



NUI Galway

**CENTRE *for* DISABILITY
LAW & POLICY**

www.nuigalway.ie/cdlp

**Statement by Professor Gerard Quinn, Director, CDLP,
to the Oireachtas Joint Committee on Justice, Defence and Equality.**

*Re: Hearing on the Mental Capacity Bill, February 29,
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Gerard.quinn@nuigalway.ie

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“The Law is the witness and external deposit of our moral life”

Oliver Wendell Holmes.

‘The Path of the Law’, 10 Harvard Law Review, 457 (1897) at 461.

The Centre for Disability Law and Policy at NUI Galway greatly appreciates this opportunity to address the Oireachtas Committee on the important subject of the forthcoming capacity legislation.

1. Why this is Important.

This issue is of primary importance. Currently, many persons with intellectual disabilities suffer the ‘civil death’ of wardship. By it their very personhood is effaced. Without legal capacity to make life choices (big and small), to have choices equal to others and respected by others, and indeed to make one’s own mistakes, it is hard to see how the promise of living an independent life and being included in the community can be made good.

Denying personhood in the name of protecting people in their ‘own best interests’ has suffocated the human spirit. It has placed people with disabilities in a cage on a pretence of placing them on a pedestal. It is hopefully a thing of the past and has no future in a Republic of equal citizens.

As is well known Ireland has still not ratified the UN Convention on the Rights of Persons with Disabilities. This is because of the need to ensure that our Victorian wardship legislation is repealed and replaced. The longstanding tradition of waiting until our legislation is in order before proceeding to ratifying such conventions is a good thing – *provided* there is all deliberate speed and provided the new legislation is actually fit for purpose. That is why we are here today.

Before proceeding let me at once express our admiration for the sterling work that has already gone in to this process within the Department of Justice and before that by the Law Reform Commission. We do not appear here today to speak on behalf of people with disabilities. We appear to offer legal view – such as it is – on the nature of the obligations contained in the UN convention which, we take for granted, as the central departure point in the relevant debate. Our views are of a piece with the Principles enunciated by a group of Irish NGOs, and facilitated by Amnesty International Ireland. These Principles ought to underpin legislation on supported decision-making and have broad support across disability, mental health and older person’s sectors.

Though adopted in 2006 and opened for ratification in 2007 the UN disability convention is not a static entity. Understandings of some of its core provisions have evolved and crystallised even since 2006 and it proves crucially important

that these understandings inform our analysis of the benchmarks that Ireland will be expected to meet and will eventually be judged on.

Treating the obligations of the convention as central in this law reform process means just that. It does not mean treating extant models of law reform as sacrosanct except to the degree that they themselves self-consciously conform to the convention. This of course begs the core question – what does the convention require?

2. The Centrality of the benchmarks of the UN Convention in Framing the Debate about Fresh legislation.

The quest for the talismanic yardsticks of the convention requires three things:

First, and most crucially, it requires an understanding of the underlying philosophy of the relevant parts of the convention and a commitment to ensure that any reforming legislation should be explicitly and visibly based on this philosophy and give concrete effect to it.

Secondly, it requires an understanding of the particular obligations incumbent on States Parties within the relevant provisions of the convention and a commitment to consciously design the framework and content of the legislation to advance our fulfilment of these core obligations. The root of the title of the Bill should be clearly traceable back to the convention. It should wear this badge at its surface and in its heart.

Thirdly, it requires that any new legislation should offer a stable platform into the future – one that is not vulnerable to negative criticism from the relevant UN organs that monitor the implementation of the convention. The point is that any fresh legislation should have the potential of being built upon progressively – a feature it would clearly lack unless it hews closely to the spirit and text of the convention.

Our intervention today therefore is about the philosophy of the convention and about those core obligations which -all are agreed – provide the benchmarks by which we will eventually be judged by the international community.

3. Philosophy - The Paradigm Shift of Article 12 – from ‘Object’ to ‘Subject.’

Article 12 of the convention is central. It both reflects and expresses the core philosophy of the convention which, to paraphrase the Chair of the UN Committee that drafted it (Don McKay), is to decisively move away from treating persons with disabilities as ‘objects’ to be managed or cared for by others – even well-intentioned others – towards treating them as ‘subjects’ capable of taking charge of their own lives and enjoying the equal protection of the law. Article

12.1 'reaffirms' what ought to have been obvious – namely that persons with disabilities have a right to recognition as persons before the law.

Primarily this means a decisive shift away from a deficits-oriented philosophy – one that first seeks out decision-making frailty on account of disability and which then finds safe ways of substituting for the decision of the person by placing decision-making authority in the hands of suitably circumscribed third parties. It means a decisive shift towards an assumption of legal capacity – one that does not turn exclusively on cognitive ability.

