

Centre for Disability Law & Policy NUI Galway

Submission on Legal Capacity the Oireachtas Committee on Justice, Defence & Equality

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The Centre welcomes the opportunity to make this submission on legal capacity to the Oireachtas Committee on Justice, Defence and Equality. The Centre for Disability Law and Policy (CDLP) at the National University of Ireland Galway was formally established in 2008. The Centre's work is dedicated to producing research that informs national and international disability law reform. Since its establishment, the CDLP has organised a number of key events to provide a space to discuss disability reform, such events include: an International PhD Colloquium (2010), an international conference on national disability strategies (2010) and a Summer School in conjunction with the Harvard Project on Disability (2011). The Centre regularly runs seminars and public lectures and produces policy briefings. The CDLP runs a Ph.D programme and a Masters (LL.M) in International and Comparative Disability Law and Policy.

Table of Contents

Executive Summary	5
1. Introduction	9
2. Background to Legal Capacity in Ireland	9
2.1 The Different Approaches to Legal Capacity	10
3. The Revolution of Article 12: Why it needs to Permeate the Bill	11
3.1 The Paradigm Shift in Action	14
3.2 The Core of the Paradigm Shift	15
4. What the World Thinks	16
4.1 The Organisation of American States and Article 12	16
4.2 Article 12 CRPD and the European Convention on Human Rights	17
4.3 The Wider European Context	18
4.4 Review of the New Capacity Legislation	19
5. Moving Away from Deficits: The Need to Explicitly Embed in the Bill a Right to Supports to Enable Persons Exercise Legal Capacity	20
5.1 The Need to Radically Re-Frame “Best Interests” to pivot on the “Will and Preferences” of the Person	21
5.2 Safeguarding Legal Capacity and Supported Decision-Making	21
5.3 The Role of Court/Tribunal/Board	23

6. Legal Capacity: The Link between Independent Living and Inclusion in the Community	23
7. Legal Capacity outside the Scope of the Bill	27
7.1 Legal Capacity and Consent to Mental Health Treatment	28
7.2 Legal Capacity and Minors	30
7.3 Right to Intimate Relationships	31
Appendix 1: Practical Suggestions for the Establishment of a Continuum of Support Arising from the Implementation of Article 12.....	33
Appendix 2: British Columbia Representation Agreements.....	37
Appendix 3: Personal Ombudsman in Sweden.....	38
Appendix 4: Quinn “Legal Capacity Law Reform: The Revolution of the UN Convention on the Rights of Persons with Disability” [Dublin: Frontline, 83, 2011, 26-27].	40
Appendix 5: Quinn “Rethinking Personhood: New Directions in Legal Capacity Law & Policy” [Vancouver: University of British Columbia, 29 April 2011].	44
Appendix 6: Quinn “Personhood & Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD”(Harvard: Harvard Project on Disability, 20 February 2010).	66
Appendix 7: Quinn “Seminar on Legal Capacity” [Brussels: European Foundation Centre, Consortium on Human Rights and Disability, 4 June 2009].	82
Appendix 8: Dhanda “Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?” (<i>Syracuse Journal of International Law and Commerce</i>: 34, 429, (2007), 457-458). (Available via Hein-online).	99

Executive Summary

The Centre for Disability Law and Policy welcomes the work towards new modern legislation on legal capacity. As the Oireachtas Committee has stated this represents an important step towards Ireland's ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD).

In the past, the fields of mental health law, non-discrimination, and legal capacity were considered separately, often without regard to the overlapping and intersecting nature of these issues. The Convention on the Rights of Persons with Disabilities recognises that considering these issues in separate silos was wrong and that the artificial lines drawn between these separate fields are increasingly blurred. Therefore, it is important to consider the impact the forthcoming legislation will have on general non-discrimination provisions and mental health law in particular. Article 12 on legal capacity is at the core of the Convention. Equal recognition as a person before the law is key to the enjoyment of all other rights. The assumption of legal capacity, and the obligation on states to provide supports to people with disabilities in order to enable them to exercise their legal capacity flows from this recognition, and these are the key attributes, which need to be embedded in Irish law, in order to ensure compliance with the Convention.

The Convention provides for a paradigm shift in thinking on legal capacity in Article 12, which moves away from thinking of people in terms of "deficits", and the lack of ability to make decisions, towards augmenting individuals' capabilities. The international law reform trend in the area of legal capacity is to downsize guardianship laws and reduce if not eliminate substitute decision-making arrangements - and instead focuses on the provision of supports to enable people to make their own decisions.

The CRPD through Article 12 clearly rejects the "status" and "outcome-based" approaches to legal capacity and insists that the "functional approach" must focus on supports to enable persons to exercise legal capacity. While the Scheme of the Bill has positive aspects it needs to be reconfigured to embody the philosophical shift of Article 12. The Scheme of the Bill regularises substitute decision-making in the form of guardianship instead of prioritising the supports that could prevent substituted decision-making from being used. These are significant shortcomings that need to be addressed, if the proposed legislation is to enable Ireland to ratify the Convention.

Article 12 of the Convention indicates that a continuum of support measures is required to enable people to exercise their legal capacity. The functional approach to assessing capacity set out in the Scheme of the Bill could yet have an important role to play in ensuring that individuals who require support to exercise their legal capacity receive the appropriate assistance. In

circumstances of last resort, where the person in question does not have any support network to assist with decision-making, the option of facilitated or co-decision-making should be considered rather than the imposition of substituted decision-making or guardianship.¹ A number of examples of best practice in this area have been included in Appendix 1, Appendix 2 and Appendix 3. New thinking around the kinds of supports for persons with disabilities to exercise their legal capacity is needed. Supports in the area of decision-making do not have to be resource intensive, as demonstrated by the British Columbia system of Representation Agreements (see Appendix 2).

It is important for the Oireachtas Committee to consider the wider European context of disability law reform. The Council of Europe and the European Union are working towards developing a deeper understanding of Article 12 and the implications it might have for regional human rights instruments in Europe. It is clear that the European Court of Human Rights has been edging closer to the core of legal capacity and has already explicitly invoked the CRPD as an interpretive aid to the European Convention on Human Rights. Among other things, this means that Ireland's out-dated legal capacity laws are already vulnerable to scrutiny in Strasbourg. Indeed, if the functional model in the Scheme of the Bill is retained without modification then it is certainly a possibility that Ireland will be found in breach of the ECHR in time.

The Scheme of the Bill does make reference to the wishes of a person that may have been expressed previously and indeed presently. However, there is no provision to have these wishes enforced legally in future circumstances where they are deemed to lack capacity. The best interests principle emerged from law and policy focused on children and it is increasingly considered inappropriate in relation to adults. A central aspect of Article 12 is the focus on the "will and preferences" of the person as the determining factor in decisions about their life and this requires moving away from a "best interests" approach, which brings with it the significant risk of paternalism. This requires a significant change in thinking and needs to be embedded in the Bill.

The CRPD envisages a reduced role for the courts in the area of legal capacity and the law reform trend in light of the CRPD is away from guardianship and substitute decision-making. The Scheme of the Bill adopts a functional approach to legal capacity, referring to informal decision making and retaining a role for the courts. The Bill should reflect that the primary

¹ Facilitated or co-decision-making involves an appointed person taking a decision based on a detailed understanding of the person's life plan, wishes and intentions, and one which has the potential to enhance the capabilities of the person in question, rather than one which is taken in their "best interests".

role of the court under the Scheme of the Bill should not be to deprive persons of their capacity. Instead it should be to safeguard persons against deprivation of legal capacity (ensuring that appropriate supports are provided for decision-making), protect against the abuse of persons considered to have impaired decision-making by third parties and ensure that safeguards that apply to supports are in place.

There is an important synergy between Article 12 (equal recognition before the law) and Article 19 (living independently and being included in the community) of the CRPD. In order to live independently in the community a person needs to be recognised as having legal capacity. Conversely development of capacity requires experience of living independently and being included in the community and forming relationships. The dynamic life experiences through which all other citizens develop their capacity and skills are denied to disabled people on the basis that a third party considers that they lack capacity. The Bill needs to provide for the removal of barriers that prevent persons with disabilities from living independently and acquiring the capacity to make decisions in all areas of their life.

The Centre notes that antiquated Irish capacity law has been highlighted as the main impediment to ratification of the UN Convention. However, the issue of legal capacity goes far beyond the scope of this Bill. There are deficiencies with legal capacity law in the context of the mental health law as it relates to adults and minors and in the criminal law in respect of capacity to consent to sexual relations. These shortcomings need be addressed in order for the State to comply with its obligations set out in the CRPD. These issues do not necessarily need to be considered as part of this Bill. However, the issues need be considered by the legislature in the round in the area of legal capacity as it moves towards ratification of the Convention on the Rights of Persons with Disabilities.

Given our evolving understanding of Article 12 and legal capacity a review mechanism should be built into the Bill. This Bill should provide for a comprehensive review based on the evolving understanding of Article 12 and will benefit from the forthcoming Committee on the Rights of Persons with Disabilities General Comment (Interpretive Guidance) on Article 12. Such a review will ensure that Irish law benefits also from the comparative knowledge on effective supported decision-making practice and developments at the European level (Council of Europe and the European Union).

1. Introduction

The term “legal capacity” is used throughout this submission as it refers to an individuals’ right to make decisions – big and small – for him/her self and have those decisions respected. When a person’s capacity to make decisions is called into question (on the basis of mental illness, intellectual disability, acquired brain injury, or other reason) the state should make available a range of responses appropriate to the needs of the person. However, the reality is that States have failed to remove significant legal barriers that prevent people with disabilities and others from making their own decisions. Legal capacity is often routinely restricted or completely denied. The Council of Europe Commissioner for Human Rights recently stated:

“A basic principle of human rights is that the agreed norms apply to *every* human being, without distinction. However, the international human rights norms have been denied to persons with disabilities. It was this failure which prompted member States of the United Nations to adopt the Convention on the Rights of Persons with Disabilities, which emphasises that people with all types of disabilities are entitled to the full range of human rights on an equal basis with others. The aim is to promote their inclusion and full participation in society. When we deprive some individuals of their right to represent themselves we contradict these standards.”²

In the past, the fields of mental health law, non-discrimination, and legal capacity were considered separately, often without regard to the overlapping and intersecting nature of these issues. The Convention on the Rights of Persons with Disabilities recognises that considering these issues in separate silos was wrong and that the artificial lines drawn between these separate fields are increasingly blurred. Therefore, it is important to consider the impact the forthcoming legislation will have on general non-discrimination provisions and mental health law in particular.

2. Background to Legal Capacity in Ireland

It is well established and accepted that the Wards of Court system (the current and exclusive mechanism for managing the affairs of persons considered to be lacking decision-making capacity) is archaic, inappropriate and at odds with human rights instruments such as the UN Convention on the Rights of Persons with Disabilities (CRPD) and the European Convention on the Human Rights (ECHR). The many deficiencies of the Ward of Court System are well documented and the case for reform of Irish law has been universally accepted.

² Hammarberg “Persons with mental disabilities should be assisted but not deprived of their individual human rights” (Council of Europe, Viewpoint, 21/09/2009). Available at: http://www.coe.int/t/commissioner/viewpoints/090921_en.asp.

2.1 The Different Approaches to Legal Capacity

There are three main approaches to assessing legal capacity: the status approach, the outcome approach and the functional approach. The status approach is the approach embodied in the Wards of Court system. Under the Wards of Court system a decision of incapacity is applied to every decision and legal transaction taken by the ward.

- The **status approach** operates by assuming that a person lacks legal capacity as they are labelled, for example, as having a disability (in particular an intellectual disability). Having the status of disabled under Irish law is sufficient to strip a person of their legal capacity and provide for the imposition of substituted decision-making by a third party. Under the status approach you either have full legal capacity or you lack capacity entirely.
- The **outcome approach** is rooted in the belief that in circumstances where a person makes a bad decision or a number of bad decisions that person should lose the right to continue make decisions.³ This approach to capacity is now out-dated, as there is recognition that “we all have the right to make our own mistakes” and that it is unjust to set the decision-making bar higher for persons with disabilities.⁴
- The **functional approach** involves a consideration of legal capacity on an issue specific basis. A person might not be able to make decisions of a financial nature but might be considered to have capacity to consent to an intimate relationship. This approach rejects the status approach and outcome approach. The functional approach presumes that a person has capacity unless proven otherwise and involves the provision of supports in order for people to exercise decision-making.

The Scheme of the Bill seeks to reform the Wards of Court system in so far as it applies to adults and replaces it with a modern statutory framework governing decision-making on behalf of persons considered to lack capacity.⁵ The scope of the Scheme of the Bill aims to extend protection for persons with mental illness, persons with intellectual disabilities, and persons who have acquired brain injuries. It aims to provide more clarity in the law for carers who assume responsibility for persons lacking capacity. The previous

³ Quinn “Personhood & Legal Capacity Perspectives on the Paradigm Shift of Article 12 CRPD” (HPOD Conference, Harvard Law School, 20 February, 2010). Available at: http://www.nuigalway.ie/cdlp/staff/gerard_quinn.html.

⁴ *Ibid.*

⁵ The proposed scheme of the Bill is available at: http://www.justice.ie/en/JELR/Pages/Scheme_of_Mental_Capacity_Bill_2008.

Government stated in the Report of the EU Disability High Level Group on the UN Convention that this legislation "... will give effect to the Convention in so far as it applies to the legal capacity issues in Article 12 of the Convention."⁶

3. The Revolution of Article 12: Why it needs to Permeate the Bill

The reform of legal capacity laws is probably the most important issue facing the international legal community at the moment.⁷ Article 12 (equal recognition before the law) of the Convention deals with the capacity of persons to have rights and also with the exercise of those rights. Article 12 states:

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

⁶ "Second Disability High Level Group Report on Implementation of the UN Convention on the Rights of Persons with Disabilities" (June 2009) at page 96. Available at: <http://ec.europa.eu/social/main.jsp?catId=431&langId=en>.

⁷ See Quinn "Personhood & Legal Capacity Perspectives on the Paradigm Shift of Article 12 CRPD" (HPOD Conference, Harvard Law School, 20 February, 2010). Available at: http://www.nuigalway.ie/cdlp/staff/gerard_quinn.html.

The Convention on the Rights of Persons with Disabilities frames an alternative way of understanding legal capacity. It acknowledges that a person may require support to exercise their decision-making ability, and that the provision of such support does not make the person a non-person before the law. It recognises that we all need support to exercise our “will and preferences”⁸ in decision-making, and focuses more on the capacity of the decision than the capacity of the person. Supported decision-making can include a whole range of processes that enable the decisions to be driven by the persons own “will and preferences”, from facilitators, and circles of support, and personal networks. There are a growing number of models of best practice in the area of legal capacity that accord with Article 12. For example, see Appendix 2 for information on formal legal representation agreements in British Columbia (Canada).⁹ There are also examples in Sweden¹⁰, Germany¹¹.

As already stated Article 12 provides for a paradigm shift in thinking on legal capacity, reducing the situations in which guardianship or substituted decision-making is imposed and increasing the emphasis on supported decision-making. This is clearly the position that is being adopted by the UN Committee on the Rights of Persons with Disabilities.¹²

The UN Committee in its concluding observations on Tunisia’s Report on its implementation of the CRPD expressed concern

“... that no measures have been undertaken to replace substitute decision-making by supported decision-making in the exercise of legal capacity”.¹³

The Committee recommended that the State Party review the laws allowing for guardianship and trusteeship in addition to taking action to develop laws and policies to replace regimes of substitute decision-making by supported

⁸ See Article 12(4) above.

