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Institute for Research and Development on Inclusion and Society
Institut de recherche et de développement sur l'intégration et la société

The Right to Legal Capacity under the UN Convention on the Rights of Persons with Disabilities: Key Concepts and Directions from Law Reform

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on the Rights of Persons
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About The Institute for Research and Development on Inclusion and Society (IRIS)

The Institute for Research and Development on Inclusion and Society (IRIS) provides research, new ways of thinking, inspiration and education to advance the citizenship, inclusion, human rights and well-being of people with intellectual and other disabilities. It builds on the legacy L'Institut Roehar Institute. IRIS is an independent Canadian research, policy, social development and educational think tank for the community living movement in collaboration with the broader disability community.

IRIS' specific areas of research and resource development are: social inclusion and life beyond institutions; disability-related supports; education, literacy and learning; child development and family life; human rights, ethics and technology; personal safety and security, employment and income; social policy and change.

IRIS' grounding assumptions are that, like others, people with intellectual and other disabilities want to be safe, included, valued, equal, free. IRIS:

- Liaises and collaborates with other experts;
- Analyzes the social and economic realities facing people with intellectual and other disabilities and gives voice to their lived experiences;
- Links issues of disability to broader research, policy, program and social development issues and agendas;
- Attracts and develops skilled researchers and analysts;
- Distributes others' research and resources that warrant positive attention;
- Provides a broad Canadian perspective and in-depth coverage;
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- Points to supportive policy and program options; and
- Helps move research and new knowledge into action through seminars, presentations, training and other knowledge mobilization strategies.

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Contents

About The Institute for Research on Inclusion and Society (IRIS)	5
Contents	7
I. Introduction	1
II. What does it mean to be a ‘person’ before the law and to enjoy ‘legal capacity on an equal basis with others’?	2
III. Are ‘disability’ and ‘incapacity’ or ‘in need of protection’ necessarily equitable?	5
IV. How do we reconstruct the threshold of legal incapacity?	7
A. Limitations of the criterion: ‘understanding the nature and consequences of all options’	8
B. Expression of intention and will as human agency	9
C. Personal identity: a ‘narrative’ approach to human agency	10
V. What are the supports needed to exercise legal capacity on an equal basis with others?	12
VI. How are assisted decision making, consent and liability to be managed in daily life?	14
VII. How should decisions be made about who gets what type of decision-making assistance to exercise legal capacity, how much, and when?	17
VIII. Suggested Directions for Law Reform under Article 12 of the CRPD	21
1. Remove equations of disability with legal incapacity	21
2. Ensure access to needed supports to demonstrate and exercise personhood and legal capacity	21
3. Recognize different decision-making statuses through which legal capacity is exercised	21
4. Provide for ‘reasonable accommodations’ in provision of decision-making assistance	22
5. Take steps to enhance and protect freedom of contract for people with disabilities	22
6. Launch pilot initiatives for supported decision making	23
IX. Conclusion	24

I. Introduction

Article 12 of the UN *Convention on the Rights of Persons with Disabilities* (CRPD) recognizes the right to recognition as a person before the law and the right to legal capacity on an equal basis with others, without discrimination on the basis of disability – not only as the capacity to have rights but the capacity to act. Enjoyment of these rights is essential if people with disabilities are to act on and exercise many of the other rights in the Convention: to live in the community and enter all the necessary contractual arrangements for doing so; to access labour and other markets; to make decisions about health care; to direct their financial affairs, etc.

Yet, along with many other people with disabilities, there is a large group of people with more significant intellectual disabilities whose legal capacity, and therefore *full* personhood before the law, is questioned and often removed only because of their ascribed disability status. Article 12 of the CRPD demands an end to this systematic discrimination. This paper is written with people with intellectual disabilities in mind, but the questions, analysis and approach may be more widely applicable to other groups as well. The aim is to examine theories of ‘personhood’ for the criteria they provide for founding and recognizing the right to legal capacity. The paper examines how current criteria of personhood and legal capacity systematically discriminate against people with intellectual disabilities in recognition and enjoyment of their legal capacity. It draws on more recent conceptions of personhood from moral and political philosophy to suggest directions for law reform that could be taken to address this barrier in law, policy and practice.

II. What does it mean to be a ‘person’ before the law and to enjoy ‘legal capacity on an equal basis with others’?

Article 12(1) of the CRPD states that:

States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

Article 12(2) states that:

States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

Article 12(3) states that:

States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

Article 12(1) reflects the language of Article 16 of the *International Convention on Civil and Political Rights* (ICCPR): “Everyone shall have the right to recognition everywhere as a person before the law.” This right is understood as a right to a ‘legal personality,’ which Volio defines as an “individual’s ‘personhood’ in society.”¹ Commentaries on the negotiations leading up to the adoption of Article 16 indicate that one of the main issues was the distinction between the rights that attach to a individual’s ‘capacity to have rights’ and a ‘capacity to act on those rights.’ Article 16 as adopted did not address the issue of legal capacity to act, or the basis on which the right to capacity to act might be restricted. However, these commentaries do assume that the capacity to act can be restricted.² Nowak makes clear in what is recognized as an authoritative interpretation of the Article 16 right to recognition as a person before the law, that “limitations on the capacity to act... which are provided for in all legal systems, do not represent a violation of Art. 16.”³

Legal capacity to act is a legally recognized status of those persons who have reached the age of majority to make binding legal arrangements with others (or it may be a lesser age in some jurisdictions for certain types of health care or other decisions, or for certain liabilities). Central to legal

¹ See Fernando Volio, “Legal Personality, Privacy and the Family,” in Louis Henkin (ed.), *The International Bill of Rights: The Covenant on Civil and Political Rights* (New York: Columbia University Press, 1981), p. 186.

