes a person’s voice. That does not mean that the protective impulse is illegitimate. Indeed, Article 16 of the UN disability treaty forces us to think through how best to protect people against, violence,

exploitation and abuse. The emphasis on new techniques of discovery under Article 12 does not banish the protective impulse – but it makes it sub-serve the person’s autonomy. A radical re-balancing is taking place. New lines will need to be drawn as experience emerges on how a support system works.

All in all, this is a new landscape for persons with disabilities, their families and services. We will all need to learn and adapt together. It is built on a faith that there is a person lurking behind the disability and that new techniques of discovery will allow us to reach that person and enable him/her to be in the world in accordance with their own worldview.

As a journey it brings out the best in all of us.

I started with a line from Albert Camus. Let me end with some words from our national poet – William Butler Yeats:

“Do not wait to strike ‘till the iron is hot – make it hot by striking.”