⁹ See in particular, NIDUS (a not for profit group set up to support personal networks) at: <http://www.nidus.ca/>.

¹⁰ See Appendix 3.

¹¹ See Appendix 4.

¹² The Committee on the Rights of Persons with Disabilities (CRPD) is the body of independent experts, which monitors implementation of the Convention by the States Parties.

¹³ “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>.

decision-making.¹⁴ The Committee also recommended that training be provided on this issue to all relevant public officials and other stakeholders.¹⁵

The United Nations Office of the High Commissioner for Human Rights stated in its guide to the Convention for parliamentarians that:

“[s]ince denying legal capacity to persons with disabilities has led to egregious violations of their rights, any law-reform process should address this issue as a matter of priority.”¹⁶

As such it recommends that parliaments should examine existing domestic law to determine if there are any formal limitations on the capacity and whether law complies with the Convention.¹⁷ It is also recommended that parliaments should consider whether in legal capacity is realised in practice, despite formal guarantees.¹⁸ The guide specifically states that State Parties to the Convention are required to take appropriate measures to ensure that persons with disabilities who need assistance to exercise their capacity receive that assistance.¹⁹ It is clear from the examination of the Wards of Court system that the safeguards fall well short of the standards set out in Article 12 of the Convention.²⁰ Furthermore, the Scheme of the Bill published in 2008 does not specify the kinds of assistance the state will provide to ensure that people with disabilities can exercise their legal capacity, before resorting to guardianship or substitute decision-making. This would seem to go against the explicit guidance of the Office of the High Commissioner for Human Rights stated above.

The Scheme of the Bill is based primarily on the recommendations of the Law Reform Commission’s Consultation Papers and final Report on Vulnerable

¹⁴ *Ibid.*

¹⁵ *Ibid.*

¹⁶ “From Exclusion to Equality Realizing the rights of persons with disabilities: Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol” (Geneva, 2007, United Nations, Office of the High Commissioner for Human Rights) at page 68. Available at: <http://www.un.org/disabilities/documents/toolaction/ipuhb.pdf>.

¹⁷ *Ibid.*

¹⁸ *Ibid.*

¹⁹ *Ibid.*

²⁰ The Wards of Court system leaves no space to reflect the rights wills and preferences of persons subject to a wardship application. The normal court practice of not meeting with the person subject of a wardship application is not sufficient in safeguarding against conflicts of interests and the exertion of undue influence. In addition, the archaic and complex nature of the wardship system means that restrictions on capacity are not proportional or tailored to personal circumstance. The Wards of Court System also fails to comply with the requirement in applying restrictions on capacity for the shortest time possible and subject to regular review.

Adults and the Law.²¹ The Law Reform Commission's work on legal capacity – which is thoroughly commendable – concluded just as the UN Convention on the Rights of Persons with Disabilities was finalised. It is more than fair to say that Article 12 has been the spur of much deep reflection since then around the world on the future of guardianship laws. While the Scheme of the Bill has positive aspects it needs to be reconfigured to embody the emerging philosophy of Article 12.

In her seminal article, Amita Dhanda presents two potential choices, which legislators can make in relation to legal capacity the first "recognises that all persons have legal capacity and the other contends that legal capacity is not a universal human attribute."²² Dhanda argues that the recognition of universal capacity acknowledges that given the opportunity, all human beings can grow and develop.²³ Therefore, she contends the opportunity for growth and development has to be afforded to all persons, the law and policy has to be geared to create diverse options.²⁴ Dhanda highlights the Swedish Personal Ombudsman²⁵ system as well as the use of Advance Care Directives as support mechanisms, which enable a universal construction of legal capacity, in accordance with the principles in Article 12 of the UN Convention.

3.1 The Paradigm Shift in Action

To illustrate the paradigm shift in Article 12 consider the legal capacity of the following:

1. Persons with a disability or an older person who can express their "will and preferences" have full legal capacity and the state should not interfere in the exercise of their legal capacity.
2. Persons with a disability or older person who with a range of supports can exercise their legal capacity should not be stripped of their legal capacity and the State are obligated to provide the necessary supports.
3. Persons who cannot express their "will and preferences" (following an accident/illness or have communication difficulties following institutionalisation) may require substitute decision-making, however,

²¹ "Consultation Paper on Law and the Elderly" Law Reform Commission (23) 2003; "Consultation Paper on Vulnerable Adults and the Law: Capacity" Law Reform Commission (37) 2005; "Report Vulnerable Adults and the Law" Law Reform Commission (83) 2006.

²² Dhanda "Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?" (*Syracuse Journal of International Law and Commerce*: 34, 429, (2007), 457-458).

²³ *Ibid.*

²⁴ *Ibid.*

²⁵ See Appendix 3.

the State is required to ensure that decisions of others are policed and have regard to the “will and preferences” of that person. Article 12 also requires contains a parallel commitment on the part of the State to restore or spark the capacity to make decisions through whatever appropriate means.

3.2 The Core of the Paradigm Shift

There is an evolving conversation around the concept of legal capacity.²⁶ It is important to recognise that legal capacity makes personal choice and freedom possible. Issues such as the ability to enter into contracts and manage financial affairs are important expressions of freedom, which require recognition of legal capacity. This Scheme of the Bill has the potential to enable people with disabilities, who have historically been denied these freedoms, to take control of their lives and participate as members of the community. Such a step will ensure that negative perceptions of people with disabilities and an assumption of lack of ability is finally challenged.²⁷ While human rights requires the state not to intrude into our personal lives it correspondingly places an obligation on the state to prevent third parties interfering with the enjoyment of our rights. The CRPD requires the state to protect the rights of persons with disabilities.²⁸

We have seen abuses by the state in the past in how it went about achieving protection. The Convention requires the correct balance to be struck. The Convention requires that we completely reconsider the way in which the State deals with the issue of legal capacity. The CRPD through Article 12 clearly rejects the status and outcome approaches to legal capacity and insists that the functional approach must focus on supports to enable persons to exercise legal capacity. In the past the “functional approach” was used to determine exactly where a deficiency lay and to put in place a very narrowly tailored regime of guardianship to enable a third party make decisions with certain procedural and substantive safeguards. Instead, a functional approach keeping with the spirit of Article 12 should determine what supports a person might need in order to enable them to exercise their legal capacity. The Heads of Bill did make a genuine effort to build on the functional approach. The Oireachtas should reflect on whether the functional approach in the Heads of Bill might be turned away from assessing incapacity towards assessing what kinds of supports (informal and otherwise) that might be appropriate to enable persons make decisions for themselves.

²⁶ See Quinn “Personhood & Legal Capacity Perspectives on the Paradigm Shift of Article 12 CRPD” (HPOD Conference, Harvard Law School, 20 February, 2010). Available at: http://www.nuigalway.ie/cdlp/staff/gerard_quinn.html.

²⁷ *Ibid.*

²⁸ See for example: Article 15 - Freedom from torture or cruel, inhuman or degrading treatment or punishment and Article 16 - Freedom from exploitation, violence and abuse.

4. What the World Thinks

4.1 The Organisation of American States and Article 12

In addition to the UN Convention on the Rights of Persons with Disabilities, there are also some regional human rights instruments, which provide guidance on the direction of legal capacity law in the 21st century. For example, the Committee for the Elimination of All Forms of Discrimination Against Persons with Disabilities (in the Organisation of American States) issued a general observation in May 2011, which states:

“The rules regarding capacity or incapacity to exercise rights under particular circumstances should not be confused with the quest for a different way of representing persons with disabilities, one that supports their autonomy, recognizes them fully as persons before the law with legal capacity, and proposes support and safeguards only when they are necessary. That means starting from what people are able to do, what they can do for themselves, and only then determining the circumstances under which they do need support, along with safeguards.”²⁹

The Committee recommended re-interpreting Article I.2(b) of the Inter-American Convention for the Elimination of All Forms of Discrimination Against Persons with Disabilities in light of Article 12 of the UN Convention, to recognise that a declaration of legal incapacity or incompetence could constitute discrimination on the basis of disability. The Committee also urged its State Parties:

“to adopt measures, in keeping with Article 12 of the United Nations Convention, to guarantee recognition of universal legal capacity, including that of all persons with disabilities, regardless of the type or extent of disability, and, consequently, to initiate without delay a process for replacing the practice of declaring legal incompetence, guardianship, or any other form of representation that impairs the legal capacity of persons with disabilities, with a practice based on decision-making with support.”

The foregoing entails taking steps to:

1. Train the general public, and justice system operators in particular, regarding the new paradigm in effect with respect to the legal capacity

²⁹ 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 fine* 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.

of all people with disabilities, including those with severe impairments, through recourse to decision-making support systems.

2. Adopt urgent measures of a regulatory nature to ensure that the judicial system disallows the approval of new declarations of legal incompetence and to foster the gradual development of decision-making support systems, as well as the regulation and implementation of institutions and mechanisms to safeguard against abuse.³⁰

3. Facilitate the review of cases in which persons with disability have been declared legally incompetent, with a view to aligning them with the new paradigm, with particular emphasis on those in which there are queries as to the existence of abuse or manipulation of interest.

4.2 Article 12 CRPD and the European Convention on Human Rights

The European Convention on Human Rights contains a number of fundamental rights and freedoms that must be protected irrespective of a person's legal capacity. Specifically, Article 5 (right to liberty and security) Article 6 (right to a fair trial), Article 8 (right to respect for private and family life), Article 13 (right to an effective remedy) and Article 14 (prohibition of discrimination) are frequently raised in cases that involve issues of capacity appearing before the European Court of Human Rights (ECtHR). In *Winterwerp v Netherlands* the ECtHR stated: "[w]hatever the justification for depriving a person of unsound mind of the capacity to administer his property... mental illness may render legitimate certain limitations upon the exercise of the "right to a court", it cannot warrant the total absence of that right as embodied in Article 6".³¹ The ECtHR has found violations of Article 6 in a number of cases where issues of legal capacity were raised, for example in circumstance where individuals were refused adequate access to a court or experienced unreasonable delays in having their applications heard.³²

Importantly the European Court of Human Rights through its case law has highlighted the trend away from the Status approach. In *Shtukaturov v Russia* it stated "...the existence of a mental disorder, even a serious one cannot be the sole reason to justify full incapacitation".³³ This is an important statement by the ECtHR acknowledging that there was a lack of proportionality in the legal response to the person's capacity in that case. Moreover, the *Shtukaturov* decision is important in that ECtHR acknowledges that the deprivation of legal capacity constitutes a serious intrusion into a

³⁰ *Ibid*, at page 10.

³¹ *Winterwerp v Netherlands* [6301/73 ECHR 4 24 October 1979] at paragraph 75.

³² See *H.F. v Slovakia* [ECHR, 54797/00, 8 November 2005].

³³ *Shtukaturov v Russia* [EHRR, 44009/05, 27 March 2008] at paragraph 94.

persons right to respect for their private and family life under Article 8 and domestic legislation has to provide “a tailored-made response” in this area. This decision brings the jurisprudence of the European Court of Human Rights into line with the vision of capacity embodied in the UN Convention on the Rights of Persons with Disabilities. This view is shared with the Council of Europe Commissioner for Human Rights who stated:

“This judgment must be interpreted to promote an approach in line with the UN Convention. Any restrictions of the rights of the individual must be tailor-made to the individual’s needs, be genuinely justified and be the result of rights-based procedures and combined with effective safeguards.”³⁴

So it is clear that the European Court of Human Rights has been edging closer to the core of legal capacity and has already explicitly invoked the CRPD as an interpretive aid to the European Convention on Human Rights. Among other things, this means that Ireland’s out-dated legal capacity laws are already vulnerable to scrutiny in Strasbourg. Indeed, if the functional model in the Scheme of the Bill is retained without modification then it is certainly a possibility that Ireland will be found in breach of the ECHR in time.

4.3 The Wider European Context

It is important for the Oireachtas Committee to consider the wider European context of disability law reform. The Council of Europe and the European Union are working towards developing a deeper understanding of Article 12 and the implications it might have for regional human rights instruments in Europe. The Council of Europe Commissioner for Human Rights has highlighted the importance of ensuring legal capacity of people with disabilities is protected, as discussed above.³⁵ Further position papers from his Office on Article 12 are expected.

The European Commission has developed the “The European Disability Strategy 2010-2020” with the aim of empowering people with disabilities so that they can enjoy their rights and participate fully in society. The strategy identifies actions at EU level to supplement national measures and identifies the support needed for funding, research, awareness-raising, statistics and data collection. Importantly the UN Convention on the Rights of Persons with Disabilities (and the related policy documents from EU institutions and the Council of Europe) informed the strategy’s objectives.³⁶ In addition, the

³⁴ Hammarberg “Persons with mental disabilities should be assisted but not deprived of their individual human rights” (Council of Europe, Viewpoint, 21/09/2009). Available at: http://www.coe.int/t/commissioner/viewpoints/090921_en.asp.

³⁵ *Ibid.*

³⁶ The objectives were also informed by the results of the EU Disability Action Plan 2003-2010, and a consultation of the Member States, stakeholders and the general public

European Union ratified the UN Convention on the Rights of Persons with Disabilities on 23 December 2010. This was the first time that the EU became a party to an international human rights treaty. The EU ratification is significant in obliging all of the EU institutions including the Court of Justice, Commission, Council and Parliament to uphold the rights of persons with disabilities. EU Ratification is also important in raising awareness of human rights violations in respect of persons with disabilities and "... mainstreaming disability rights across all areas of EU competency and taking concrete steps towards ensuring that the rights of persons with disabilities are respected, protected and fulfilled".³⁷ In addition, EU member states have shared best practice on implementing the UN Convention, including the introduction of supported decision-making mechanisms in light of Article 12, at meetings of the high level group on disability.³⁸

New modern legal capacity legislation is an important step towards Ireland's ratification of the UN Convention on the Rights of Persons with Disabilities. However, it is also important to acknowledge the significance of Ireland's position as a signatory to the Convention – which implies a willingness to uphold the principles of the Convention, and not to take steps, which would be contrary to the spirit and purpose of the Convention. Therefore, it is crucial that the forthcoming legislation be drafted with the paradigm shift of the Convention in mind.

4.4 Review of the New Capacity Legislation

Given our evolving understanding of Article 12 and legal capacity a review mechanism should be built into the Bill. This Bill should provide for a comprehensive review based on the evolving understanding of Article 12 and will benefit from the forthcoming Committee on the Rights of Persons with Disabilities General Comment on Article 12. Such a review will ensure that Irish law benefits also from the comparative knowledge on effective supported decision-making practice and developments at the European level (Council of Europe and the European Union).

³⁷ See <http://mdac.info/content/mdac-welcomes-european-union-ratification-un-convention-rights-persons-disabilities>.

³⁸ See for example, "Second Disability High Level Group Report on Implementation of the UN Convention on the Rights of Persons with Disabilities" (June 2009). Available at: <http://ec.europa.eu/social/main.jsp?catId=431&langId=en>.