² See *Ibid.*; Manfred Nowak, *U.N. Covenant on Civil and Political Rights: CCPR Commentary* (Strasbourg: N.P. Engel, 1993); Office of the United Nations High Commissioner for Human Rights, “Legal Capacity: Background conference document prepared by the Office of the United Nations High Commissioner for Human Rights (Geneva: Author, 2005).

³ See Manfred Nowak, *Ibid.*, p. 283.

capacity is the right to enter agreements to give effect to one's own intentions and decisions related to one's person and property; to retain and exercise rights in relation to one's private life; and to be held legally responsible and liable for one's actions in contract, tort, property and criminal law – i.e. to be one to whom legal obligations attach. Depending on the legal system, adults can lose their legal capacity on a legally-prescribed determination that they are not capable of making a particular decision, or indeed all decisions, related to their personal care, health care or property/finances; or that some form of substitute decision making is required to protect their personal interests or to prevent them from undue risk of harm to themselves or others (sometimes agents or representatives are authorized to make this determination on an informal basis). When this happens people can be placed under some form of guardianship or some other substitute decision-making arrangement. **Article 12 calls for an end to such laws where they provide for this determination on the basis of disability, and where they do not provide people with disabilities access to supports and reasonable accommodations to exercise their legal capacity.**

Before the CRPD, the right to legal capacity was also recognized in Article 15 of the *Convention on the Elimination of All Forms of Discrimination Against Women* (CEDAW). Article 15 provides that: "States Parties shall accord to women, in civil matters, a legal capacity identical to that of men and the same opportunities to exercise that capacity." Article 12(2) of the UN CRPD reflects the language of CEDAW in recognizing that "persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life." Presumably, 'others' means those who are non-disabled.

Effectively, the interpretation of Article 16 of the ICCPR, and the provisions of Article 15 of CEDAW and Article 12(1) and 12(2) of the CRPD *extract* the right to legal capacity or the right to act, from the right to be recognized as a person before the law. This means that the right to recognition as a person before the law cannot be diminished on the basis of any of the usual incapacity criteria, but these Conventions appear to provide no restrictions on diminishing the legal capacity to act, provided, since CEDAW and CRPD, that such restrictions are not made on the basis of sex or disability.

Having one's legal capacity to act is central to one's agency as a person. If one can inherit property (thus having one's legal personality recognized as under the predominant interpretation of Article 16 of the ICCPR), but not be able to exchange that property for other assets to pursue one's life goals (because one is found not to have the legal capacity to make the necessary legal dispositions), it is difficult to see how one's full personhood is being recognized and protected. Volio (1981) suggests that

the right to legal personality implies both the capacity to have rights and the capacity to act, and states that “... when the law restricts the rights implied in ‘legal personality,’ it does so by way of exception; by narrow, explicit norms of limited character, usually relating to age, incapacity, etc.”⁴

It appears then that the CRPD’s Article 12(1) recognition of people with disabilities as persons before the law recognizes basic civil rights of people with disabilities – e.g. to be registered at birth, to be free from exercise of arbitrary power by the State, from being sold into slavery, to have fundamental freedoms like freedom of association, etc. protected. This is an important recognition and protection of some of the rights of legal personality or personhood. However, on its own, it falls short of protecting the right to one’s agency, to act in the world by entering legal relations with others and to being a person who is recognized as one who can take on legal obligations of a contractual or tortious nature.

If Article 12(1) (right to recognition as persons) does not challenge and protect against the current systematic denial of legal capacity to many people with intellectual and other disabilities, what is the basis on which to do so? Article 12(2) provides the ground to do so in its recognition that that people with disabilities have a right to legal capacity on an equal basis with others. But what is that basis? Non-disabled ‘others’ enjoy legal capacity to act to the extent that they are not found ‘incapable’ of acting – by virtue of intoxication, inability to protect themselves from undue risk to themselves or others, or what some legislation defines as ‘mental impairment or incapacity.’ But is this not a tautology since some legislation defines incapacity as equivalent to or caused by a disability? And if so, doesn’t the CRPD make any findings of incapacity of anyone at any point a violation of Article 12? And if that is the case, is the defense of ‘incapacity’ in contract or criminal law, or any interventions authorized by the state to make decisions for a person found in need of protection, a violation of the right to legal capacity without discrimination on the basis of disability?

⁴ See Fernando Volio, *op. cit.*, p. 187.

III. Are ‘disability’ and ‘incapacity’ or ‘in need of protection’ necessarily equitable?

In other words, does the CRPD effectively extinguish the validity of the dividing line that the legal category of ‘incapacity’ or similar legal constructs (e.g. in need of protection) has drawn between those deemed legally capable and those deemed legally incapable in some or all respects? This would be the case if certain types of disability and ‘incapacity,’ as the term is used in law, were equitable. The CRPD could then be used to challenge any restriction of legal capacity on the basis of assessed incapacity.