It is therefore important that any replacement legislation should be visibility based on an assumption of capacity – which can be supported where fragile – rather than on a quest for frailty which can be 'handled' by displacing decision-making authority into the hands of a third party.

4. Core Obligations of Article 12.

Article 12.2 recognises that persons with disabilities enjoy the right to exercise their legal capacity on an equal basis with others in all spheres of life. Decoded this means that individuals are not just the bearers of moral rights in the abstract but are also considered to have full moral agency to exercise their rights. An early and persistent attempt was made in the drafting process to deflect the force of Article 12 by insisting on a distinction between a right to hold rights (which a baby has) and the right to exercise rights (which an adult has) and to confine the right to legal capacity to those with full cognitive ability. This did not succeed.

The resulting text (Article 12.1) comes close to creating an almost irrebuttable presumption of legal capacity. Mental incapacity and legal incapacity were conflated in the past. Now they are separated out. This seemingly counterfactual insight fits well with modern philosophies of personhood which de-emphasises the centrality of cognition and with modern psychology which emphasises the extent to which decision making is always driven by a mix of cognitive with non-cognitive inputs. Indeed, modern neuro-science now emphasises the extent to which the mind is itself a relational concept which pivots as much on human relationships as it does on innate cognitive ability.

As if to reinforce this paradigm shift – this decoupling of an analysis of mental capacity on the one hand from questions about legal capacity on the other – sub-paragraph 3 of Article 12 goes on to oblige States to take appropriate measures to provide people with disabilities the support they may need in exercising their legal capacity. Sub-paragraph 3 is widely taken as emblematic of the paradigm shift and spearheads it in the context of legal capacity.

Note, Article 12.3 does not confine itself to a right to supported decision-making. Instead it speaks of supports in the broader context of exercising legal capacity. So we are not just looking at supports at a particular point in time to enable a person make a decision. We are looking at supports in the round and through

time which may enable a person to develop their legal capacity. It is implicitly assumed that persons have some spark of capacity that is capable of being augmented and supported.

There is no mystique here. Supports are what we all rely on every day – informally and formally – to help us navigate through life. Most of this support is freely available in the social capital of our daily lives – and Ireland is acknowledged as rich in this respect. Of course, it is precisely this kind of social capital that has been absent in the lives of persons with intellectual disabilities due to their isolation on the community. One can imagine a continuum of supports to enable a person develop their legal capacity and decision-making abilities. One can image different sets of supports depending on a persons’ life situation. For example, different supports will be needed to spark the will and preference of a person who is just emerging from an institution as contrasted to someone already living independently.

Building up these supports primarily means connecting people with their communities – something already stated as a goal of national policy and which is clearly congruent with the Time to Move on from Congregated Settings Report (2011) of the HSE. New models of service delivery are emerging in Ireland led by groups like *Aiseanna Taciochta* which builds on circles of supports in a person’s life. The notion of supports just builds on these evolving models.

If law is needed here it is needed primarily to confer legal effect on the will and preference of the person as it emerges through the prism of expanded social circles of support. That is why it is our view that attention must be given to enacting legislation similar to the Representation Agreement legislation in British Columbia which compels third parties such as doctors and landlords to treat with the freely chosen representatives of the person. Other publicly available supports that already exist or are in the process of evolution (advocacy, community development) can be relatively easily re-tasked to provide the kinds of supports envisaged by Article 12.3. This does not necessarily require a fresh injection of new resources – but it does require imagination in linking supports – both public and private – to the core task of enabling people assume control over their own destinies.

Doubtless the move to a support paradigm will carry with it its own set of dilemmas requiring new lines to be drawn. For example, care will be needed to ensure that ‘support’ does not even unwittingly cross the line whereby it becomes in effect substitute decision-making. Ways of handling differences within the circle of support will have to be found. An appropriate oversight mechanism will be required to set standards and police them. But the difficulty in drawing new lines should not deter any initiative in this direction. Article 12.4 on safeguards will be particularly relevant here.

Article 12.5 draws out the implicit logic of what preceded it by making explicit provision with respect to the right to exercise financial autonomy. The link between legal capacity and the right to independent living is obvious. Essentially what we are talking about here is the right of the individual – suitably supported

if need be – to manage his/her own financial affairs. Indeed, it is hard to see tangible progress being made in the direction of individualized budgets – which is a stated goal of public policy in Ireland – without making explicit provision for this expanded right to control and manage one’s own financial affairs.