5. Moving Away from Deficits: The Need to Explicitly Embed in the Bill a Right to Supports to Enable Persons Exercise Legal Capacity

Article 12 of the Convention requires a move away from thinking of people in terms of deficits. This does not mean that deficits do not exist rather that the issue should be framed positively in terms of supports, which can be provided. This means that the Scheme of the Bill should contain a menu of less restrictive alternatives to guardianship, and that before considering whether guardianship is necessary (if at all), all possible alternatives to support the person's capacity should be explored.³⁹

One of the key issues with the Scheme of the Bill is that while it makes reference to supported decision-making in the guiding principles there is no follow through in making supported decision-making a reality. The way in which supported decision-making is dealt in the Scheme of the Bill does not accord with the notion of supported decision-making in Article 12 of the CRPD. Article 12 requires the follow through and places a positive obligation on the State Party to the Convention in this regard. The provisions relating to informal decision-making as provided for in the Scheme of the Bill lack detail. The informal decision-making process needs to be shored up in order to prevent this being a *de facto* substitute decision-making process that undermines the human rights protections created elsewhere in the Scheme of the Bill. Article 12(4) of the CRPD requires that these shortcomings be effectively addressed.

The Centre for Disability Law and Policy welcomes the need to recognise the validity of informal or community support mechanisms which recognise that we all have "shared personhood" and make decisions in consultation with others. The Scheme of the Bill already refers to recognising informal decision-making; however, these provisions need to be animated by the philosophy of Article 12, to enable people to reach their full potential in terms of legal capacity, to ensure that supported decision-making provisions are not exploited to enable substituted decision-making "through the back door" without the appropriate safeguards.

Article 12 of the Convention indicates that a continuum of support measures is necessary to enable people to exercise their legal capacity. In circumstances of last resort, where the person in question does not have any support network to assist with decision-making, the option of facilitated or co-decision-making should be an option rather than the imposition of

³⁹ See Appendix 1,2 and 3 for examples of best practice.

substituted decision-making or guardianship.⁴⁰ The functional approach to assessing capacity set out in the Scheme of the Bill could have an important role to play, in ensuring that individuals who require support to exercise their legal capacity, receive the appropriate assistance. As already discussed in detail Article 12 requires new thinking around the kinds of supports needed for persons with disabilities to exercise their legal capacity.⁴¹ Supports in the area of decision-making do not have to be resource intensive, as demonstrated by the British Columbia system of representation agreements.⁴²

5.1 The Need to Radically Re-Frame “Best Interests” to pivot on the “Will and Preferences” of the Person

The Scheme of the Bill does make reference to the wishes of a person that may have been expressed previously and indeed presently. However, there is no provision to have these wishes enforced legally in future circumstances where they are deemed to lack capacity. The best interests principle emerged from law and policy focused on children and it is increasingly considered inappropriate in relation to adults.⁴³ As stated a central aspect of Article 12 is the focus on the “will and preferences” of the person as the determining factor in decisions about their life and this requires moving away from a “best interests” approach, which brings with it the significant risk of paternalism. This requires a significant change in thinking and needs to be embedded in the Bill.

5.2 Safeguarding Legal Capacity and Supported Decision-Making

The availability of a range of alternative community supports outlined above, such as representation agreements for people with disabilities, will significantly limit the need for court involvement, which is the most resource intensive aspect of the current Scheme of the Bill. Instead, this submission proposes that the role of the court/tribunal under the Scheme of the Bill should be to safeguard against the deprivation of legal capacity and abuse of persons where they receive supports that assist them in exercising their legal capacity. In addition, the over-use of a court-based model in the Scheme of

⁴⁰ Facilitated or co-decision-making involves an appointed person taking a decision based on a detailed understanding of the person’s life plan, wishes and intentions, and one which has the potential to enhance the capabilities of the person in question, rather than one which is taken in their “best interests”. See Appendixes 1, 2, and 3 for examples of good practice.

⁴¹ See Appendixes 1, 2, and 3 for examples of good practice.

⁴² See Appendix 2 for a discussion of Representation Agreements.

⁴³ For a discussion in the origin of the best interests principle see “The Best Interests of the Child: Towards a Synthesis of Children’s Rights and Cultural Values” [Florence: UNICEF, Innocenti Studies, 1996]. Available at: http://www.unicef-irc.org/publications/pdf/is_best_interest_low_eng.pdf.

the Bill could lead to the retention of a medical model approach in assessing capacity or defining “best interests” and the danger of an over reliance on medical opinion.

The new capacity legislation seeks to strike the correct balance between autonomy and protection, in order to uphold the principles of the UN Convention on the Rights of Persons with Disabilities. The Centre considers that the Scheme of the Bill published in 2008 fails to strike the appropriate balance in this respect. It is important to understand that a person is entitled to the full spectrum of rights regardless of whether they are stripped of their right to capacity. There is a common law presumption of capacity, and the Centre welcomes the express provision in the Scheme of the Bill of this presumption of capacity. This express provision is important as it protects persons against paternalistic and inappropriate assumptions about capacity and the type of life that they should lead. The Scheme adopts a time-specific and issue-specific functional approach to capacity. The Centre notes that any reform of the law in this area is to be welcomed as our law is entrenched in the status and outcome approach to assessing legal capacity. However, the approach detailed in the Scheme of the Bill places a premium on assessing whether a person was able to comprehend the nature and consequences of a decision in the context of the available choices when the decision is made.

There is provision for the regular review of decisions on capacity under Head 14. The court is required to review decisions at regular intervals but not periods longer than 36 months. This does not comply with the principles set out in the Schedule. In particular, it does not comply with the functional approach to capacity, which is time and issue specific. Under Head 41 on transitional provisions existing wards can make an application for a review of a declaration that a person lacks capacity to make decisions. Head 41 (1) states:

“... it shall be open to a person to whom this Act applies who has been taken into wardship under the jurisdiction of the High Court or Circuit Court existing at the time immediately before this Act comes into force, to make an application to the court for a review of his or her position, and such application shall be treated as if it were an application under Head 14 for a review of a declaration that the person lacks capacity to make a decision or decisions.”

Existing wards will not be able to automatically benefit from the legislation when it eventually comes into force. The Bill should make the review mandatory and should specify a time period in which the review has to take place. If the proposed system under the Schedule remains unchanged then existing wards will not be benefiting from legislation that aims to comply with human rights standards and Irish law will continue to be at odds with the requirements of the CRPD and ECHR.

5.3 The Role of Court/Tribunal/Board

The CRPD envisages a reduced role for the courts in the area of legal capacity and the law reform trend in light of the CRPD is away from guardianship and substitute decision-making. As discussed above Article 12 requires a range of supports to ensure that a person can exercise their legal capacity and the State is obliged to provide these supports. The Scheme of the Bill adopts a functional approach to legal capacity, referring to informal decision making and retaining a role for the courts. The Bill should reflect that the primary role of the court under the Scheme of the Bill should not be to deprive persons of their capacity. Instead it should be to safeguard persons against deprivation of legal capacity (ensuring that appropriate supports are provided for decision-making) and protect against abuse of persons considered to have impaired decision-making by third parties.

The Oireachtas Committee should be aware that there is a persistent danger that courts may defer to a medical model approach in deciding on capacity and be overly reliant on medical opinion when a person's capacity is called into question. The CRPD has embedded the social model of disability in its text as a counter to the medical model that was dominant for so long and which stripped persons with disabilities of their identity as a rights holder. The Bill needs to ensure that the social model is embedded in law and that the dominance of the medical model is ended.

6. Legal Capacity: The Link between Independent Living and Inclusion in the Community

This section of the submission considers the synergy between Article 12 (equal recognition before the law) and Article 19 (living independently and being included in the community) of the CRPD. The core message here is that in order to live independently in the community a person needs to be recognised as having legal capacity. Conversely development of capacity requires experience of living independently and being included in the community and forming relationships. The dynamic life experiences through which all other citizens develop their capacity and skills are denied to disabled people on the basis that a third party considers that they lack capacity. The Bill needs to provide for the removal of barriers that prevent persons with disabilities from living independently and acquiring the capacity to make decisions in all areas of their life.

As discussed extensively above Article 12(2) refers to the right of persons with disabilities to enjoy legal capacity on an equal basis with others "in all

aspects of life". This includes the right to make decisions about financial and legal matters, health care decisions, and personal decisions such as choices about where and with whom to live – a choice that most of us take for granted. Since this is such a crucial issue for persons with disabilities, it is impossible to consider the concept of legal capacity without reflecting on its impact on the promise of independent living for people with disabilities and the process of deinstitutionalisation – a key commitment of the current Minister for Disability, Equality, Mental Health and Older People.

As defined in Article 19 of the CRPD the right to independent living right asserts "... the equal right of all persons with disabilities to live in the community, with choices equal to others". Article 19 includes three specific commitments on the part of state parties:

- That persons with disabilities will have the opportunity to choose where and with whom they live, and not be obliged to live in any particular living arrangement
- People will have access to the residential and community supports they need to support living and inclusion in community
- Generic community services and facilities will be available on an equal basis to disabled people and they will be responsive to their needs

In the light of the move towards deinstitutionalisation both in Ireland and internationally these commitments have wide-ranging implications for Irish law and policy in relation to legal capacity and living independently. As it stands aspects of Irish law and policy hinders people's ability to make choices about their place of residence and their access to community. In particular, many people who are deemed to lack legal capacity encounter difficulty in accessing finance to purchase a home, signing tenancy agreements and opening bank accounts. One example of barriers faced by persons with disabilities is in the area of social welfare payments to disabled people. Having control over one's income, with support if necessary, is a key ingredient in enabling people to have autonomy in their choices. Yet many people who are deemed to lack the capacity to manage their money have their social welfare payments paid to an Agent (usually a family member or staff member of a care provider) appointed by the Department of Social Protection.⁴⁴ This is an "all or nothing" provision of indefinite duration that gives complete control of this key aspect of the person's life to a third party regardless of the person's level of capacity.

On an informal level assumptions about people's capacity means that they are often denied the opportunity to form independent relationships in the community through ordinary participation, usually rationalised as protecting

⁴⁴ Department of Social Protection accessed on 17/8/2011 www.welfare.ie/EN/Topics/payments/Pages/AppointmentofAgents.aspx

the person. The area of informal decision-making (Head 16) in the proposed legislation leaves very wide scope for others to make decisions based on what they consider to be the person's "best interests" on the basis of their personal assessment of the person's capacity. This includes personal care decisions, which can quite easily be interpreted as encompassing all manner of decisions about residential circumstances, personal relationships and community participation. It is imperative that the new legislation obliges everyone surrounding the person to start from an assumption of capacity in the area of informal decision-making and put in place structures to support the person in exercising and developing their legal capacity.

Exercising the right to Independent Living is inexorably bound up with the issue of capacity. In order to develop capacity a person must have experience of exercising capacity in the different ways and experience can only be gained by actually participating in community life. Legal capacity is a continuum that connects with everything needed to enable the person to flourish – a right to make decisions and have them respected, a place of one's own, a life in the community connected to friends, acquaintances and social capital, whether in public or private settings.⁴⁵ Few of us as young adults have the capacity or skills to manage a household budget for a family while working and raising children. Yet most people develop the capacity and the skills to do just this, and we do this gradually over time through experience, making mistakes and learning from these mistakes. The key thing is that if one does not have a disability – particularly a cognitive impairment or a mental illness – one's right to gain experience and to make mistakes is taken for granted, and it from this that we are enabled to develop our decision-making skills and our independent living skills. None of us is born with in-built independent living skills or decision-making skills; we acquire these as we progress through life. Based on an assumption of a lack of legal capacity people with disability have been denied the vital experiences necessary to develop the skills that enable the development of their capacity. It is difficult to envisage how the right to independent living can be realised without positive assumption about people's capacity and having structures in place which affirm and support people's capacity in all manner of personal and community settings.

Irish law does not include a specific commitment to Independent Living; however, the *European Convention on Human Rights Act 2003* contains elements that are directly related to independent living. Under the Act the Irish government is obliged to apply all statutory provisions and to perform its functions in a manner compatible with the Convention. The government is also obliged to take account of the rulings of the European Court of Human

⁴⁵ Quinn, G "Rethinking Personhood: New Directions in Legal Capacity Law & Policy". [Paper presented at University of British Columbia, Canada, 29 April 2011). Available at: www.nuigalway.ie/cdlp/documents/events/Vancouver%20GQfinal.pdf.

Rights (ECtHR) in the development or amendment of legislation. In relation to Independent Living the most relevant provision of the ECHR Act is Article 8 – Right to Respect for Private and Family Life. The ECtHR has drawn broad definitional lines around the concept of a “private life” under Article 8; the key elements of which are:

1. Private life includes the right to relationships with others.⁴⁶
2. An individual’s ‘private life’ is not restricted solely to activities within the home or private sphere.⁴⁷
3. Private life encompasses not only respect for an individual’s physical welfare but also for psychological welfare and for unhindered personal development. As stated in *Botta v Italy* “... the guarantee afforded by Article 8 of the Convention is primarily intended to ensure the development, without outside interference, of the personality of each individual in his relations with other human beings.”⁴⁸

Clearly people with disabilities also have these rights in Irish law and the State is obliged to protect these rights and refrain from interfering with them. If people are to be afforded the opportunity for the development of their personality in their relations with others without outside interference, then they must not be hindered in their participation in community and decision-making by assumptions about their incapacity. The overall thrust of Irish government policy in relation to people with disability is to maximise people’s level of independence. Towards 2016 – the national partnership agreement – has as its vision that people with disabilities will have “... the opportunity to live a full life with their families and as part of their local community, free from discrimination ... [and] ... Every person with a disability would be supported to enable them, as far as possible, to lead full and independent lives, to participate in work and in society and to maximise their potential.”⁴⁹ The review of disability services undertaken by the Office for Disability and Mental Health in 2010 adopts as a key goal for disability services the full inclusion and self-determination for people with disabilities. These goals reflect the object and purpose of Article 19 of the CRPD. In June 2011 the report of the HSE working group on congregated settings has recommended a model of service for people with intellectual disability currently accommodated in large group settings, to enable them live in

⁴⁶ *Niemietz v Germany* [(13710/88) European Court of Human Rights, 16 December 1992] at paragraph 29.

⁴⁷ *Ibid.*

⁴⁸ *Botta v Italy* [(153/1996/772/973) European Court of Human Rights 24 February 1998] at paragraph 32.

⁴⁹ “Towards 2016: Ten-Year Framework Social Partnership Agreement 2006 – 2015” [Government Publications, Dublin 2006] at page 66.

communities with full access to mainstream services and supports needed to enable people to live independently.⁵⁰ The Department of Health and the HSE has committed to implementing the recommendations of this report.

Overall then it is clear that Irish disability policy is moving in the direction of enhancing people's independence and supporting their participation in community, aims which are in congruence with Article 19 of the CRPD. There are many structural barriers that need to be addressed to enable this aim to be realised. The law on legal capacity is one of the key areas. It is difficult to see how the ideals of independent living and community inclusion can be achieved without legislation, which requires that positive assumptions be made about people's capacity and the development of structures that positively support people to exercise their capacity. Assumptions about incapacity, both formally and informally, have been used to isolate people from communities and restrict their autonomous decision-making, thus denying them the opportunity to develop their skills and capacities. In other words the vital life experiences through which all other citizens develop their capacity and skills are denied to disabled people on the basis that a third party considers that they lack capacity.