However, on closer examination, it becomes clear that ‘disability’ as the term is defined in the CRPD and ‘incapacity’ or similar legal terms, are **not necessarily** equitable; they operate at different analytic levels. A person *with* a disability may be deemed incapable in some respects, but not necessarily so. A person *without* a disability may be deemed temporarily incapable or in need of protection at a certain point in time. The CRPD defines disability in Article 1 as a long-term condition: “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

On the other hand, a deemed status of ‘incapacity’ or ‘in need of protection’ can be temporary states not equated with disability, and as such have meanings that are distinct from disability. Incapacity or diminished capacity is a defense in contract law for breaching the provisions of a contract. In health law it is a basis for determining whether a person can give informed consent for health care decisions. In criminal law it is a defense from criminal responsibility for one’s actions, or the basis on which one can be declared unfit to stand trial. ‘In need of protection’ is a determination in some jurisdictions that the State can intervene to remove a person from a situation and place him or her in a care arrangement and/or under the substitute decision making powers of a designated authority. In effect, one of the ‘bases’ on which non-disabled ‘others’ enjoy legal capacity, is precisely their right to invoke incapacity, as temporary or as long term as it might be, as a defense in contract, tort and criminal law. It would be difficult to argue that this right to invoke incapacity, as a basis on which ‘non-disabled others’ exercise legal capacity, is a violation of Article 12. Such a defense is foundational to contract, tort and criminal law.

However, where Article 12 would challenge assessments and findings of incapacity is where, by definition as it often is, incapacity is equated with disability. In some jurisdictions, States have imposed very blunt instruments to deny legal capacity – on the basis of a disability status, like a general diagnosis of ‘mental disorder’ or ‘intellectual disability.’ Plenary forms of guardianship or other regimes still in place in a number of countries (like the Wards of Court

system in the Republic of Ireland) remove all legal capacity on the basis of a diagnosis or other assessment that is equated with mental incapacity. In much of the existing legislation, and even recent proposals, there remains an equation between disability and incapacity that the CRPD would challenge – for example defining ‘mental incapacity’ as a ‘mental disorder,’ or assuming that incapacity is ‘caused’ by ‘mental disease’ to use the stereotyping language of some legislation, or that it can be deduced from causes like a dementia.

Increasingly, these approaches to regulating legal capacity have been brought into question and successfully challenged in the courts. More recent statutory reform efforts (in the Republic of Ireland and elsewhere) have focused on the functional test of decision making capacity. This approach to determining legal capacity to act is to be distinguished from a ‘status’ approach (based on disability) or an ‘outcome’ approach based on a prior decisions or patterns of decision making. A ‘functional’ approach to determining decision making capacity is increasingly recognized in both statutory law and jurisprudence and challenges the predominant status and outcome approaches. It is defined as follows:

This approach assesses capacity on an “issue-specific” basis. The approach enables capacity to be determined on a particular matter. Therefore, a decision on one’s capacity in relation to a matter (for example, the capacity to make financial decisions) will not necessarily be determined in the same way or with the same result in relation to another matter (for example, the capacity for human relations). This approach is in the ascendant mainly because it is closer to human rights values and law, favouring a “tailor-made” approach to determining capacity. With this approach there is still a need to guard against paternalistic assumptions which may distort objective assessments of functional capacity.⁵

With its non-discrimination and reasonable accommodation provisions, the CRPD would require that: any findings or assessments of incapacity be definitively disentangled from disability or disability-related ‘causes’; that only a functional, decision-specific test with no reference to disability status or diagnoses be applied in assessing or finding incapacity or a status of ‘in need of protection’; and further that reasonable accommodations and supports to exercise legal capacity be provided in demonstrating capacity.

The aim must now be to ensure that substitute decision making systems no longer target people with disabilities, are invoked only on the basis of incapacity assessed by the functional test, un-related to disability, and only then after state authorities have met a very high threshold of undue hardship in supporting and accommodating an individual with a disability to demonstrate and exercise their legal capacity.

⁵ See, Amicus Brief in the European Court of Human Rights, in the case of D.D. v. Lithuania, Application No 13469/06, by the European Group of National Human Rights Institutions, April 2008.

IV. How do we reconstruct the threshold of legal incapacity?

If the interpretations of Article 16 of the ICCPR essentially suggest that the right to recognition as a person before the law is an inviolable and inalienable right; but that the right to legal capacity to act is not, on what basis do we bring into question the thresholds and criteria on which legal capacity has for so long been equated with disability? It requires revisiting the theory of personhood on which the boundary between those deemed legally capable of acting and those deemed legally incapable gets drawn.

So how *do* we get recognized before the law as persons with a legal capacity to act? What are the criteria? How is the dividing line drawn? And how must we redefine the criteria so that the status of disability is no longer the basis on which legal capacity to act can be restricted or removed all together?

Following Volio (1981), recognition of one's legal personality or personhood implies recognition of both one's capacity to have rights, and one's capacity to act. It is what might be called recognition of one's 'full personhood.' Article 16 of the ICCPR and Article 12(1) of CRPD recognize only half of these rights; they protect only the right to have rights. Thus, they do not protect one's full personhood, which requires protecting the capacity to act as well. To remove that portion of one's recognition of full personhood that enables one to exercise legal capacity or agency, should be seen as a profound violation that requires the highest order of justification.