5. The Need for a Stable Legislative Platform that Facilitates Progressive Achievement into the Future.

The convention innovates by mixing obligations of immediate effect (such as non-discrimination) with obligations of result to be achieved progressively. Not everything can be achieved immediately particularly where costs are associated. That does not rob the obligations of all significance. International treaty monitoring bodies do have tools with which to measure whether sufficient progress is being made.

However, progressive achievement could be undermined by not accentuating a positive philosophy in the legislation from the outset. What one wants to avoid is tacking on a positive philosophy later on and in piecemeal fashion onto an essentially negative philosophy that highlights deficits. The optics alone would make the positive philosophy seem like a bolt-on to an essentially negative default setting. Defaults matter. It will be much easier to build progressively with a positive philosophy of supports if the underlying legislation itself is positive in tone and content.

6. A Clear Global Consensus on the Support Paradigm of Article 12.

Our views on Article 12, no matter how well reasoned, count for little unless there is a substantial swell of authoritative opinion (*opinio juris*) to support it. It is true that Article 12 was crafted with a degree of ‘constructive ambiguity’ to bring reluctant States along. It is true that it might be interpreted to not only allow for substitute decision-making (guardianship) to continue but to see this as primary and supports as secondary. And it is true that some States have made either interpretive declarations or even outright reservations to this effect.

However, a settled body of opinion has crystallised since 2006 which now tips our understandings of Article 12 decisively in the direction of a support – and non-deficits – paradigm. We point to the following sources as separately and cumulatively reinforcing this view.

First, in a 2009 report the **Office of the United Nations High Commissioner for Human Rights** has stated its view,

In the area of civil law, interdiction and guardianship laws should represent a priority area for legislative review and reform. Legislation currently in force in numerous countries allows the interdiction or declaration of incapacity of persons on the basis of their mental, intellectual or sensory impairment and the attribution to a guardian of the legal capacity to act on their behalf. Whether the existence of a disability is a direct or indirect ground for a declaration of legal incapacity, legislation of this kind conflicts with

the recognition of legal capacity of persons with disabilities enshrined in article 12, paragraph 2.

And

Besides abolishing norms that violate the duty of States to respect the human right to legal capacity of persons with disabilities, it is equally important that measures that protect and fulfil this right are also adopted, in accordance with article 12, paragraphs 3, 4 and 5. This includes: legal recognition of the right of persons with disabilities to self-determination; of alternative and augmentative communication; of supported decision-making, as the process whereby a person with a disability is enabled to make and communicate decisions with respect to personal or legal matters; and the establishment of regulations clarifying the legal responsibilities of supporters and their liability.¹

Of course, the Office is not the body that officially interprets the convention – but its word is exceptionally weighty in the international legal order.

Secondly the relevant treaty monitoring body – to which Ireland will be answerable once it ratifies the convention – the **UN Committee on the Rights of Persons with Disabilities** is drawing conclusions on State reports based very much on a positive understanding of Article 12. The Committee has recently considered the reports of Spain and Tunisia – both countries that still operate guardianship systems for people with disabilities which remove or restrict the person’s right to make decisions. In both cases, the Committee expressed concern

...that no measures have been undertaken to replace substitute decision-making by supported decision-making in the exercise of legal capacity.²

With respect to both countries, the Committee recommended that the state

...review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person’s autonomy, will and preferences.³

It is not hard to predict that exactly the same conclusions would be drawn by the Committee against Ireland unless it too took steps to replace guardianship with supported decision-making. The Committee is currently working on its own general Comment on Article 12 (effectively laying out in depth its considered views on the interpretation of Article 12). Given the tone and content of the Committee’s conclusions so far, the General Comment will likely be an extended commentary on what the supported decision-making paradigm means rather

¹ U.N. Office of the High Commissioner of Human Rights, *Thematic Study on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities*, ¶ 45, U.N. Doc. A/HRC/10/48 (26 January 2009)

² “Consideration of reports submitted by States parties under article 35 of the Convention: Concluding observations of the Committee on the Rights of Persons with Disabilities” [Committee on the Rights of Persons with Disabilities: Fifth session, 11-15 April 2011] at page 4. Available at: <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session5.aspx>.

³ Consideration of reports submitted by States parties under article 35 of the Convention: Concluding observations of the Committee on the Rights of Persons with Disabilities” [Committee on the Rights of Persons with Disabilities: Sixth session, 19-23 September 2011] at page 5. Available at: <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session6.aspx>.

than a defence of moving to it from a guardianship model.