7. Legal Capacity outside the Scope of the Bill

Under Head 20 of the Scheme of the Bill it was stated that nothing in this Act affects the law concerning the capacity and consent required of a person to:

- a. capacity and consent to marriage or civil partnership,
- b. consent to a judicial separation, a divorce or a dissolution of a civil partnership,
- c. consent to a child being placed for adoption
- d. consent to the making of an adoption order
- e. consent to have sexual relations
- f. voting at an election or at a referendum
- g. acting as a member of a jury.

The Centre notes that antiquated Irish capacity law has been highlighted as the main impediment to ratification of the UN Convention. However, the issue of legal capacity goes far beyond the scope of this Bill. There are deficiencies with legal capacity law in the context of the mental health law as it relates to adults and minors and in the criminal law in respect of capacity to consent to sexual relations. These shortcomings need be addressed in order for the State to comply with its obligations set out in the CRPD. These issues do not necessarily need to be considered as part of this Bill. However,

⁵⁰ "Time to Move on From Congregated Settings: A Strategy for Community Inclusion" [Dublin: Health Service Executive, June 2011].

the issues need be considered by the legislature in the area of legal capacity as it moves towards ratification of the Convention on the Rights of Persons with Disabilities.

7.1 Legal Capacity and Consent to Mental Health Treatment

The Oireachtas Committee should note that the UN Special Rapporteur on Torture Manfred Nowak in 2008 stated that Article 12 of the CRPD recognises persons with disabilities equal right to enjoy legal capacity in all areas of life, including deciding where to live and whether to accept medical treatment.⁵¹ Importantly he also indicated that deprivation of liberty in conjunction with involuntary interventions might amount to torture depending on the circumstances.⁵²

The Scheme of the Bill fails to set out how it impacts the *Mental Health Act 2001*. The positive aspects of the Scheme of the Bill should have equal application to everyone including persons detained involuntarily under the *Mental Health Act 2001*. The definition of what is a voluntary patient needs to be set out very clearly in the new legislation. It is noteworthy that the UN Committee Against Torture recently expressed concern at the fact that the definition of a voluntary patient is not sufficiently drawn to protect the right to liberty of a person who might be admitted to an approved mental health centre.⁵³ The Committee was also critical of the lack of clarity on the reclassification of mentally disabled persons from voluntary to involuntary. The Committee recommended that the Ireland review the *Mental Health Act 2001* in order to ensure that it complies with international standards. In that regard the Committee Against Torture recommended that the Ireland report on the specific measures taken to bring its legislation into line with internationally accepted standards in its second periodic report.⁵⁴

There is informal decision-making provided for in the Scheme of the Bill. However, there are no safeguards put in place and the lack of safeguards in circumstances may lead to infringement of the rights of persons deemed to lack capacity. There are a number of human rights issues that should be considered. Amongst the issues that require consideration is the issue of consent to treatment under the *Mental Health Act 2001*. From a cursory

⁵¹ "Promotion and Protection of Human Rights: Implementation of Human Rights Instruments" [United Nations General Assembly, 28 July 2008] at page 10. Available at: http://apt.ch/region/unlegal/rapporteur_disabilities.pdf.

⁵² *Ibid*, at page 16.

⁵³ "Consideration of Reports Submitted by States Parties Under Article 19 of the Convention: Concluding Observations of the Committee Against Torture" [Geneva: Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, 17 June 2011] at page 8. Available at: <http://www2.ohchr.org/english/bodies/cat/docs/co/CAT.C.IRL.CO.1.pdf>.

⁵⁴ *Ibid*.

reading of the Act it seems that the right of a competent person to refuse treatment is expressly provided for in sections 56 and 57. However, sections 59 and 60 provide for the administration of Electro Convulsive Therapy (ECT) and medication to persons unable or unwilling to consent.⁵⁵ There are some procedural safeguards provided for in that the Act that require the opinion of a second psychiatrist in order for the treatment to be administered without consent. However, a major shortcoming in the legislation is that there is no requirement that the second opinion be independent. As the law currently stands a person who does not want treatment can be treated even though their refusal is a competent one. Mental Health Tribunals as provided for under the 2001 Act do not have any power to enquire into decisions made in respect of treating persons involuntarily detained and there is no provision in the Act for a person to seek a review of treatment decisions.

It is important to note that the *Mental Health Act 2001* does not provide for "advance directives" that would allow a person with a mental health problem to set out in advance how they want to be treated in circumstances where they become involuntarily detained. The Law Reform Commission in their recent work on advance care directives did not make recommendations on the use of proxy decision-making in the mental health field and suggested that a further review would be preferential. However, there is an argument for not distinguishing advance directives for mental health care and advance directives for other types of health care as it discriminatory and results in the affording of fewer rights to persons who experience mental health problems.⁵⁶

With the exception of the right to legal representation at Tribunal hearings the 2001 Act does not provide a right to advocacy services. It is important to note also that capacity is not defined in the *Mental Health Act 2001* and that this should be addressed in order to ensure that the rights of persons involuntarily detained receive the fullest protection possible.⁵⁷ The Act falls silent on how the capacity of a person is decided upon. Current practice means that it is up to the consultant psychiatrist to make decisions for a person deemed to lack capacity, through the application of a best interests approach with regard to treatment. The Act does not embody a functional

⁵⁵ The *Mental Health (Involuntary Procedures) Bill 2008* seeks to amend the provisions of the Act relating to electro-convulsive therapy (ECT).

⁵⁶ "Power is Planning: Self-Determination Through Psychiatric Advance Directives" [Washington: Bazelon Center For Mental Health Law]. Available at: <http://www.bazelon.org/LinkClick.aspx?fileticket=kdy5IA1a7To%3D&tabid=104>.

⁵⁷ There is a presumption of capacity in the *Mental Health Act 2001*. However, it is not sufficiently stated in the Act and there is a need to address this. This is important from a human rights perspective as it reinforces that treatment cannot be done without the consent of the person receiving the treatment. This is particularly important for persons detained involuntarily.

approach to capacity and this needs to be addressed in light of Article 12 of the CRPD. Article 12 of the CRPD does require that the issue of supported decision-making, which is not provided for in the Act needs to be addressed. Importantly, section 4(3) of the Act expressly refers to the right to dignity, bodily integrity, privacy and autonomy. Unfortunately the “best interests” principle is afforded greater prominence in the Act and this is not consistent with the concept of capacity as articulated in Article 12 of the CRPD.⁵⁸

The definition of a voluntary patient in the 2001 Act needs to be amended and should only include persons who have the capacity to decide whether to consent to admission to a psychiatric setting.⁵⁹ In circumstances where a person is considered to lack capacity to make decision about their medical treatment and where it is considered that they require psychiatric treatment then a better practice would be to admit such persons to a designated centre under the 2001 Act by way of a process similar to the admission of involuntary patients under the 2001 Act. That procedure would better comply with Article 5 of the ECHR.

7.2 Legal Capacity and Minors

The Law Reform Commission last month published its “Report on Children and the Law: Medical Treatment”.⁶⁰ In its Report the Commission recommended that 16 and 17 year olds should be presumed to have full capacity to consent to and refuse health care and medical treatment including in the area of mental health. The Commission recommended that this should be done on the basis of a functional test that the minor understands the health care decision and the consequences of the decision.

The Centre endorses the recommendation of the Law Reform Commission and considers that it is wholly appropriate that the capacity of minors with a disability aged 16 and 17 have capacity to make health care decisions and that the state is obliged to provide supports where necessary to enable “minors” exercise their legal capacity. However, the Centre is aware of evolving thinking on the issue of the capacity of minors within the UN Committee on the Rights of the Child (CRC) and suggests that more research might be needed to ensure that the revolution of Article 12 might be mapped over onto the CRC.

⁵⁸ There is no provision for community treatment orders under the *Mental Health Act 2001*. It has been noted that a number of mental health service providers are utilising section 26 of the Act as a type of community treatment order. This also needs to be considered from a rights perspective.

⁵⁹ This is the position that the Human Rights Commission has also adopted.

⁶⁰ See www.lawreform.ie.

7.3 Right to Intimate Relationships

Section 5 of the *Criminal Law (Sexual Offences) Act 1993* on the Protection of Mentally Impaired Persons was written with the intention of protecting persons with intellectual disability from sexual exploitation and abuse. Section 5(5) of the *Criminal Law (Sexual Offences) Act 1993* defines a "mentally impaired" person as meaning someone "... suffering from a disorder of the mind, whether through mental handicap or mental illness, which is of such a nature or degree as to render a person incapable of living an independent life or of guarding against serious exploitation."⁶¹ The use of the term "mentally impaired" and the concept as set out in the Act are unsatisfactory and outmoded.⁶²

Many service provider organisations have received legal advice that they would be in breach of their duty of care if they permitted persons whom they support to engage in sexual activity or have an intimate relationship. There is a fear about criminal liability under the 1993 Act as persons receiving services or supports could be deemed "incapable of living an independent life". This has raised questions of how to define living independently in the community.

It is unclear whether living with your family or living in a group home could be considered as living independently in the community. It has long been discussed that this legislation is out-dated and in fact discriminatory in prohibiting people with intellectual disability from entering into intimate relationships. It also operates on the out-dated status approach by assessing capacity on the basis of where a person lives and does not respect the person's "will and preferences". People with intellectual disability are subjected to a higher test of capacity to consent to sexual relations than their "non-disabled" counterparts. In fact the test of capacity is set at a higher test than that for marriage. In aiming to protect people, the *Criminal Law (Sexual Offences) Act 1993* has served to cut off any prospect of intimate relationships for persons with intellectual disabilities and as such is completely at odds with the UN Convention. Concerns about the duty of care have had an intrusive and negative impact on organisations supporting friendships and relationships, and have intruded on basic human rights such as the right to a family and private life under Article 8 of the ECHR. The *Criminal Law (Sexual Offences) Act 1993* needs to be amended as part of the changes to legal capacity Legislation to ensure the right to intimate relationships. There is clearly a need for legislation to safeguard persons from sexual exploitation, however, the 1993 Act does not strike the correct balance required by the Convention.

⁶¹ Available at: <http://www.irishstatutebook.ie/1993/en/act/pub/0020/print.html>.

⁶² See "Consultation Paper on Vulnerable Adults and the Law: Capacity" Law Reform Commission (37) 2005 at pages 136-145.

Article 16 of the CRPD requires Ireland to "... take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects." However, it should be noted that this obligation to protect must be done on an equal basis with others and is not a mandate for the State to restrict the other rights and freedoms outlined in the Convention. In this regard Article 16 guards against paternalism and cannot be used as a rationale for restricting the rights of persons with disabilities from entering into intimate relationships.

Article 12 requires that the exercise of capacity to decide on entering into such relationships should be respected and that where necessary supports be provided. While the Scheme of the Bill falls silent on the legal capacity to enter into intimate relationships the State will have to address the issue in order to be in compliance with the Convention.

Appendix 1: Practical Suggestions for the Establishment of a Continuum of Support Arising from the Implementation of Article 12

There needs to be a broad framework or continuum of actions to effectively implement Article 12 of the UN Convention. The framework is a simple, common sense continuum of required actions in seven broad areas specifically driven by the rights of people with disabilities (especially people with intellectual disabilities and mental health difficulties). This continuum of actions should contain the following elements:

1. Advance planning
2. Self determined Decision-Making
3. The Right to Information (including financial rights)
4. Reasonable Accommodation
5. Provision of Advocate Support
6. Supported Decision-Making
7. Co-Decision-Making and Facilitated Decision-Making
8. Financial Rights

1. Advance planning

The first step is for a legislative framework to provide for advance planning to ensure that the individuals' rights and "will and preferences" are known prior to occasions when they may not be able to express them. There are numerous examples of Enduring Powers of Attorney or Advance Care Directives, which can be used in relation to any aspect of decision-making: medical or healthcare decisions, personal decisions (including where and with whom to live), and financial decisions. Advance Care Directives should be provided for as a mechanism as their effective use will avoid situations of conflict in determining a person's "will and preferences" and avoid guardianship in circumstances where the person has already made their wishes known or identified an individual who they would like to represent them in situations where decision-making capacity is fragile.

2. Self-determined Decision-Making

Since the Bill should follow the guidance of Article 12 in outlining a strong assumption of legal capacity, there must be follow through by promoting understanding of the right to self-determined decision-making. The Bill should recognise that people with disabilities enjoy legal capacity on an equal basis with others and that includes the right to make bad decisions and the right to take risks – which persons identified as non-disabled currently enjoy. An obligation on professionals and service providers working with people with disabilities to have regard to the right to self-determined decision-making should be addressed via a range of information and awareness programmes.

3. Right to Information (including financial matters)

In order to facilitate decision-making, all relevant information must be provided to the person. This right does not just apply when a decision needs to be made but should be respected in all aspects of a person's life. The Bill should reinforce the requirement for information to be made accessible to assist the widest audience to be able to understand information provided on key areas. This will require shifting the locus of responsibility from the person receiving the information to those presenting the information to make sure that it is understandable to the widest audience.

The recognition of existing abuse of rights in respect of financial matters was well recognised in the drafting of Article 12(5), including inheritance, and property rights, day to day control of financial affairs, and equal access to bank loans, mortgages and other forms of financial credit. While the Bill should reinforce the right to information on matters affecting the person, further measures will be needed to promote an understanding of the financial rights of persons with disabilities. In particular, the authority of banks to determine its own rules in this area is a specific hurdle, which the Bill can go some way towards addressing, by requiring national standards which respect the capacity of persons with disabilities to be developed.

4. Provision of a Range of Reasonable Accommodations

A range of reasonable accommodations to assist the understanding of information given to people with disabilities will be required. This will include technological equipment, sign interpreters, and accessible and easy to read formats. Ensuring that meetings where decisions are made include the person at the centre of the decision or their chosen representatives is key to enabling decision-making as envisaged in Article 12. The Bill can reinforce and strengthen the existing obligation to provide reasonable accommodation to persons with disabilities provided for in the *Employment Equality Act 1998-2008*, the *Equal Status Act 2000-2008*, and the *Disability Act 2005*. Again, the shift in onus of responsibility to information providers to ensure that people with disabilities receive reasonable accommodation is a key measure the Bill could provide to ensure that the provision of information and communication is effective and supports individuals to exercise their legal capacity.

5. Provision of Advocate Support

The Provision of a range of advocate supports is required to enable effective decision-making, from support for self-advocacy, peer-to-peer advocacy, citizen advocacy to more formal support in a range of ways including state-appointed advocates and legal advocacy on areas of consent to treatment, health, housing and other issues. The Bill could recognise advocacy as a less

restrictive alternative to the imposition of substituted decision-making, and introduce statutory powers for advocates in the National Advocacy Service (as envisaged in the *Citizens Information Act 2007*).

6. Supported Decision-Making

The Bill should also recognise the need for a range of systems for supported decision-making, extending from informal supported decision-making to formal legal systems that ensure that individuals remain present and do not become invisible before the law and where their rights and their “will and preferences” are acted upon. Some examples of supported decision-making systems include the Representation Agreement in British Columbia⁶³ and the Personal Ombudsman system in Sweden.⁶⁴ There are legislative templates for both these forms of supported decision-making, which could be adapted to the Irish context and included in the forthcoming Bill.