For most people, the act of having their legal capacity recognized by others is not usually a conscious procedure or administrative affair. It does not usually take place in the courts. It is a culturally-based ascription and often an unconscious one. Social and scientific codes of 'normal' human development have evolved for communication, mental capacity, physical mobility and agility, although throughout history these have been based on assumptions about disability, race, gender, sexual orientation and other grounds. These codes, often discriminatory, are used as a kind of lens in society for recognizing 'persons' – by doctors, bankers, employers, etc. These often unwritten codes enable one party to a legally regulated relationship to affirm that an individual who appears before them to give informed consent, or apply for a loan, or sign an employment contract – is indeed a person to whom legal rights and obligations can attach in entering this relationship.

Throughout history many individuals have not been considered full persons before the law. The struggle for civil, political, social and human rights has in many ways been about the criteria of full personhood, including legal capacity that will be recognized by the law, given that these criteria advantage certain groups over others. Human rights movements continue to challenge

racialized and gendered codes for recognizing individuals as full persons, and many legal codes of personhood have changed as a result. So the criteria of what it means to be recognized a full person before the law – the criteria of what it means to have rights and to act on those rights – can be changed in law, policy and practice.

The disability rights movement knows what this struggle is all about, and that the laws for recognizing persons as equal are not yet disability-neutral. Article 12 of the CRDP is an historic opportunity to make fully visible the codes or criteria that disentitle people with disabilities from recognition of equal and full personhood before the law, and to change those codes so they are inclusive without discrimination on the basis of disability.

To make these changes in law, policy and practice we first need to know what criteria currently in law tend to disentitle recognition of legal capacity from people with disabilities. With this understanding, States Parties can re-write the criteria for recognition to make them disability-neutral and therefore consistent with Article 12.

A. Limitations of the criterion: ‘understanding the nature and consequences of all options’

One of the main criteria used to disentitle people with intellectual disabilities from the right to legal capacity, in particular people with more significant intellectual disabilities, is that a person must be able to understand the nature and consequences of all the options available to him or her in any particular situation, or with respect to any particular decision, and to voluntarily make and communicate a clear choice. Most mental capacity laws, protection laws, substitute decision making laws, and criteria of legal capacity in contract, tort, property and criminal law rest on this criterion. Simply stated, it means that to be recognized as a person with legal capacity to act, one must have the capabilities to understand the nature and consequences of one’s actions or inactions, or of a decision one may want to make, or contract one may wish to enter. Within the context of a range of choices, a person must be able to act voluntarily and to be able to communicate their decision to others. For many people with disabilities, even further tests are often applied, like how ‘reasonable’ is the decision a person wants to make, whether it is in their ‘best interests.’ Both of these tests have been used in a discriminatory manner to remove from people the right to determine the direction of their own lives, and their ‘dignity of risk.’

Many people with intellectual disabilities are not able to meet the usual test of decision-making capability – understanding the nature and consequences of all available options, and communicating a clear choice in ways that most others understand. Indeed, most people *without* disabilities do not meet this criterion, if one considers the complex health procedures which a patient may need to decide on, or the complex legal and financial transactions which people authorize everyday with their signatures. Nonetheless, this is the test that gets

triggered when others question the legal capacity of a person with an intellectual disability to make a health care decision or sign a lease agreement for an apartment, or even open a bank account.

But is this the only test of legal capacity and demonstrating one's decision-making capability?

B. Expression of intention and will as human agency

What are the actual 'tests' of legal capacity and decision-making capability that most people have to demonstrate in their day-to-day affairs? Most definitions of contract capacity, for example, in any number of case law books, or even the authoritative Restatement (Second) of Contract Law published by the American Law Institute, and also that of the 'Principles of European Contract Law' of the European Commission, simply define 'intention' as the basis of a person's capacity to enter a contract. If there is mutual intention to contract, there is a contract, and a decision to contract is thereby recognized. What needs to be demonstrated is intention to act. This threshold for recognizing legal capacity is in fact pretty low. The vast majority of people with intellectual disabilities could easily step over it, if they were not blocked by disabling assumptions that immediately set the threshold that much higher when it comes to their desire to enter contracts or make agreements with others. Moreover, jurisprudence has also found that the basis of a 'justiciable right to decide' is that a person can express their intention or happiness at choosing one course of action over another.

This idea that intention is the basis of human action and reflects human agency is consistent also with the theory of human action that analytic philosophy, and the philosophy of law turn attention to, with the question: How are we to determine that a particular set of events in which a human being was involved represents intentional action on the part of a human agent to whom decisions and consequences can be attributed? While this area of analytic and legal philosophy has a long and rich tradition, there is substantial agreement around the set of ideas that what constitutes human agency is action which is informed by intentions, which are motivated by a person's beliefs and/or values about things they want or don't want. How we know whether action is intentional lies in how we describe the actions of others and their consequences as intentional or not.

For example, where some might describe a person's behavior, through a psychological assessment, as the sign of 'irrationality,' others, who have personal knowledge about the person, can re-describe his or her actions as intentional; that is, the behavior communicates an intention or will to do or not to do something. In this account of intention, what is critical is that another person or group of people who know a person well can provide a description of his or her behavior that draws the connection between a person's intention and behaviour.