It is important to point out that the CRPD is already applicable to Ireland via the back door of the **European Convention on Human Rights**. The European Court of Human Rights has already invoked the CRPD as an aid in interpreting States obligations under the ECHR itself (even against States like Switzerland that have not even signed the CRPD). The jurisprudence of the European Court is moving in a positive direction with respect to Article 12. Its recent judgment in *Stanev v Bulgaria* (January 2012) shows that the Court is scrutinising exist guardianship laws ever more closely. This case involved a man who was unable to challenge his detention and degrading treatment in a social care facility without the consent of his guardian, leading the court to find that guardianship regimes such as Bulgaria's violate the right to a fair trial under Article 6 of the ECHR. Therefore, if Ireland introduces an adult guardianship system as a primary replacement for the Ward of Court system, it will not only court the criticism of the UN Committee but may well expose Ireland to an ECHR challenge. Further similar cases are pending before the Court. Prudence alone would counsel against this.

We understand that the **High Commissioner for Human Rights in the Council of Europe** – Thomas Hammerberg – will issue his own Issues Paper on legal capacity reform in Europe between the drafting of this statement and the hearings today. We hope and anticipate that it too will endorse this move toward a positive philosophy of supports and look forward to a presentation on this Paper by the Office here today.

The relevant developments are not confined to the UN or Europe. The relevant monitoring committee of the **Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities** has recently (May 2011) issued its own General Observation on the interpretation of that convention in light of Article 12.⁴ This convention is part of a series of human rights treaties adopted by the Organization of American States (OAS). It states its view that Article 12:

...implies a change of paradigm away from substitution of a person's will...to the new paradigm based on decision-making with support and safeguards...

and

the support envisaged by the convention as 'appropriate' focuses on abilities (more than disabilities) and on elimination of obstacles in the environment so as to facilitate access and pro-active inclusion in social life...

In short, this clear trend in favour of the move to the support paradigm as the

⁴ Committee for the Elimination of All Forms of Discrimination Against Persons with Disabilities, General Observation of the Committee for the Elimination of All Forms of Discrimination against Persons with Disabilities on the need to interpret Article I.2(b) in light of the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities in the context of Article 12 of the United Nations Convention on the Rights of Persons with Disabilities, [OEA/ Ser.L/XXIV.3.1, CEDDIS/doc.12(I-E/11) rev.1] at page 9.

chief departure point in the drafting of fresh legislation is palpable. It would be fair to say that anything else would expose Ireland to valid criticism at the relevant international monitoring mechanism.

Furthermore, practical legislative models for various aspects of supported decision-making already exist and are emerging in Canada, Germany, Sweden, Hungary and India.

7. Conclusions.

Ireland takes international law very seriously. That is why there has been a delay. It follows that the letter and spirit of international law should be controlling. Let me be even clearer. We will not be judged by how elegantly we have transposed and tailored solutions in other countries to Ireland. We will be judged solely on how closely the letter and spirit of our law maps over onto the core obligations of the UN Convention.

Practically speaking this means imbuing the new legislation with a positive philosophy which assumes legal capacity and which responds to frailty by augmenting and developing capacity. It means mapping on the core obligations of Article 12 onto the law. This means in essence providing a statutory framework for a supported regime which can be amplified in secondary instruments as time and experience is gained. And it means having an organic platform capable of growing over time but provided always that the initial philosophy is positive and one that can bear further growth.

In cases of last resort, where support has been provided but has not led to a decision, or where the person's will and preferences cannot be discovered, the international consensus is that a mechanism known as facilitated decision-making or 'co-decision-making' is more appropriate than guardianship. The difference between facilitated decision-making and guardianship is significant. Guardians make decisions in the 'best interests' of persons, whereas facilitated decision-makers make the decision that they think best corresponds with what the wishes of the person would be.

Legal capacity legislation based on supported decision-making legislation would require the establishment in statute of an Office of Personal Decision-Making. This office could act as a first point of contact for anyone who has a concern about an individual's decision-making and the Office could facilitate the acknowledgement/creation of support networks or circles of support for people with disabilities. Formal agreements for circles of support would need to be provided for in legislation, and should be registered with the Office. It is vital that these agreements are open to anyone to make and easy to use, otherwise adults in need of support will be discouraged from entering this process.

The quote at the outset of this statement from Oliver Wendell Holmes is a timely reminder that law reform is too important to be left wholly to the lawyers.

Because it rests ultimately on the moral sensibilities of the community and because the world community has now decisively moved to the support paradigm we have a unique opportunity in Ireland to again set standards in the field of disability. It is in this spirit that I commend the move to the support paradigm as the primary departure point to you in framing new legislation.

I would like to acknowledge and thank Dr Eilionoir Flynn and Anna Artstein-Kerslake in helping frame this statement and in facilitating so much of the work of the Centre in collaboration with many others on this topic.

Thank You.