7. Co-Decision-Making and Facilitated Decision-Making

As a last resort, when all other less restrictive support mechanisms have failed to resolve an individual situation, the Bill should outline the circumstances in which substituted decision-making can be used. Types of substituted decision-making, which would be compliant with UN Convention, are often referred to as co-decision-making or facilitated decision-making, and these systems have a number of striking differences from guardianship or out-dated wardship mechanisms. Co-decision-making and facilitated decision-making mechanisms have as their core principle the “will and preferences” of individuals and are not focused on “best interests” – as this is often interpreted simply as a persons “best medical interests”. Instead, a facilitator or co-decision maker is appointed and must make the decision which comes closest to the “will and preferences” of the person and one which can augment the future development of that person’s decision-making capacity, however, limited this capacity may at first appear to be. Understanding the “will and preferences” of the person can be a lengthy process, especially where individuals do not use easily recognised systems of communication. However, the outcome is predicated on a human rights-based approach to legal capacity, as enshrined in Article 12 of the UN Convention.

These systems will require a series of safeguards, as set out in Article 12(4) “... Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to

⁶³ See Appendix 2.

⁶⁴ See Appendix 3.

the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.”

All of the support mechanisms described above require safeguards to ensure that the rights of the person are protected throughout the entire process. Therefore, the role of a court or tribunal in the forthcoming Bill could be to ensure that every available less restrictive alternative has been attempted and that co-decision-making or facilitated decision-making is only used as a last resort, in a manner that gives the utmost priority to the will and preferences of the person.

Appendix 2: British Columbia Representation Agreements

The British Columbia's *Representation Agreement Act 1996* provides an example of best practice in this area.⁶⁵ The legislation provides for the establishment of a system that facilitates adults to decide in advance on issues. The Act embraces a presumption of capacity in respect of persons with intellectual disabilities and mental illness. Persons who would not be normally considered as having capacity under contract law are permitted to enter into representation agreements and are entitled to amend or revoke them.

The provision of representation agreements circumvents court involvement in these issues. The representation agreements allow persons to nominate a person to make decisions for them in different aspects of their lives under certain circumstances. These areas under section 7 of the *Representation Agreement Act 1996* include the adult's personal care, including, routine management of the adult's financial affairs subject to the regulations. This can include payment of bills, receipt and deposit of pension and other income, purchases of food, accommodation and other services necessary for personal care and the making of investments. Section 7 also covers major health care and minor health care decisions, obtaining legal services etc. It is open to the adult to choose their support and in what areas. Section 8 of the Act provides for a test of incapability for standard provisions.

The test involves consideration of the following:

- Whether the adult communicates a desire to have a representative make, help make, or stop making decisions;
- Whether the adult demonstrates choices and preferences and can express feelings of approval or disapproval of others;
- Whether the adult is aware that making the representation agreement or changing or revoking any of the provisions means that the representative may make, or stop making, decisions or choices that affect the adult;
- Whether the adult has a relationship with the representative that is characterised by trust.

⁶⁵ *Representation Agreement Act* [RSBC 1996] CHAPTER 405. Available at: http://www.bclaws.ca/EPLibraries/bclaws_new/document/ID/freeside/00_96405_01.

Appendix 3: Personal Ombudsman in Sweden

The “personligt ombud” (personal ombudsman) support model was developed in Sweden based on a recognition that existing legal capacity systems did not meet the needs of many with mental health difficulties, who fell between the cracks of the support mechanisms provided by local municipalities and had difficulties in accessing their rights. In many ways it is similar to personal and peer advocacy for people with disabilities provided in Ireland by the National Advocacy Service and the Irish Advocacy Network.

This started as a pilot project in Sweden, and due to client satisfaction, reduced numbers of in-patient hospitalisations and the savings in expenditure made, it was expanded in 2000 to a nationwide programme of about 300 ombudsmen supporting 6000-7000 people with mental health problems.⁶⁶ The ombudsman is a professional (often from a social work or legal background) who works solely for the individual and on the basis of their “will and preferences”, not by reference to perceived “best interest”. The ombudsman has no connections with or responsibilities to medical professionals, social services or any other authority or person. Each municipality runs its own personal ombudsman system linked to the national programme.⁶⁷ Personal ombudsmen are funded by the municipalities, but are often hired through non-governmental organisations to reduce the potential for conflicts of interest to arise, especially where individuals want to complain against the municipality. Clients control all the information provided to the personal ombudsman, and confidentiality must be respected. When the relationship between a client and his personal ombudsman comes to an end, the ombudsman must return all information to the client, or otherwise destroy it in the client’s presence.

It may take a long time before the ombudsman and the individual develop a relationship of trust where the individual can talk about what kind of support he/she wants, but the ombudsman is obliged to wait, even if the client’s life may appear chaotic. This type of support has been successful in helping also those who are most hard to reach and who were usually left without support. This includes people with mental health problems who are homeless or live in isolated rural areas avoiding all contact with authorities. To reach this group, the ombudsman has to actively seek contact on the individual’s terms.

A number of characteristics have contributed to the success of the personal ombudsman model. These include:

⁶⁶ The Swedish National Board of Health and Welfare (2009), *Egen kraft – egen makt, En antologi om arbetet som personligt ombud* [Your own strength – your own power, An anthology about the work of personal ombudsmen], page 15.

⁶⁷ The Swedish National Board of Health and Welfare (2008), *Ett nytt yrke tar form – Personligt ombud, PO* [A new profession is born – personal ombudsman, PO].

- No bureaucratic procedure is required to get a personal ombudsman. Requirements to fill in forms would prevent many who need the ombudsman, to get one. A simple yes to the question from an ombudsman to the client if he/she wants an ombudsman is enough.
- The ombudsman does not work ordinary office hours, but has flexible hours and is prepared to work with his/her clients also in the evenings or on weekends. A 40-hour week with flexible working times is used as a model to achieve this.
- The ombudsman is comfortable to support the client in a number of matters. The priorities of the individual are not always the same as the priorities of authorities or the relatives. Clients' first priorities may not concern housing or occupation but relationships or existential matters. An ombudsman must be able to discuss also such matters - and not just "fix" things.⁶⁸

This is a good model of supported decision-making that respects the will and preferences of the individual and does not require an assessment of capacity before support is provided. The Swedish experience demonstrates the pragmatic benefits of the scheme, not only in terms of enhancing self-determination for individuals with mental health difficulties, but in reducing the numbers of in-patient hospital stays, and therefore reducing the levels of state expenditure in mental health (which can be significant). The Centre would welcome the inclusion of references to a personal ombudsman scheme in the forthcoming capacity legislation.

⁶⁸ Jespersson "Personal Ombudsman in Skåne – A User-controlled Service with Personal Agents" in Stastny and Lehmann (eds.) *Alternatives Beyond Psychiatry* 2007, page 299ff.

Appendix 4: Quinn “Legal Capacity Law Reform: The Revolution of the UN Convention on the Rights of Persons with Disability” [Dublin: Frontline, 83, 2011, 26-27].

Legal Capacity Law Reform: The Revolution of the UN Convention on the Rights of Persons with Disability

What should modern legal capacity laws look like? Most international attention is focused now on Article 12 of the new Convention on the Rights of Persons with Disabilities which guarantees ‘Equal Recognition under the Law.’ Indeed, many commentators say that Article 12 is the very lynchpin of the new Convention. The emphasis placed in Article 12 on respecting the person’s will and preferences reflects the revolution in the Convention in moving away from treating persons with disabilities as ‘objects’ to be managed or cared for by others, to ‘subjects’ capable of determining their own destinies and deserving of equal respect. What is so different about this and what difference does Article 12 make to the debate about the reform of legal capacity law in Ireland?

From a philosophical point of view the right to make decisions for oneself is profoundly important. It acts as a sword to enable one to make one’s own choices (e.g., where to live, with whom to live) and have those choices respected by others. It also acts as a shield fending off others when they purport to make decisions for us—even when well intentioned. Legal capacity to make decisions is said to flow from a recognition of personhood—something that does not depend on cognitive ability.

This is not to say that decision-making deficits do not exist. However, the typical response of the law in the past to these deficits—all around the world and not just in Ireland—is to allow others to make decisions in the place of the individual. This is so-called ‘substitute decision-making’. In the more extreme case this is done through plenary guardianship (which means the third party assumes the right to make all decisions and totally supplants the person) or partial guardianship (the right to make certain kinds of decisions).

The UN Convention on the Rights of Persons with Disabilities is self-consciously designed to roll back the typical response of the law to any sign of a weakness in decision-making capacity. The drafters set their sights against several aspects of the past—and in the process, they set out a wholly new approach. What were they against?

First of all, the drafters of the Convention wanted to abolish the ‘status-based’ approach to legal capacity. Put simply, they wanted to break the connection between one’s status as a person with a disability and any quick assumption of legal incapacity. So it is not permissible under Article 12 to

deprive a person of the right to make decisions for themselves simply because they have a disability. The analogy was women. In previous centuries women suffered a form of 'civil death' in that their personhood was merged with that of their husband and they were denied the legal right to make decisions for themselves. It took several hundred years to roll this back. Similarly, the drafters felt that persons with disabilities suffer a similar 'civil death' through plenary guardianship laws and this had to be stopped.

Secondly, the drafters wanted to abolish the 'outcome' approach, whereby legal incapacity might be inferred from a series or pattern of 'bad decisions'. The point made by many delegations is that everybody enjoys a certain 'dignity of risk' to make their own mistakes. Most people learn from their mistakes—others continue to make the same mistakes. We don't deprive 'ordinary' people of their right to make their own decisions simply because they make the same mistakes. The argument was put (and accepted) that if a pattern of 'bad' decisions was a ground to deprive someone of capacity then quite a lot of people would stand to lose it.

Thirdly, the drafters wanted a different kind of response to frailty with respect to decision making (besides substitute decision-making or guardianship). Instead of focusing on deficits as a ground for depriving people of their capacity, they wanted instead to place an emphasis on positive measures to support people in whatever level of capacity remained. That is why there is such a strong emphasis in Article 12.3 on the obligation of the State to put in place supports to enable people with disabilities to exercise their legal capacity—an idea that includes (but goes far beyond) supported decision-making.

'This concept of 'support' in Article 12 is critically important—and it should form the lynchpin of any future Irish legislation. It is hard to see how legislation that did not explicitly include this would be in compliance with the Convention. And there is a logical link between supports to enable persons with disabilities enjoy legal capacity and other provisions in the Convention. For example, it is hard to see how people could develop their decision-making capacities unless opportunities were afforded them to live independently and be included in community life. At one level one might say that the right to choose where to live, and with whom, depends on having legal capacity to make that choice. In that sense the achievement of Article 19 (right to live independently) depends on Article 12 (right to make decisions). But it could equally be said that independent living is a precondition to enable people to develop their own decision-making capacities. That is why the expected Irish report on 'congregated settings' is actually quite crucial to the debate on Article 12.

What does the notion of 'support' entail in practical terms? Three different scenarios might be kept in mind. First, there is the relatively straightforward

case of someone who clearly has the capacity to form their own will and preferences, but who may require a measure of assistance in making decisions. Secondly, there may be someone who similarly has the capacity to form their will and preferences, but who may have difficulties in communicating them (this includes others besides those with intellectual disabilities). Here the task of supports or supporters is to divine the will and preference and express it for the person. Thirdly, there is the case of a person who—to all outwards intents—cannot form their own will and preference, perhaps because of decades of isolation in an institution. Here the supports may take the form of ascribing to the person their will and preference (given their culture and background), as well as embedding them in a web of community and social connections in order to spark the expression of their will and preference through time. This may look like substitute decision-making (guardianship), but it is not substitute decision-making as in the past. Superadded under Article 12 is an extra obligation to work actively to spark the will and preference.

It is worth bearing in mind that 'supports' need not be cost-intensive and therefore a financial drain on the state. In British Columbia, for example, 'representation agreements' can be entered with people who know the individual. The decisions made in these agreements bind others, such as doctors, dentists and landlords. And even if the supports cost the state, the state is still obliged to 'progressively achieve' their implementation under Article 12. In other words, the present lack of resources is no excuse not to put in place a system of supports that can grow through time.

There is a considerable body of opinion to the effect that guardianship laws (especially plenary guardianship laws) are completely inconsistent with Article 12. From this perspective, narrow guardianship laws that only target particular areas of decision making are also inconsistent with the Convention, even when multiple safeguards are added. One law reform trend around the world has been to whittle down guardianship laws and insist on safeguards like the principle of proportionality, etc. A fear is that if any exceptions are allowed (i.e., to allow even limited guardianship) then, because of the sheer weight of history, the exception will quickly become the rule. Therefore some maintain the legal fiction of complete capacity for all in all circumstances. In order to meet this, some states have entered 'reservations' to Article 12 to the effect that they are allowed to continue with guardianship measures. Other states have entered 'interpretive declarations' to the effect they understand Article 12 to still allow for guardianship (albeit more tightly drawn).

Perhaps the better view is that although the Convention decouples notions of incapacity from disability, there are still decision-making deficits that have to be handled. On rare occasions this will mean making decisions 'for' persons with disabilities as well as 'with' them and in response to their wishes.

However, this should not be mistaken for guardianship law as usual. The new obligation to 'support' means that even in these cases efforts have to be made to augment existing capacity and grow capabilities.

What would be the practical implications of a new regime based on the assumption of capacity and the notion of supported decision-making? For one thing, it would substantially boost the right to say no! This would include a right to say no to medical interventions and the like. Put another way, it would enhance the right to give (or withhold) informed consent to medical treatments. Incidentally, many of the drafters of the Convention were at pains to point out that the notion of 'best interests' has no (or very substantially diminished) place in the context of adults with disabilities. For another, it would substantially enlarge one's right to create one's own legal universe with others. This would include contract powers—e.g., to manage one's own financial and banking affairs, to enter into contracts with landlords, to sue or vindicate one's rights in one's own name, etc. Third parties (e.g., bankers) have a legitimate interest in the 'reliance' interest' in such arrangements. They need to know that agreements will stand up and can be enforced. This is why it is so important to put into place (i.e., give legislative standing to) 'supports' such as 'representation agreements.'

Article 12 is causing a revolution around the world – especially the move toward a supported decision making model. The new UN Committee on the Rights of Persons with Disabilities is currently drafting a General Comment (an important interpretive guidance) on Article 12. The Office of the UN High Commissioner for Human Rights is on record as stating that substitute decision-making is, in its view, inconsistent with Article 12.

In my view, any proposed Irish legislation that did not explicitly provide for a right to support in exercising legal capacity would be inconsistent with Article 12. It is not good enough to leave this to inference, as appears to be the case under the current Heads of Bill for the Capacity Bill. This notion of 'supports' need not mean an expanded state- driven bureaucracy. It is best if it doesn't, since the lives of people with disabilities are far too enmeshed in intrusive regulatory regimes that most of us would reject in our own lives. But it would mean giving legal force to such innovations as 'representation agreements' as found in British Columbia. Ireland has yet to ratify the UN Convention. It has signed it, which indicates firm intention to ratify. In any event it is clear that plenary guardianship laws are already in violation of the European Convention of Human Rights.

1916 promised to remove the Poor Law from Ireland—it is time to make good on that Republican dream a hundred years on.

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Appendix 5: Quinn "Rethinking Personhood: New Directions in Legal Capacity Law & Policy" [Vancouver: University of British Columbia, 29 April 2011].

An Ideas Paper

'Rethinking Personhood: New Directions in Legal Capacity Law & Policy.'

Or

How to Put the 'Shift' back into 'Paradigm Shift'.

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

University of British Columbia,
Vancouver, Canada.
29 April 2011.

1. Introduction.

- (a) The Paradim Shift and the Counter Revolution.
- (b) Reasons to be a Counterrevolutionary.
- (c) Taking the Counter Revolution Seriously.