In their description are made the links between a person's intention or will, the actual things a person does, how they move, the sounds they make, the things they want to happen, and the interventions of others to assist a person in giving effect to those intentions; helping that person carry out, through consequential actions, the intentions they set. Through what Joel Feinberg calls the 'accordion effect,' the descriptions and re-descriptions of human action and their consequences can be told and written to reveal human agency, or to deny it.⁶

This criterion of legal capacity to act - that one is able to express their will and intention to do or not to do something, and that it serves as a basis for agency in at least some description - has strong foundations in law and philosophy. It is much more disability-neutral and inclusive than the criterion of demonstrating understanding of the nature and all consequences of a range of choices available, to which people with intellectual disabilities are so often subject.

C. Personal identity: a 'narrative' approach to human agency

The expression of will and intent is both legally and philosophically sound as a basis for ascribing personhood and human agency. However, on its own, it may still not be enough for some parties to recognize the legal capacity and decision making capability of an individual with more significant disabilities. They may not be convinced that a person's will and intention expressed and described in one situation or at one point in time, can be trusted enough over time to constitute their intention as the basis of legal relations like a contract. This is the criterion of 'personal identity' first formulated by the Enlightenment philosopher John Locke in the 17th century. His related theory of the 'continuity of consciousness' through time as the basis of self-consciousness influenced major political philosophers including Jean-Jacques Rousseau and Immanuel Kant and their use of 'reason' and rationality as the tests of moral and legal personhood and capacity to act.

When the usual criterion of legal capacity states a person must understand the nature and 'consequences' of a range of choices and decide among them, the test is requiring a measurement of 'personal identity.' That is, the test is requiring, on the part of an individual, a capacity for memory, so that the person who acts to enter a contract at one point in time, can be trusted by the other party to understand its 'consequences' for their obligations into the future. Thus, testing for memory is often one of the main ingredients of capacity testing. It is why people with significant intellectual disabilities – for whom remembering and generalizing learning from one situation to another may be difficult without supports; or who, like anyone else, may demonstrate different states of

⁶ See, for example, Joel Feinberg, *Doing and Deserving* (Princeton: Princeton University Press, 1970); Donald Davidson, *Essays on Actions and Events* (New York: Oxford University Press, 1982); and H.L.A. Hart and Tony Honore, *Causation in the Law*, 2nd ed. (Oxford: Clarendon, 1985).

consciousness and memory on an episodic basis – are so often found incapable or in need of protection and thus substitute decision making.

This idea of personal identity has been roundly critiqued in moral philosophy of personhood; and jurisprudence in some competency cases can be read similarly. Moral philosopher Paul Ricoeur, feminist philosopher Seyla Benhabib, Alisdair MacIntyre and a growing number of other philosophers present an alternative account of personal identity in the idea of the ‘narrative self.’⁷ In *Oneself as Another*, Ricoeur challenges directly the philosophical and legal notion that we can only demonstrate that we are the same person through time by showing that we have the same mental state through time. Rather, he suggests, we all experience discontinuities in ourselves, we all become ‘other’ to ourselves through changes in character and mental state over time, conflicting desires and wishes, changes of mind. What ascribes personhood to us, as a person who is to be trusted through time, is that we can answer the question – ‘Who are you?’ ‘Who is she?’ – with a coherent narrative, a life story that makes sense of all the changes, and losses, and new directions and discontinuity, of illness and of healing, that make up any person’s life. We become a person to the extent that we can, or that others who have personal knowledge about us can, tell a coherent story about who we are.

It is from the vantage point of these alternative criteria of full personhood and legal capacity – of 1) my capacity to express my will and intent, at least to others who know me well, and who can then ascribe agency to my actions in their descriptions to others; and 2) being able to tell ‘who’ I am, my life story of values, aims, needs and challenges, or having others do that for me – that we can build a more robust and inclusive legal recognition of what it means to have legal capacity and decision-making capability. It is on the basis of these criteria that we can achieve disability-neutrality in securing equal recognition of legal capacity without discrimination on the basis of disability.

⁷ See, for example, Paul Ricoeur, *Oneself as Another*, Translated by Kathleen Blamey (Chicago: University of Chicago Press, 1992); Seyla Benhabib, *Situating the Self: Gender, Community and Postmodernism in Contemporary Ethics* (Cambridge: Polity Press, 1992); Alasdair MacIntyre, *After Virtue: A Study in Moral Theory* (University of Notre Dame Press, 1984, 2nd edn.).

V. What are the supports needed to exercise legal capacity on an equal basis with others?

If we accept these more inclusive criteria of full personhood and legal capacity as a starting point, it is important to take a systemic approach to the 'supports' to exercise legal capacity as provided for under Article 12.3. This is required given the long-standing and historic disadvantage that people with disabilities face in having their right to legal capacity recognized, protected and promoted. Recognition of needed supports should include:

1. Decision-making assistance for demonstrating and exercising one's full personhood including one's legal capacity to act. Assistance would refer to provision of any type of assistance to an individual in making a decision, expressing their will, or having others help communicate their personal identity to potential parties to a legal arrangement. Assistance provided on an informal basis would be recognized and would include aids, interpreters, etc. as well as supported decision-making networks or representatives. These are people designated by an individual on the basis of trust and commitment to assist a person in making decisions and to help represent them in exercising legal capacity but without being substitute decision makers. It would also include assistance to other parties to understand a fuller conception of personhood, alternative means of communication, and their duty to accommodate others' unique expressions of intention and personal identity. Thus, decision-making assistance would include:
 - Informal assistance of family and friends in making daily decisions and carrying out activities of daily life
 - Individualized plain language assistance, assisted/adaptive communication, visual aids, etc.
 - Supported decision-making representatives/ networks (which includes assistance in developing and maintaining supported decision-making representatives/networks, registration systems so that individuals can designate those who are to represent and assist them in decision making, conflict mediation, monitoring)
 - Support to other parties engaging in relations with an individual with a disability – to help those parties understand how a person communicates, and to meet their duty to provide reasonable accommodation
 - Protections from liability for support decision-making representatives/ networks and other parties in assisting a person in making decisions, and for entering agreements with an individual via supported decision making. Liability should be protected provided

such actions are done with a duty of care and not negligence. Practice guidelines would need to be developed

2. Information and awareness campaigns about human rights, legal capacity, decision-making assistance, including supported decision-making networks;
3. Advocacy support to individuals to exercise and protect their right to legal capacity;

Community support systems that provide that provide individualized, flexible and responsive disability-related supports.

VI. How are assisted decision making, consent and liability to be managed in daily life?

Decision-making assistance in (1) above can be of a formal or informal nature. Most of us make our decisions interdependently, with the assistance of others. The vast majority of our decision-making assistance usually comes from our family and friends. Once in a while we need the assistance of a lawyer to advise us or help manage our affairs. For people with intellectual disabilities it is no different. The majority of decision making-assistance should be informal, given in the context of valuing personal relationships in their lives, in regular communities where they are known and valued as contributing members. In these situations, at home, or with their doctor, those at the bank, at their workplace, the college they go to, the providers of any paid services, their faith community, those at the pub and the recreation centre all know the individual as a person. Through the bridges built by their family and friends, others are able to communicate with the individual and assist in and respect their decision-making autonomy. More and more people with intellectual disabilities, even with very significant disabilities, are living their lives in regular neighbourhoods and communities just like this.

However, we also know that the majority of people with intellectual disabilities, their families and their communities have not been supported to enable community living and inclusion that result in these outcomes. The result is that many are not living in relationships with others that help nurture their unique life goals and path, their contributions and potential. Thus, they are not seen by others to have the personhood, much less the legal capacity to make the daily decisions and the big decisions about their lives. In this context, others make decisions for and about the individual on a regular basis whether under formal or informal substitute decision making.

One of the main challenges in a law reform strategy to recognize the right to legal capacity and decision-making assistance is how to account for the vast majority of decisions that need to be made in a person's daily life – decisions about personal care and activities of daily living, which can include decisions about nutrition, personal hygiene, bathing and toileting assistance if needed, taking regular medications, where to go in a day, what to do or not do, etc. When assistance is needed from others to carry out these activities, there is a concern by many service providers of disability-related supports and informal carers as well (family, friends, volunteers) about how the personal decisions involved, for instance taking regular medication, or the physical touching of a person's body in assisting with lifts, toileting and bathing, get made, and the consent required for these purposes.

These are important concerns. Self-determination and autonomy are often realized most profoundly in the small decisions of daily life, decisions which over days and years add up to the direction and quality of one's life. How best to manage consent and capacity to consent in these contexts? How best to protect the liability of those providing assistance in care and daily life?

There have been three main approaches to respond to this concern:

- Declare the person incapable and appoint a substitute decision maker - a family member, a 'public guardian' or even the service provider. Liability of those providing daily care is covered to the extent that due diligence is taken in carrying out assistance in daily care and activities.
- Provide for agents like a 'legal assistant' who is mandated by the courts or other state authorities to assist a person in managing decision making in daily life and to make substitute decisions as needed. This regime is less restrictive than guardianship, but leaves the discretion up to the agent about when they are making assisted or substitute decisions.
- Protect 'informal decision making.' This scheme, implemented in the UK and being further explored in the Republic of Ireland, provides statutory protection for 'informal decision making.' Care providers are protected from liability in making substituted decisions to the extent that providers take steps to assure themselves the person is not capable of making the decision, take the person's wishes into account and exercise due diligence.

All of these schemes are based effectively on a 'functional test' of capacity. A primary aim is to protect care providers from liability for acting without consent in daily decisions. However, the framing of the problem is constrained by the assumption that recognition of legal capacity rests entirely on the criterion of understanding the nature and consequences of all options, and communicating those in ways that most others understand. More expansive criteria like those outlined above provide for a fourth option.

- In situations where others (including those providing assistance in activities of daily life) may not be able to fully understand (at least at first) how an individual communicates or discern their intentions, provide for an individual to be able to appoint supported decision-making/networks or representatives, as outlined above. To the extent that a individual can designate representatives who have personal knowledge about and commitment to the person, who can understand their ways of communicating intention, and who can present the individual's 'personal identity' to others, that individual's full legal capacity is protected. Supported decision-making networks/representatives can work with those providing daily assistance to understand a person's needs, wishes, ways in which the person will accept being touched, how they communicate. Statutory regimes can still provide for protections from liability for supported decision-making networks/representatives and service providers for assisting a person in carrying out their daily activities on this basis, to the extent they all exercise due diligence and are not negligent in their responsibilities.

VII. How should decisions be made about who gets what type of decision-making assistance to exercise legal capacity, how much, and when?

To guide law reform efforts consistent with a reformulation of the criteria of full personhood and legal capacity, we might begin with a general concept of decision-making assistance in the exercise of legal capacity, both informal and formal, as defined above.