2. Myths of the Counterrevolutionaries.

- (a) Personhood - a Soft Political Premise, Not a Hard Commitment.
- (b) 'Essentialism' and Personhood – doesn't work in Peoria.
- (c) Justice and its Blind-Spots: The Inadequacy of Contractarian Theories of Justice.
- (d) The Myth of the Masterless Man – Who is He?
- (e) Cognition and the Masterless Man – not Captain Kirks' Style.

3. Reconstructing the Revolution – Time to Engage the Peasants!

- (a) Leaving Myths Aside for Realities.
- (b) Building on the Realities.
- (c) A New Role for Law.

4. Conclusions – its not about Disability, ts about the Human Condition.

1. Introduction.

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

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

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

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

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

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

And so legal capacity to me is a continuum that connects with everything needed to enable the person to flourish – a right to make decisions and have them respected, a place of one's own, a life in the community connected to friends, acquaintances and social capital, whether in public or private

settings. Personhood is broader than just capacity – and these broader connections serve to augment capacity in a virtuous circle.

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

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

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

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

(a) The Paradigm Shift and the Counter Revolution.

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

There is nothing new here. Some years ago the British Overseas Development Office tried to figure out how £1 billion in development aid in a

particular country left no mark whatsoever. A key finding was that, contrary to popular misconceptions, policy-makers actually work to very simple policy narratives that either facilitate, block, skew, distort or deflect change. They are shorthand and even a substitute for deep thinking. That's fine and even normal – we can't all think deeply all the time.

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

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

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

Ok – so the logic of Article 12 points in a completely new direction – one which makes perfect sense to us within an admittedly narrow community of advocates and maybe within an admittedly self-referencing theoretical framework – one that has yet to break out to connect into more general political and legal debate about the nature of the human condition, its inherent fragility and the extent to which, in truth, we all depend on each other's support for identity, a sense of self and for the myriad of cues – formal and informal – that help us plot a course through life's many travails. I say plot a course when in reality most of us stumble on from one life event

to the next. A wise man once said that a career is not something you create – its something you look back on. Kant saw us as in being in hyper self control. The Greeks, on the other hand, saw Delos – our personal destiny – as lying totally beyond our personal control. Although I hate it when students say this - the truth is probably somewhere in between.

So much for logic. We would do well to remind ourselves that, as Holmes once pointed out, 'the life of the law is not logic but experience'. In other words the beauty and symmetry of the new paradigm will not in itself shift these stubborn policy narratives. I wish it did. I have spoken before about the 'temptation of elegance' – the idea that the inner beauty of our constructs is itself enough to move others. Ambassador Don Mackay – the exceptionally able and wise chair of the drafting proces that led to the convention - surely qualifies as a 21st century Cicero – but even Cicero met a sticky end! I am not suggesting that Don is going to meet a sticky end – only that eloquence alone won't do. No. Something else is needed. In the past I have called this the need for new politics of disability – and the need to build bridges between disability politics and ordinary politics - of which more anon.

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

(b) Reasons to be a Counterrevolutionary.

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

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

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

By the way, if you want to see deep unreflective – even unselfconscious - predudice in action look to the recent analysis of the Council of Europe's

Venice Commission in how it treats the issue of the right to vote for persons with intellectual disabilities.

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

Again, there is nothing new here. We all do this to some extent even in our own lives. And notice the peculiarly modern phenomenon of 'boxitis' - lets capture the new paradigm is a set of values so that our organisation becomes a 'values led' organisation. And how do we know its values led - why we tick the important boxes of course! I call this the bureaucratisation of ethics! To my mind there is no inevitable correlation between a 'values led' organisation and one that actually anchors itself on a sense of the centrality of the person.

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

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

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

lack of this social capital) only truly serve if they enable life-plans to be fulfilled.

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

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

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

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

(c) Taking the Counter Revolution Seriously.

What to do?

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

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

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

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

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

So where are the deeper fault lines and where might the breakthroughs occur? Really, the debate at the heart of Article 12 exposes some deep fault-lines which, like the proverbial dragon, should be brought out into the open before slain. To do that we need to dig deeper to explore the reasons for the counterrevolution – and expose some of the myths upon which they rest.

2. Myths of the Counterrevolution.

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

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

Now that theory of justice has its flaws and its blind-spots. The disability convention and Article 12 in particular – whether by accident or design –

addresses these flaws and, in the process, expands the underlying theory of justice. This expansion benefits persons with disabilities. But it has repercussions for all. This may become ever more obvious as progress is made in drafting another thematic convention on the rights of the elderly.

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

(a) Personhood – a soft Political Premise, not a Hard Commitment.

First, personhood.

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

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

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

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

substitute-decision making is a symptom of civil death – of the surrender of the personhood of one person to another.

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

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

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

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

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

The whole point of our political & legal order is to create an uncoerced space for the self, for the masterless man, to assume plenary power over their own

destinies. The legal order is there to protect this space – to allow individuals create their own mini-legal universes in free association with others. This can only be done if one is 'self'-possessed and 'self'-driven. From this angle there is internal pressure to define the 'self' – the person – as being rational and capable of plotting one's own course which implies weighing options and risks and deciding accordingly.

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

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

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

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

(b) Essentialism and Personhood – doesn't work in Peoria!

So whats screened out by the 'myth system'?

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

games simply because he couldn't count how many bullets he fired from his toy gun!

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

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

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

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

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

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

So this reductionist and essentialist picture plays to the notion of the masterless man – wandering purposively through life. Although we all aspire to be masterless man (and women) we all acknowledge that we (our sense of self) is a relational concept. It comes about – it individualizes – as a result of socialisation. Don't trust me – look to the recent work of neuroscientist Antonio Damasio. The Mind does not exist in some atomistic desert beloved by Thomas Hobbes. It is an intensely social artifact, melding as it individuates.

Maybe a story brings this point home. I once did a very naughty thing when playing cowboys with my younger brother. I pointed a loaded potato gun (loaded with tiny pebbles) directly at my brother. Wham! I got him first time! No need to reload. I felt like Atilla the Hun at the gates of Constantinople – final victory was in sight. The problem of sibling rivalry is solved once and for all. He screams. Out runs my mother. There was no use denying I pulled the trigger. What to do? Well, I knew how devout my

mother was so I quickly played the Catholic card. When confronted I didn't deny it – I just passed on responsibility by saying 'the devil tempted me!' I didn't suffer from Irish Catholic guilt – I knew the devil was the guilty party. That bought me about 30 minutes peace while my mother struggled with a way to respond! Aha. I knew I had her. Hoist by her own petard! As a 9 year old I had successfully internalized her worldview (while never actually believing it myself) and negotiated a temporary reprieve by playing to her emotional commitments and knocking her off balance. What amazingly social (as well as cunning) animals we are! I became her in order to undo her. By the way, this is when I had the first stirrings to become a lawyer!

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

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

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

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

Stay hovering! If deprived of this social capital, of the raw material out of which we emerge individuated and into which we continually affirm our selves as we alter our selves, what chance do we have of constructing a sense of self, a solid identity and the inner resources to face the slings and arrows of life? Now I grew up a few doors away from a boy with Downs Synrome. His father was a policeman – a very jolly policeman. He was

always in our games and ran around with us. We were an adventurist lot – no health & safety for us! He lived among us and not apart from us – and I am sure this helped him to move on in life as his parents passed away.

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

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

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

(e) Cognition and the Masterless Man – Its Just Not Captain Kirks' Style!

What then of cognition – rationality – as the *sine qua non* in enabling the masterless man conquer the universe? Cognitive psychologists have – as you might expect – long worked in the field of decision making. And, surprise, surprise, they have come up with some conclusions that are strikingly at odds with this essentially politically driven notion about the centrality of cognition.

To make a long story short they question the very integrity of the divide between cognition and emotion. They depict decision-making as very complex, very intuitive and – wait for it – very reliant on experience as well as the innumerable cues and supports of others.

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

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

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

3. Reconstructing the Revolution – Time to Engage with the Peasants!

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

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

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

(a) Leaving Myths Aside for Realities.

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

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

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

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

Similarly bound up with the full implementation of Article 12 debate is Article 29 on the right to participate in political and public life. The Romans understood freedom as public – the right to be involved and to participate. Out of this evolved civic virtue – a sense of connectedness to the collective.

That too is not just an outcome of enhanced legal capacity – it is one of its preconditions.

In reality, cognition tends to be a minor element in helping us plot a course through life and make decisions. Strange that we can 'see' this and yet avoid its implications. We allow ordinary people to vote on the fate of the nation even when we know that most people do not vote rationally. Why can't we build a more realistic picture of ordinary decision-making and then build a legal capacity structure to reflect that rather than the myth of rationality?

(b) Building on the Realities.

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

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

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

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

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

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

And what of law? What role should law play?

Let me make an observation in passing. And it speaks to one of the hidden dangers inherent in any social model. My day is not micro-managed by anyone. I change my mind a lot and change my plans a lot. I think we all instinctively repudiate any assertion of power that effectively canalizes our existence. Now legalism is all about control. These controls attach themselves to the many arms of the State – but they also attach themselves to other entities like service providers when invested with State authority to achieve certain ends. Nothing bad here you might say...power needs a corrective. But, in the context of expanding something as fragile as personhood, legalism – even well intentioned legalism - has its costs. Legalism is good at protecting people against certain things – but what persons with intellectual disabilities need most is to re-engineer services to augment capacities. Legalism likes to mitigate risk. But more space for risk seems needed if capacities are to be augmented. Legalism can contaminate the philosophy of an organization – lead it into losing sight of the underlying goal which is respecting dignity and expanding autonomy. Now don't get me wrong – I am all in favour of protection. But somehow or other the convention calls into question the balance between protection and expanding autonomy. I don't know how the balance can be re-struck but I do know that excessive legalism can be the kiss of death for the kinds of innovation called for in the convention

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

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

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

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

And what of the legal implications of mistakes! And there will be many and some will have lasting consequences. Who picks up the pieces – who is liable and who bears the costs? Its back to legalism again! Clearly a new social contract with consequential legal changes is needed to create breathing space for the new paradigm. Carl Auerbach once wrote a stunning book on Justice without Law – on how to achieve just results in a community setting without exclusive reliance on the rule of law. It’s a bit Utopian and we all need law to protect us. But we still need this re-balancing to take place. Otherwise, we will end up with very restrictive practices that will stifle the growth of supportive decision-making regimens.

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

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

4. Conclusions: Its Not about Disability – its about the Human Condition.

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

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

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

And in truth we are all vulnerable. We all count on innumerable supports just as we brush them off in favour of our own liberty. Its not just that society has a problem acknowledging this for persons with disabilities. Its that society has a problem acknowledging this – period! It is in this sense that the struggle of others – like the elderly – are our struggles.

So in a sense Article 12 provides an occasion to reveal and expose the partiality of our collective commitment to personhood – good on personhood, not good on the causes of personhood. So I see the debate as a subset of a larger debate about citizenship, about mutual support, about connectedness

to social capital, about independent living, about participation. And it needs to be re-positioned there. If it continues to be a disability-specific debate it will be dragged down by decades if not centuries of baggage.

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

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

Its up to us to make it so.

Appendix 6: Quinn "Personhood & Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD"(Harvard: Harvard Project on Disability, 20 February 2010).

CONCEPT PAPER

'Personhood & Legal Capacity

***Perspectives on the Paradigm Shift of
Article 12 CRPD.'***

By

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**HPOD Conference
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20 February, 2010.**

- 1. Introduction.**
- 2. Personhood – Conflicting Impulses & the Enthronement of Rationality.**
- 3. Legal Capacity – Generating Space in the Lifeworld.**
- 4. The Paradigm Shift – Why we need a new Vocabulary.**
- 5. The Text.**
- 6. Conclusions.**

1. Introduction.

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

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

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

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

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

It is frequently said that Article 12 of the CRPD is emblematic of the paradigm shift of the convention. I agree. And it is worth stating what that is before we proceed. It is the deceptively simple proposition that persons with disabilities are 'subjects' and not 'objects' – sentient beings like all others deserving equal respect and equal enjoyment of their rights.

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

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

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

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

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

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

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

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

I want to proceed by laying out what I believe lies at the bottom of the debate – namely conceptions – sometimes competing conceptions – of personhood. These conceptions are largely unstated but exert a powerful undertow. I want to work outwards from this notion (or notions) of personhood and onwards to the legal tool of capacity that help to secure notions of personhood in the lifeworld. I see legal capacity as instrumental to personhood. I want to use this vantage point as a rust solvent to clear away some easy or formulaic understandings of Article 12 and to arrive at a conceptual frame that helps us to truly grasp the profound paradigm shift of Article 12.

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

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

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

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

Now – certainly in liberal democracies – that foundational premise sees personhood in a peculiar way and for its own reasons. All of which is tied to the priority placed on the private sphere over the public sphere. This implies a certain image of civil society – an uncoerced space where individuals seek individual fulfillment often alone but often with others acting together in concert. The legal universe is not populated with moral absolutes – but it facilities persons to identify their own ‘good’ and then create their

own legal universes with reciprocal rights and obligations freely entered into with others.

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

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

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

The social dimension to personhood is also screened from view by liberal foundationalism. It is this dimension that provides the parameters for the self – that supports the self – that valorizes our sense of self – just as it creates enough space to exercise voice or exit when the social fabric no longer proves conducive.

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

Even the much vaunted notion of 'dignity of risk' cannot escape the gravitational pull of foundationalism. It is predicated on a spatial image of

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

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

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

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

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

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

So what do I get from the above. First of all, there is no necessary reason why rationality should be given such pride of place in describing personhood. The wholly irrational is no less a person. We see this irrationality in everyday life and mostly it is a cause of comment like 'he is such a character'. And practically none of us make decision – from the most minor to the most important without support. Like most of the guys here, when I visit the

supermarket I always have my cellphone to make sure I am getting the right product at the right size at the right price – as well as tame my wholly irrational tendency to impulse shop.

3. Legal Capacity – Generating Space in the Lifeworld.

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

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

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

Now the universe of what could be enforced against the will of persons with disabilities in the past was too large – probably on an assumption that such persons were not true subjects but objects with correspondingly more leeway for intervention. This is no longer possible because of the CRPD. But my larger point is that the liberating potential of Article 12 lies in its promise to open up zones of affirmative choice for persons with disabilities and not just to foreclose the deprivations of third parties or of the State itself.

This brings me to another unseen element in the debate. Lets get it into the open. There is of course a fundamental contradiction in rights talk. Just as rights negate State power they also call upon State power to intervene and structure civil society as well as forestall the actions of 3rd parties that would

deny us our freedom. Even the First Amendment which is cast in absolutes allows for some intrusions. This is not considered to be a denial of freedom – but rather prudent interventions to augment freedom. As Locke would put it these are the ‘wise constraints that set us free’. Its not a side constraint on freedom – its actually an entailment of the prime directive of freedom.