However, in order to maximize individual autonomy it may be necessary to distinguish between people who may require assistance, but who want to exercise decision making on their own, without formally designating representatives; and those who may require representatives/supported decision-making networks to assist. We also need to distinguish situations where people who may require supported decision-making networks/representatives to exercise legal capacity actually have those networks and relationships in their lives, and situations where they do not. This is necessary so that State interventions do not unnecessarily restrict autonomy in the provision of support and, at the same time, maintain the integrity of supported decision making as a form of decision-making assistance and not simply a more supportive substitute decision-making approach. Therefore, it could be helpful to recognize two distinct decision-making statuses, both of which provide people with full legal capacity, and to distinguish both from substitute decision making:

- ***Autonomous decision-making status*** – under this status a person is recognized as someone who can make and communicate his or her decisions in ways that other parties are able to understand, possibly with some individualized assistance like visual aids, informal advisors, plain language, or augmentative communication technologies. However, this assistance is short of supported decision-making representatives/networks that are chosen by the individual and legally mandated to assist and represent a person in legal relations and agreements. Under this autonomous status, the person would not require others to represent him or her in entering contracts, giving informed consent, instructing counsel, etc.
- ***Supported decision-making status*** – This is a status which respects and protects a person in exercising their full legal capacity, as with autonomous decision-making status. However, it is based on an individual selecting others to represent him or her in making and exercising decisions. Supported decision-making networks are based on a fiduciary relationship of trust with an individual. They are a group of people who commit to assisting that person make and carry out decisions consistent with their intentions and life goals, and in the context of long-term

personal relationships and knowledge of the person. For the majority of people, informal support networks suffice. However, in some situations people may require legally-recognized supported decision-making networks because even with accommodations others are unable to understand their unique forms of communication, or may not be able to recognize their personhood without the formal intervention of particular representatives recognized for this purpose. The capacity for a person to appoint a support network, who will act in a fiduciary relationship to the individual, is a lower threshold than the usual standards of contractual competency. It is the capacity to identify others in whom one trusts, and to in some way signal that identification.⁸

The reason for distinguishing supported decision-making status from autonomous decision-making status – both of which ground a person’s full legal capacity – is that an individual’s need for some minimal assistance in exercising legal capacity should not be a reason necessarily to impose on him or her the requirement of a representative or supported decision-making status. That is, we must be careful about the ‘slippery slope.’ We must be concerned that in efforts to provide people with decision-making assistance, we do not necessarily require them to have formally recognized supported decision-making networks/representatives.

- ***Substitute decision making?*** – What about people who are currently under substitute decision making and who may not be able to meet the criteria of personhood without significant assistance from others, and who are without valuing personal relationships? This is the case for many people with intellectual disabilities. Because of being confined and isolated, they do not have people or supports in their lives who know them well and value them, and that would help them have their personhood recognized before other parties and the law. Hopefully, in the future this should not happen, because under the CRPD people have a right to the supports they need to maximize their potential, to be fully included and participate in society, live independently in the community with others, to have their personhood fully recognized, and to exercise their legal capacity. But what should States Parties do now?

Under Article 12, there is a presumption, or there should be, that all persons currently under substitute decision making have full legal capacity until proven otherwise, according to more inclusive criteria of legal personhood along the lines outlined above. We know that many people with intellectual disabilities have been placed under substitute decision making only on the basis of their disability status. With minimal or possibly no decision-making assistance, many could fully exercise their legal capacity. A fuller range of supports as defined

⁸ For an example of a statutory statement of the threshold of ‘incapacity’ for appointing supporters/representatives, which shifts the burden to others parties, see British Columbia, Canada, *Representation Agreement Act*.

above would still need to be put into place to maximize the potential of people to maintain and exercise their legal capacity.

However, for those who may require more formally recognized supported decision making to maintain legal capacity, and who are isolated and alone, a critical concern is that they could have ‘supported decision makers’ appointed *in name* only. In many instances, such supporters would be acting as substitute decision makers. Such arrangements could undermine the integrity of supported decision making as a status with full legal capacity.

Provision for reasonable accommodation – Provision of reasonable accommodations may provide part of the answer to this challenge. Under Article 5 of the CRPD States Parties must provide for reasonable accommodations to ensure that persons with disabilities are able to enjoy all the rights and freedoms outlined in the Convention. This obligation also applies, then, to Article 12. It may be more consistent with advancing individual rights to legal capacity that in situations where an individual is currently under substitute decision making because of a lack of assistance, or lack of personal relationships with others who know a person well enough to be supported decision makers, that we recognize that fact. If we do not, what would it mean to say that one of the legal safeguards on supported decision making under Article 12.4 is that it not be substitute decision making by another name?

If we name that this boundary point currently exists and that we need to do everything possible to prevent its further application, it could be the trigger for assessing whether reasonable accommodations have in fact been made. Such accommodations would require investment in decision-making assistance including supported decision-making networks for legal capacity. It provides the point at which to assess whether reasonable accommodations have been made, to the point of a very high threshold of undue hardship, in assisting an individual to actually be recognized as a person before the law and provided with the assistance/support to exercise his/her legal capacity. Appropriate safeguards and requirements would have to be established for requiring ongoing investment in supports for persons who remain under substitute decision making so that they can attain legal capacity as soon as possible.

Burden of proof for demonstrating legal capacity – It is critical to ensure that individuals themselves do not have to prove they meet externally-imposed standards of capacity beyond the inclusive criteria of full personhood and legal capacity suggested above. Moreover, the demonstration that they may not meet such a standard should fall on other parties, who must operate within clear guidelines for the duty to accommodate. Given how foundational the right to recognition as a person before the law and the right to legal capacity are, a very high threshold for the duty to accommodate should exist for all other parties to contracts and legal relations. Under Article 5, the State would have obligations to assist in developing the capacities of physicians and others to engage in legal

relations with persons with disabilities, and the burden of proof that someone is not capable would shift in their direction.

VIII. Suggested Directions for Law Reform under Article 12 of the CRPD

The analysis above suggests six broad directions for law reform to realize the rights protected under Article 12.

1. Remove equations of disability with legal incapacity

It is critical to examine and reform provisions in contract, criminal, substitute decision making and other laws to remove any thresholds of legal capacity based on categories of disability or stereotyping language based on disability. Any criteria for recognizing personhood or legal capacity must be based on inclusive and disability-neutral criteria. Any findings or assessments of incapacity must be definitively disentangled from disability or disability-related 'causes'; only a functional, decision-specific test with no reference to disability status or diagnoses must be applied in assessing or finding incapacity or a status of 'in need of protection.'

2. Ensure access to needed supports to demonstrate and exercise personhood and legal capacity

Provide for a systemic approach to supports as outlined above including supports for assisted decision making and development of supported decision-making networks, information and awareness, individual advocacy and reform of community supports systems.

3. Recognize different decision-making statuses through which legal capacity is exercised

In order to ensure people access supports to exercise legal capacity in a way that maximizes individual autonomy, it may be helpful to explore a two-step approach to recognizing need for decision-making assistance. The approach would recognize the two types of decision-making status described above (autonomous and supported decision making), both with full legal capacity. In making determinations about whether a person even requires decision-making assistance if another person questions their decision-making capacity, and if so, the status through which a person would best be assisted, the following kinds of questions might be asked.

- a. First and foremost, is the person able, with or without, individualized assistance as needed (visual aids, plain language, interpreters, assistance to other parties to understand, etc.), but short of mandated supported decision-making representatives/networks, to communicate his or her will and intention to others sufficient for all the parties to enter into needed legal arrangements and have decisions made consistent with the person's intentions?

- b. If not, is the person able to choose a supported decision-making network of trusted support persons/representatives to assist the individual in making decisions and in communicating his/her intentions and personal identity to others?

4. Provide for 'reasonable accommodations' in provision of decision-making assistance

The 2-step approach to recognizing the need for decision-making assistance suggests a related approach for defining the tests of reasonable accommodation.

- a. Is the person perceived as able to make and communicate this decision on his/her own, without support (functional test as outlined above)?
- b. If not, is the person able, *with some decision-making assistance*, to communicate his or her intention sufficiently for the purposes of this decision/action? If so, what type of assistance is necessary for this purpose?
 - i) Is the person able to communicate his/her intention, with accommodations that are needed to manage this particular decision/act or enter this legal arrangement – like an interpreter, translator, augmentative communication device, communication assistance to other parties – but short of a mandated supported decision-making network/representative?
 - ii) If not, is the person able to engage a supported decision-making network/ representatives who will assist in making decisions and communicating the person's intentions and personal identity to others? Recognition of the role of the supported decision-making network, in a fiduciary relationship with the individual, and assistance in facilitating the development and maintenance of this network is the main accommodation required in this case. Other accommodations in b(i) above may also be needed in this case.
 - iii) Have reasonable efforts been made, to the point of undue hardship, to provide these accommodations including – where it is determined that b(ii) accommodations are required – investment in development of valuing personal relationships and personal knowledge that would help establish supported decision-making networks?

5. Take steps to enhance and protect freedom of contract for people with disabilities

People with disabilities have often been denied the opportunity to enter contractual relationships with others that could advance their social and

economic well-being, on the basis that they lack contractual competency. Steps should be taken by States Parties and regional institutions to consider reform of statutory provisions and principles of contract law in the name of assuring 'freedom of contract' for people with disabilities. Reforms might include protection of clauses that contract away recourse to a contractual incapacity defense in certain circumstances; representation by third party supported decision-making networks and protection of those representatives from liability for contracts they negotiate on behalf of an individual; and affirmation of capacity for contracting purposes, according to the criteria for personhood and for providing reasonable accommodation for this purpose, as suggested above.

6. Launch pilot initiatives for supported decision making

Much can be learned from pilot initiatives for reform of law, policy and practice. Inclusion International is currently supporting pilot demonstration initiatives for supported decision making in Hungary and India, which are based on its eight-point Agenda for Supported Decision Making outlined in the Foreword to that document. A Pilot Project Design Guide has been created for these initiatives, which is proving helpful in design and implementation. It could be used to replicate projects in other countries.

IX. Conclusion

Article 12 of the CRPD demands a fundamental re-alignment in the historic relationship between state 'protection' and the right to autonomy that has so systematically disadvantaged people with disabilities. To achieve this re-alignment States and civil society need to operate with a more inclusive definition and criteria of full personhood and legal capacity, adequate supports and the right to reasonable accommodation. With these conditions sufficiently realized, we can fundamentally redraw the ground for recognizing, promoting and protecting the right to legal capacity on an equal basis, without discrimination on the basis of disability. This is the goal to which our law reform efforts must aspire. Article 12 requires nothing less.