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

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

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

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

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

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

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

The status-based assumptions rested on a binary view of capacity – you either had it *in toto* or you lacked it *in toto*. It doesn't take much to see how this rested on stereotypes about disability which, by definition, lacked the finesse to be able to assess each individual's circumstances. And it doesn't take much to understand that capacity is **not a binary concept** – I can have variable levels of capacity to make different kinds of decisions. And of course, with respect to areas in which I have reduced capacity, why should the first interventionist impulse on the part of the State be to take my capacity away and allow others to make decisions for me even when they are corralled to make those decisions in 'my best interests' – a concept that actually finds a better home in the context of children. No, if the underlying value of 'auto-nomy' is taken seriously, then the first impulse of the State should be to shore up my capacity, to enhance residual capacity even in (or perhaps especially in) old age and to assist me to make and express decisions for myself. Further, the status-based approach seems obviously over-influenced by the emphasis placed on rationality by liberal foundationalism. And indeed, it pays scant regard to the natural social supports already there and which can be engineered into place to augment personhood.

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

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

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

for the minority? In other words, there is a profound contradiction between tolerating extremely poor choices and decision-making in non-disabled people on the one hand and then raising the bar exceedingly high for persons with disabilities – so high that most non-disabled people would have difficulty surmounting it!!!

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

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

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

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

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

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

A third group might be those whose will or preference is well nigh impossible to detect. It is possible to imagine a community of interpretation forming around the individual to ascribe to him/her a will or a preference with respect

to a certain action/inaction given the kind of community/culture he/she lives in. That assumes that he/she has been embedded in a culture and living independently. There are some dangers inherent in the idea of a community of interpretation. First of all, the fact that I was born in conservative, Catholic Ireland doesn't necessarily mean that I will turn out conservative and Catholic. The right to be different is somehow smothered here. And indeed, what happens when the community of interpretation cannot agree? Where/who is the tie breaker? The role of law and regulation is vital here.

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

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

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

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

It might be said we should deny this out of a fear that if we allow some decisions to be made 'for' then this will work backwards to corrode any advances made for the vast bulk of persons with disabilities. Carl Schmitt used to say 'he who controls the exception controls the rules'. I sympathize

with this view especially when we realize just how awful the history has been and when we realize that it will take culture (especially legal culture) time to catch up with the paradigm shift of Article 12. It could be said that because the judiciary are so used to the old system that any new exception (decisions' for') will become the norm.

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

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

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

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

Thirdly – ant to me at any rate – most importantly, this perspective actually underplays the power of the paradigm shift for those 5% for whom there should be an added obligation to divine the will if at all possible and create social embeddedness that allows a some flash the will to emerge. Human rights cannot accept social determinism. Because we believe in personhood we must believe that all have the potential to exert will in the world. Likewise, human rights cannot accept medical determinism. Medicine is not exempt from social determinants – its categories, its diagnoses are also socially bound. We cannot trade-off the reality that decisions will be 'made for' some people under the carpet in the hope of cementing into place the paradigm shift only for the majority.

5. The Text.

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

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

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

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

To me Article 12.3. builds on this background reality that affects all of us. It assures us the supports necessary to enable us to enjoy our legal capacity. Again, to me at least, this goes deeper than decision-making. And yes it does apply to even those who – to all outward appearances – cannot form or express a preference or exert their will. The purpose of the supports in this

instance is to work to retrieve the will – no matter how hidden – or to create conditions of social embeddedness to spark the will. Now if you say to me ‘fine, but decisions will still have to be made for’ such persons’ – I agree. But the difference is – while I agree – I will see a role for the obligations contained in 12.3. That’s what I mean by not confining the paradigm shift to the 95%.

Is Article 12.3. subject only to the obligation of ‘progressive realization’? At first blush yes. However, there are interesting case studies from around the world about how supports can be harnessed from the community at virtually no cost to the State. These models need to be highlighted and propagated. My sense is that the State needs to act to put in place a regulatory regime that allows these supports to emerge, to be treated seriously by third parties and policed. To paraphrase the slogan ‘we don’t want your welfare, we want our rights.’

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

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

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

6. Conclusions.

What are my conclusions.

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

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

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

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

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

Appendix 7: Quinn "Seminar on Legal Capacity" [Brussels: European Foundation Centre, Consortium on Human Rights and Disability, 4 June 2009].

**European Foundation Centre
Consortium on Human Rights and
Disability.**

Seminar on Legal Capacity

4 June, 2009.

Brussels.

An Ideas Paper

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- 1. Introduction.**
- 2. Getting Beyond the Traditional Non-Discrimination Agenda to encompass Visions of 'Human Personhood'.**
- 3. Legal Capacity Debate taps into our Legacy Values.**
- 4. Core Legacy Values: Dignity and Autonomy.**
- 5. Facilitating Freedom – Protecting Citizens – Can they be Reconciled?**
- 6. Two traditional Approaches to Legal Capacity, Status & Outcomes.**
- 7. Equality and the Functional Approach.**
- 8. Social Solidarity Points to Assisted Decision-Making.**
- 9. Conclusions.**

“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”.

Arthur Koestler, **Darkness at Noon**, (1940) at 204-205.

1. Introduction.

It's a real honour to be here today and to contribute to this important event on the future of legal capacity law and policy in Europe.

This is an inaugural seminar of the European Foundation Centre's consortium on disability and human rights. Bringing together the world of philanthropy and disability is important – not least because it offers the promise of harnessing the vast experience of philanthropies in supporting social change across a broad range of fields. It is gratifying to see this inaugural seminar focus on *the key* challenge in Europe – and indeed throughout the world.

I was asked to set up the debate, outline its contours, show where the fault lines lie and then allow others to focus on Article 12 itself and its specific requirements. So I will keep this non-technical and try and draw out why this reform debate is so important – in both practical terms and also symbolically.

There is now a wealth of legal and policy instruments in the field including the pioneering Recommendation (99)4 of the Council of Europe in 1999, the important Hague Convention on Vulnerable Adults which seeks to minimize conflicts of laws in this field but on the basis of common understandings of what legal capacity means, and of course Article 12 of the UN Convention on the Rights of Persons with Disabilities. We have had the milestone decision of the European Court of Human Rights in *Shtukaturov v Russia* in 2008 which effectively took sides in favour of a new paradigm on legal capacity by saying that “the existence of a mental disorder, even a serious one, cannot be the sole reason to justify full incapacitation”. That was followed up by an important *amicus brief* on a legal capacity issue lodged by the European Group of National Human Rights Institutions (basically the combination of European human rights commissions and ombudsmen) which is in your materials for today [*DD v Lithuania*]. Incidentally this was the first time ever that NHRIs ever intervened as a body before the European Court. And of course there is the important International Disability Alliance Legal Opinion on Article 12.

However, this is an ideas paper and not a legal analysis. I am extremely grateful for the opportunity to stand back and try to give expression to my own evolving understating of what is at stake.

The stakes are formidably high. If you are deemed legally incapable then your legal personhood is stripped away – your destiny is placed in the hands of others. You become like the fictional character in Koestler’s famous novel about powerlessness in the face of arbitrariness in a police State – except in this instance power is ostensibly exercised ‘for your own good’. You might have thought that such incapacity laws and policies would be put on the defensive in our liberal–democracies which are characterized by a deep commitment to personhood. You would be wrong – and probably surprised at the ease with which people can be made legally incapable in the laws of most countries. I have called them the ‘legally disappeared’. This is something that seems to cross every culture, every political and economic system.

Article 12 seeks to roll all that back. It goes to what Professor Conor Gearty calls the ‘visibility’ of persons with disabilities in society – and in law. It is a ‘visibility project’ of the highest order.

2. Getting Beyond the traditional Non-Discrimination agenda to encompass Visions of ‘Human Personhood’.

We have got to this point in part because Europe has come a long way since the 1990s in disability. I think it would be fair to say that Europe’s disability law reform agenda has now matured and is moving far beyond non-discrimination to encompass profound issues of human personhood and citizenship. We are now at the point that we can talk about more than non-discrimination.

Or, to put this another way, the equality ideal that animates non-discrimination law is now crossing over into fields of law that had hitherto remained disconnected.

I cannot let the occasion go without mentioning that two of the founding fathers of that development are here today – Miguel Angel Cabra de Luna and Hywell Ceri Jones. Much of the success of the last 15 or so years at EU level is due to their often unseen work. Rest assured that much of the credit for putting in place a positive dynamic of change at European level is down to their vision and dogged persistence. And in their capacity in the world of philanthropy in the EFC they have been instrumental in arranging today’s event. Thank you so much for your wonderful work and support.

We are also here because of the adoption of the UN Convention on the Rights of Persons with disabilities. I have called this a Declaration of Independence

for 650 million persons with disabilities worldwide – what the UN calls the ‘world’s largest ‘minority.’ The Convention is quickly becoming a real driver of change – of hard law reform – throughout the world.

You are all no doubt aware that the EU will ratify – or affirm – the Convention – soon. The stage is therefore set not merely for reform within our Member States (where the bulk of legal competence for change still remains) but also at EU level. The legal capacity issue is an issue for our Member States. Having said that, it is obviously important to work towards unified or coherent approaches. This is fully in keeping with the commitment made by the EU Presidency in Berlin in 2007 to seek a common approach to core challenges in implementing the Convention.

And most importantly we are here because much remains to be done. The gap – maybe the inevitable gap – between the ‘myth system’ of law and the UN Convention and the ‘operation system’ of our laws and policies need to be rationally addressed and closed. How we close these gaps – how open and responsive the process is – is as important as closing the gaps themselves.

In its own way Article 12 is the vehicle that enables us to complete the non-discrimination journey which protects people against the behaviour of third parties by **giving voice back to people to direct their own lives.**

3. Legal Capacity Debate taps into our Legacy Values.

Ladies and gentlemen, the debate about legal capacity and the reforms called for by Article 12 is crucial. The revolution contained in Article 12 is emblematic of the paradigm shift that has been taking place in the disability field over the past 15 years or so at European level. And it cuts to the core of the Convention.

Allow me to make one or two preliminary points before getting to the core of today’s subject. It is said that while lawyers may spend years sharpening their minds that they usually do so at the expense of narrowing them. There is something to this – but it has more to do with the inherent compartmentalization of the field rather than personal failings. Reflect on this for moment. Those who have been active in the field have been divided between

- (1) those (like me) who are American influenced and trained on the philosophy of equal opportunities,
- (2) those who focus on traditional civil liberties issues especially with respect to mental health law and the civil commitment of persons with mental disabilities, and

(3) those who focus on intellectual disability and associated issues like legal capacity and deinstitutionalization.

Its quite remarkable to me how these three fields did not traditionally interact despite their obvious commonalities. They orbited one another but were seldom conscious of the forces that held them together.

One result of this compartmentalization was that the legal capacity was seen as a technical issue – marginalized to the fringes of disability law and calling for technical solutions. Not any more. If the Convention has done one thing it has enabled a common language to emerge across all three fields – producing a unified field theory, if you will, of disability law.

This is as it should be. For one thing, the debate about legal capacity does not just affect those with intellectual disabilities – it also affects those who, through sensory and physical impairments, are often deemed incapable because of the difficulty of expressing their own wishes. This is not the same thing as incapacity but it often conflated into it.

It is the addition of the equality of opportunities perspective that utterly transforms the field of legal capacity. It lifts it from the ghetto of technical niceties and elevates it to centre stage within an integrated disability reform agenda.

Why and how? Some see Article 12 as a 'revolution'. To me, to understand the 'revolution' in Article 12, you have to peel away law and reveal some basic values, some basic premises.

In truth, there is no revolution since these basic values are (or were **supposedly**) universal – they have been with European civilization for centuries and are well reflected in human rights instruments at both the global and European levels for the past 50 years or so. They now form part of our cosmopolitan world value system – based on universal human rights.

What is happening is that these values are at last becoming real in the context of disability – thus breaking down barriers into the no-go area of legal capacity which was considered a technical outlier of the law rather than a core foundation of human personhood.

4. Core Legacy Values: Dignity and Autonomy.

I speak of the core values of dignity and autonomy. I stress, these are not revolutionary – they are actually our legacy values. But of course, it is their application to disability that is revolutionary if only because they were somehow discounted in the past – or felt not to apply with full force – in the disability field.

Standing back from the technical debate, what we are witnessing now is a realization that these values matter with just as much force in the disability sector. The question why they were discounted in the disability field for so long is deeply interesting and tells us much about how contradictions can be too easily accepted in culture – in all cultures. The task of revealing the effects of this exclusion also consumes much effort. But plotting what the disability field would and should look like if this is reversed is now where most of our creative energies are rightly focused.

Spare a moment to reflect on the essence of these values – on their **complementarity** as well as on some of the **inherent tensions**.

Take dignity, the notion that all human beings are ends in themselves and not means to other ends. And reflect for a moment on how persons with disabilities were viewed traditionally as 'objects' to be pitied or managed or worse – and not as 'subjects' deserving equal respect. This cultural default has predisposed us to tolerate intrusions into personhood in the field of disability that would not be accepted by others.

Take autonomy – at once an ***a priori assumption*** and a also a ***practical goal*** of our liberal-democracies. Our European civilization compels us to the view that it is not for Government to dictate our ends – it is for us to decide our own ends – our own personal destinies – and it is then the job of Government to facilitate freedom. The Greeks would call this our 'Telos'. Kant assumed that the human spirit had this innate predisposition. Hegel saw it as the spirit of personhood and freedom working itself pure in an impure world. Rawls saw this as 'right' in the sense that the rightful aim of Government was to respect, create space for and facilitate our own individual conceptions of the 'good'. We all see it as common sense.

Unpack this further and you end up with the view that we – as individuals – through our own choices (whatever they maybe **and we do have the right to assume moral risks**) – create our own legal universe. That is to say, the primary role of law is to allow and **enable such life choices to be made** by erecting a zone of freedom and to **protect us** in their pursuit. These choices – emanating from our autonomy - could be extremely intimate, they could relate to our human associations, our social world, our economic engagement, our personal and other property. People don't come pre-packaged into property, medical treatments and sex!

This isn't just about making one's own choices about how to live. Its also about **resisting the choices others seek to make for us**. Autonomy can be used positively to expand our zone of freedom. It can also be used as a shield to fend off others who purport to know better. You don't have to be Frederick Hayek to see the value of this.

5. Facilitating Freedom – Protecting Citizens – Can they be Reconciled?

However, let us note an inherent or seeming contradiction before we move on.

I said the **primary role** of the State was to **facilitate freedom** on the one hand and to **protect us** in the exercise of that freedom on the other. This is what 'critical legal scholars' call the 'fundamental contradiction' between valuing freedom on the one hand - and then using the very ideal of freedom to undo itself by justifying intervention and protective measures on the other hand.

Now, from the rarefied perspective of liberal legal and political theory, this is not a contradiction – just a natural implication of a commitment to freedom. Just as the ideal of autonomy fends off unwarranted intrusion on the one hand – **it also calls for it** on the other hand. After all, Locke called for 'wise constraints that set us free'. Those 'constraints', those protective interventions could be motivated by using the '*parens patriae*' power - .i.e., intervening for the sake of the person. Or they could be animated by the 'police power' – i.e., intervening to protect people (and the pursuit of their freedoms) against others.

In a way, Article 16 of the Convention sets out a *legitimate expectation of intervention* to protect one from violence, exploitation and abuse. Of course, this primarily means intervening to police the actions of *others*. However, one of the arguments shoring up anachronistic legal capacity laws is the fear that by expanding autonomy we simply expose persons with disabilities to more dangers. In a sense Article 16 intimates a sense of vulnerability that law enforcement agencies should be more alive to than in the past. This is, of course, **not the same as saying that vulnerability equals incapacity**. But it is to say that heightened vulnerability (or a perception of heightened vulnerability) was the window through which an excessively paternalistic impulse led to findings of incapacity that were not truly warranted in the past.

Let me cut to the bone. Its probably fair to say that many (most!) protective measures in the past were not primarily motivated out of a sense of vindicating the moral worth of persons with disabilities. It is quite striking, for example, that many of the early guardianship laws were enacted to protect assets or property rather than people. True, there is a deep connection between property and personhood. But most interventions in the past were not really motivated out of a desire to enhance personhood – just to control assets. Now, there is nothing wrong with seeking to protect assets

against the greed and depredations of others. I suppose the real point is that this approach only protected one slice of personhood and seemed to send the signal that the law was more interested in property than people.

And rampant paternalism grossly distorted the protective impulse. Indeed, one perverse result of intervening to protect one against others had been institutionalisation – i.e., placing people in institutions **where their exposure to violence, exploitation and abuse was even worse!** And reflect for a moment on the social construct of ‘vulnerability.’ People don’t come ready-made as vulnerable. Their vulnerability is as much a social creation in the sense that it is brought about by social arrangements that are not sensitive to circumstances.

Now let me honestly pose a difficult question. Is this paternalism an ineradicable feature of legal capacity laws? Should one ever admit to even a kernel of legitimacy in the impulse of the State to protect since, historically speaking, the ensuing measures nearly always ended up objectifying people and exposing them to abuse? In other words, isn’t there a slippery slope at play here? Once we admit of the legitimacy of the interventionist impulse do we not provide a coach and four through which personhood will be systematically denied?

This is undoubtedly a consequentialist argument against even recognizing the concept of incapacity – and it builds on centuries of experience. I suppose the hard question is what do we make of this experience? Do we use it to deny the very existence of incapacity – on a theory that such a concession will always be abused? Or do we try and **cabin and reinvent the notion of incapacity** in a way that finds a better balance between **freedom** and **protection**. I think this question goes to the heart of the debate about the meaning of Article 12.2.

Well, to say the least, the balance between autonomy and protection (if there ever can be one) certainly wasn’t present in our inherited laws on legal capacity. An excess of paternalism and an overly protective attitude led us to draw the line too much against the autonomy of persons with disabilities in the past.

The stakes are extremely high both for individuals and for society. If an individual is stripped of his/her legal capacity then your chance to create your own legal universe – to live the life you want to pursue and to resist intervention – is gone and placed in the hands of others. You become an ‘object’ not a ‘subject’ – ok, maybe an object that is ‘safeguarded’ – but still an ‘object’.

I would also say the stakes are also high for society because if the imbalance is allowed to persist then it detracts from the value of our collective

commitment to freedom – it reveals its partiality – it reveals how the core values count but then count for less in the field of disability. No self-respecting liberal-democracy that takes its legacy values seriously can allow this to persist.

It probably appears clear to you by now that one side of the liberal-democratic ethic – the impulse to protect against others and even against oneself – was predominant in our traditional laws on capacity.

Now, the beauty of the insertion of the value of equality in traditional fields like legal capacity is that it enables us to begin see the imbalance for what it is - and to redress it.

6. Two traditional Approaches to Legal Capacity, Status & Outcomes.

How did the imbalance manifest itself and how to do we break free from the past?

In an effort to clarify what sometimes seems like a bewildering field let me briefly distinguish between the different approaches to legal capacity.

The first was the so-called **status approach**. That is to say, if you were labeled disabled or had a particular intellectual disability it was simply assumed – often by operation of law – that you lacked legal capacity. This status then was sufficient to strip you of legal capacity – of human personhood. Someone else – or some other entity – made decisions for you.

The status-based assumptions rested on a binary view of capacity – you either had it *in toto* or you lacked it *in toto*. It doesn't take much to see how this rested on stereotypes about disability which, by definition, lacked the finesse to be able to assess each individual's circumstances. And it doesn't take much to understand that capacity is **not a binary concept** – I can have variable levels of capacity to make different kinds of decisions. And of course, with respect to areas in which I have reduced capacity, why should the first interventionist impulse on the part of the State be to take my capacity away and allow others to make decisions for me even when they are corralled to make those decisions in 'my best interests' – a concept that actually finds a better home in the context of children. No, if the underlying values of dignity and autonomy are taken seriously, then the first impulse of the State should be to shore up my capacity, to enhance residual capacity even in (or perhaps especially in) old age and to assist me to make and express decisions for myself.

To complete the picture, the second approach to capacity was – is- the so-called **outcomes approach**. That is to say, while we may not make assumption about the lack of capacity based on one's status as, say, a

person with an intellectual disability, we can certainly make them by inference from bad decisions or a pattern of bad decisions or a flawed process of decision-making. But wait a minute! We all make bad decisions. Indeed, we all probably make bad decisions all the time in certain aspects of our lives. It actually helps define who we are! As for a bad process of decision-making, one is tempted to ask should a large sector of the electorate be deemed incapable of voting just because they keep returning 'bad' political parties (whatever that is) to power. Don't laugh - Joseph Schumpeter actually called for this in the 1930s!

Nobody seriously suggests an **outcomes** approach now. And the reason is simple. We all have the right to make our own mistakes. All life is an experiment - sometimes we never learn. Sometimes we suffer the consequences. And generally speaking, the loss is allowed to lie where it falls. In a way, its how we learn and grow.

Why is intellectual capacity so different? Well, you might counter it is different precisely because the disability is intellectual which means a reduced capacity to process information and make knowing choices. Yet, just because some of us are assumed to have full capacity doesn't mean that we use this capacity to rationally sift information and make cold analytic choices. Life just isn't like that for the vast majority - why does it have to be like that for the minority?

In other words, there is a profound contradiction between tolerating extremely poor choices and decision-making in non-disabled people on the one hand and then raising the bar exceedingly high for persons with disabilities - so high that most non-disabled people would have difficulty surmounting it!!!

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

7. Equality and the Functional Approach.

The bridge here is the equality idea - how it gives life to notions of dignity and autonomy in the specific context of disability. This is new. It is what the Convention brings to the broad disability field. And it clearly animates Article 12.

Presuming for the moment that it can be successfully purged of paternalism (which of course begs the core question!!!)- the protective impulse of our liberal-democratic systems is ethically sound - one can even explain it as a

necessary inference of our commitment to freedom. But even if sound – and this is the crucial qualifier – it has been vastly overplayed in the context of disability. If you are denied the right to make decisions for yourself then is it any surprise that the skills needed to do this become under-developed. The absence of these skills is then pointed to as a justification for overbroad incapacity laws. But the argument is plainly circular. Surely the correct response is to impart skills where needed and ease people into taking charge of their own lives.

When we talk of honouring the legal capacity of persons on an 'equal basis with others' – as Article 12.2 does – we mean just that. We don't intervene in the decision-making capacity of non-disabled people because of their status as an Irishman or a Belgian. As Maitland said the history of freedom is mainly a march 'from status to contract' – which assumes autonomy and a capacity to enter into reciprocal bonds and obligations. We don't intervene because 51% of the population 'plainly' voted for the wrong party (whatever that is) and we don't intervene because I happen to still support Manchester United rather than Barcelona!

Equality of respect means extending to persons with disabilities the same expansive latitude allowed to others to shape their own lives and make their own mistakes. We may disapprove but disapproval as such is no warrant to intervene! It seems that John Stuart Mill has yet to arrive in the disability field.

Now, all people – and not just persons with intellectual disabilities – may have functional limitations. But actually, these limitations are generally constitutive of who we are as people. It gives us identity – its does not detract from our identity. It is only where these functional limitations reach extremes is there is some colourable warrant for intervention and even then the intervention should not take the form of denying or detracting from capacity. Yes, but what shape should we put on this intervention – and should it be called an intervention?

8. Social Solidarity Points to Assisted Decision-Making.

Now its time to add another value to those of dignity, autonomy and equality. It is well known to us in Europe. This is the value of social solidarity.

Some see this as the defining value of Europe. Some see it as defining European essentialism as against, say, American essentialism. I don't. I simply see it as a natural entailment of freedom. Every society rests on some implicit terms of social co-existence. My freedom is never pursued in complete isolation. To a certain extent I rely on others to achieve my ends –

and to a certain extent I rely on social supports to exercise my formal freedoms.

In a profound way this is true of all citizens. There is a political economy of individual freedom that cannot be ignored – and here, by the way, is where I part company with Hayek. Its only more obviously true with persons with disabilities.

Why do I inject the value of solidarity into the mix? Its because if we are serious about respecting the autonomy of persons with disabilities on an “equal basis with others” (Art 12.2) then we need to take the next logical step of putting in place practical supports for what is called ‘assisted decision’ making. If we adopt the function approach to capacity then our first impulse upon discovering some lack of functional capacity should not be to remove it but to support it. This is what Article 12.3 gets at. In the context of ageing this is what is meant by the phrase ‘adding life to years’.

Now, you will say, ‘hey that costs.’ And so we inevitably stray into the zone of economic, social and cultural rights and the perennial problem of reconciling their ‘progressive achievement’ with resource constraints. To me, we miss the point if we view the issue exclusively through the lens of economic, social and cultural rights as ends in themselves. Properly framed, this is about minimum social supports to give reality to individual choice and autonomy – something most people take for granted even in a recession! So to me the question is not ‘how much does State X value economic, social and cultural rights’. To me the question is ‘how much does State X value freedom and autonomy and what supports is it willing to put in place to ensure that all citizens can exercise their basic rights equally’.

Is cost a barrier? Sure. But reflect on this. Moldova, one of Europe’s poorest countries is in the process of adopting a national disability strategy which is configured in the right direction. If poverty were an excuse for delay then Moldova would never have done this. The fact that it has shows that what matters is the dynamic of change – the steady roll-out of programmes to facilitate people making their own decisions.

Indeed, the cost must be meaningfully compared with current guardianship systems. It may well be the case that by giving voice back to people that some things they presently have, they don’t want and can forego. And the elaborate guardianship systems – and associated institutionalisation – are themselves quite costly to administer. I do not want to give the impression that cost savings is the basic premise on which to rest the case of assisted decision making. The case is as much moral as it is economic. But a job of work needs to be done at European level to demystify the cost implications – to peel away encrusted assumptions and prejudices. I believe the Swedish

example of PO-Skane of which we will hear more today is most instructive in this regard.

Now, there is an inherent danger with assisted decision making and lets be aware of it. Assisted decision making might cross the elusive line to become – in effect – substitute decision making. I am no expert in how to configure effective ‘assisted decision making’ regimes. But lack of knowledge about how it can be done, or a fear about how to police the line between assisted and substitute decision making is no excuse for not moving in the right direction. There are plenty of countries out there – or States or Provinces within countries such as Canada, Australia and Sweden – that have very practical experience in doing this over many years. Lets get the information and skills flowing to make sure we can embed best practice here in Europe. Incidentally, the Conference of States Parties under the UN Convention could be an excellent platform for transferring this know-how.

It is surely right to be concerned about dangers to vulnerable people. And in a way, Article 16 of the Convention against violence, exploitation and abuse requires States to be alert to these dangers. This tension between expanding autonomy to make owns own decisions – **as well as one’s own mistakes** – and protecting people against personal disasters will not go away.

Yet surely the fundamental point in the march toward reform is that the massive dignity of risk that is afforded to others is denied to persons with disabilities by relying on the very possibility of danger to justify stripping one of legal capacity. There surely is a better way of reconciling these equally legitimate goals of State. The impulse to protect is fine so long as it is not unduly conflated by paternalism. Ways can and should be found to both **protect** and **enable** – without stripping people of legal capacity.

9. Conclusions.

What are my conclusions? I have not descended into hard law – into Article 12. That is for Gabor and others.

But I hope I have explained why the issue of legal capacity is crucial. And I hope I have clarified the values that are animating change – values that are deeply embedded in Article 12.

Ladies and gentlemen, we can have wonderful equal opportunity laws that break down arbitrary barriers. We can put in place excellent social support mechanisms and place a floor of provision under all. We can protect people against all sorts of depredations. Yet if we don’t take the next logical step of enabling persons with disabilities to take charge – and remain in charge - of their own lives then the kind of freedom we impart could best be described

as 'managed freedom'. The message of Koestler is that Europe is not built on a philosophy of 'managed freedom.' *Respublica Europa* calls for public freedom – the right to belong and the right to be recognized as a human being. Its as fundamental as that.

And it is this sense of public freedom – of autonomy and equal dignity of risk - that is now forcing us to roll back protectionism and paternalism.

At some stage we will have to confront the issue of reservations. As is well known, any reservation that defeats the object and purpose of a treaty is not valid. To me, it seems plain that a reservation that preserves space for a State Party to maintain plenary guardianship laws is unacceptable. And a reservation that allows a State Party not to introduce a programme of assisted decision making is not acceptable. But I suppose the Achilles heel of this jurisprudence is that it is unclear (to say the least) whether a treaty-monitoring body (like the new UN Committee on the Rights of Persons with Disabilities) has the legal authority to pronounce of reservations. And even if it has, it is also unclear what legal implications flow from a declaration of invalidity. But the beauty of our European Constitutional order is that it would be heard to reserve to Article 12 (in the manner indicated) and still remain faithful to Article 8 of the European Convention on Human Rights. I think this underscores the critical importance of regional mechanisms in the implementation of the CRPD. No doubt the strategic litigation before the ECtHR will continue and will hopefully bring greater clarity. No doubt when the CRPD is confirmed by the EC it will become cognizable by the European Court of Justice in part because it will have quasi-constitutional status situated somewhere between the Treaties and secondary EC law.

Of course the Strasbourg Court will probably not reach the issue of assisted decision making since this gets it into the field of positive obligations where its natural reflex is to be cautious. However, the natural reflex of the European Committee of Social Rights would lead in this direction and I can see Collective Complaints pointing in this direction in the future.

If I have any proposals to make today it would be to the effect that the EC could do an important job by stimulating research that points to the feasibility of the new paradigm in Europe. A part of this should include meaningful cost-benefit analysis building on experience elsewhere (especially in Sweden) and factoring in the real costs of the existing paradigm. There will be transition costs and there will be ongoing costs. But we have yet to rationally weigh these up against the cost efficiencies as well as the other benefits. We are in a recession and the simple (unchallenged) assumption will be that the costs of the new paradigm are prohibitive. This needs to be rationally unpacked and demystified. This is real added value at EC level.

Another proposal might well be to revisit the programme of the Europa Rechts Academie (ERA) which is the primary vehicle of the EC to train the judiciary. The ERA does a tremendous job. It would be surely proper to task it to train the judiciary on the CRPD since once we confirm it at EC level it will have a quasi-constitutional status for us.

I started by referring to Professor Gearty's characterization of the role of human rights as a 'visibility project'. Many here today will recall the famous 1995 European Day Publication that exposed the invisibility of persons with disabilities in EU treaty law. Thanks largely to the EDF, the European Parliament and a very receptive European Commission, that invisibility in treaty law and in secondary legislation has been massively eroded. New gateways have been forged into the economic and social space of Europe.

Its time now to move on now – to uncloak the invisibility of the human personhood of persons with disabilities through overbroad incapacity laws that come from an older paradigm. Its time to move on from 'managed freedom' which never sat well with our core European human values and toward supported freedom which plays to our highest instincts of social solidarity. Let the debate begin.

Article 12

Equal recognition before the law

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

Appendix 8: Dhanda “Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?” (*Syracuse Journal of International Law and Commerce*: 34, 429, (2007), 457-458). (Available via Hein-online).