The Support Model of Legal Capacity: Fact, Fiction, or Fantasy?

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INTRODUCTION

Since the entry into force of the 2007 United Nations Convention on the Rights of Persons with Disabilities (CRPD), there is an emerging consensus in international human rights discourse on the notion that all human persons, regardless of their decision-making capabilities, should enjoy “legal capacity” on an equal basis—that is, the right to be recognized as a person before the law and the subsequent right to have one’s decisions legally recognized.1 The United Nations Committee on the Rights of Persons with Disabilities has stated that the right to legal capacity on an equal basis with others requires that decision-making mechanisms based on a philosophy of “support” replace substituted mechanisms such as adult guardianship.2 “Support” in the exercise of legal capacity refers to a broad cluster of decision-making arrangements, all of which have at their core the will and preferences of the individual. By contrast,

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substitute decision-making regimes permit the removal of legal capacity from certain individuals and vest it in third parties, who generally base decisions on the perceived objective best interests of the person. Most legal systems in the world have not yet made the shift from substitute decision-making to a support model, and many have questioned whether such a radical reform is even possible.³

In this Article, we explore a plausible legal framework within which to ground a support model of legal capacity and fully replace regimes of substituted decision-making. We ground our argument in the lived experience of people labeled with a disability. We focus particularly on individuals with cognitive disabilities, as they are generally more likely to have their decision-making ability called into question, and consequently, to have their legal capacity denied. However, we claim that such a system of support will ultimately benefit all individuals, not just persons with disabilities. The Article further examines reform efforts underway and the contributions of legislative change and judicial activism. Since the entry into force of the CRPD, many countries have begun to reform their laws on legal capacity, as described below in Section III. While significant challenges remain to ensure the full replacement of substitute decision-making regimes, international developments described in Sections III and IV, are clearly trending towards the recognition of support to exercise legal capacity.

The denial of legal capacity to certain groups of persons on the basis of perceived characteristics of inferiority is not a new phenomenon. Indeed, women, slaves, and racial and ethnic minorities, among other groups, have long been denied legal capacity. However, at present, it appears that a diagnosis of a disability, and in particular a cognitive disability,⁴ is the one remaining characteristic upon which contemporary society is willing to justify stripping legal capacity from a person. Take for instance the following example, adopted from the facts of a European Court of Human Rights case, as reported by the Mental Disability Advocacy Center:

You have a verbal argument with your girlfriend. She calls the police, and when they arrive, she explains that you have a diagnosis of schizophrenia, so they take you to a psychiatric hospital. On arrival at the hospital, you refuse to

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³ This statement is based on authors’ experiences engaging in legal capacity law reform around the globe. For a discussion of the challenges of reform specifically in the United Kingdom see Peter Bartlett, The United Nations Convention on the Rights of Persons with Disabilities and the Future of Mental Health Law, 8 PSYCHIATRY 496 (2009).

⁴ In this article, the term cognitive disability is used to describe a broad range of disabilities, including psycho-social (mental health) disabilities, developmental disabilities, acquired brain injuries, and dementia.

take neuroleptic drugs because when you took these during your previous hospital stays they negatively impacted your eyesight. The psychiatrists ignore your wishes, stating that your illness means you do not understand the treatment required, and that you do not have legal capacity to make this kind of decision. They forcibly administer the medication, and as a result your vision is impaired for a year. You are detained for twenty days inside the psychiatric hospital. You cannot complain to a court because your guardian (a local government bureaucrat you have never met) has consented to your placement in the hospital and your treatment, so you are considered a “voluntary” patient.

As the above example demonstrates, the removal of legal capacity can have significant consequences, even when it occurs in relation to a single decision or area of decision-making (e.g., consent to medical treatment or financial decision-making). Where legal capacity is removed, one’s ability to challenge the removal or appointment of a guardian is, at best, compromised and often non-existent. Similarly, a disabled person’s views with respect to treatment are often inappropriately ascribed to the illness or disability, equated with a lack of understanding of the situation, and therefore ignored.

In the case above, the circumstances in which the plaintiff found himself are certainly not unique to the Czech Republic, where the case occurred. Similar instances take place daily in other countries, including the United States, where a combination of adult guardianship provisions and mental health laws allow for individuals to be detained and treated against their will. Once detained, individuals have little recourse to legal redress when a guardian has consented to detention and treatment. These grievous human rights violations cannot be addressed simply by introducing more due process protections or merely allowing more weight to be given to the individual’s wishes. These types of incremental changes, while important, will not address the totality of the discrimination experienced by persons with disabilities, and those with cognitive disabilities in particular. The denial of legal capacity is a serious interference with an individual’s civil rights. It is paramount to the denial of personhood because it leaves the individual stripped of the freedom to engage with society to


have her will and preferences realized on an equal basis with others. Only by a radical re-balancing of autonomy, and protection across various legal frameworks, and through recognition of legal capacity as a universal attribute inherent in all individuals by virtue of their humanity, can true reform be achieved.

I. THE CASE FOR A SUPPORT MODEL OF LEGAL CAPACITY

Legal capacity includes both the ability to hold rights and to be an actor under the law (e.g., to enter into contracts, vote, and marry). The law’s recognition and validation of an individual’s will and preference is the key to accessing meaningful participation in society. Mental capacity—the decision-making ability of an individual—is distinct from legal capacity: mental capacity naturally varies among individuals, and may differ depending on environmental factors.

In modern times, the use of the functional approach to legal capacity denial has conflated the concepts of mental and legal capacity. The functional approach came into widespread use only in the late twentieth century, and the CRPD is the first major international human rights instrument to bring attention to the violations that occur under such an approach. The functional approach purports to assess mental capacity and deny legal capacity accordingly. An individual’s decision-making skills are accepted as a legitimate basis for denying legal capacity, and lowering one’s status as a person before the law. Because functional tests of mental capacity require either a “mental disability” or a finding of an “impairment of the mind or brain,” it is almost exclusively people with cognitive disabilities who have their legal capacity restricted on the basis of perceived decision-making skills.


10. Other approaches to legal capacity have also embraced the conflation of legal and mental capacity. For a discussion of the functional approach as well as other approaches to legal capacity law, see Dhanda, supra note 1.

11. For a discussion of the functional approach in US law, and the need to move to a system compliant with Article 12 of the CRPD, see Kristen Booth Glen, Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship and Beyond, 44 COLUM. HUM. RTS. L. REV. 93 (2012).

12. The England and Wales Mental Capacity Act allows third parties to make ad hoc determinations that an individual’s decision-making skills or mental capacity are lacking. The third party may then impose her own determination of what is in the best interests of the individual, with no obligation to follow the will and preference of the person. See Mental Capacity Act 2005, c. 9, §§ 2-4 (Eng.); COURT OF PROTECTION PRACTICE: 2012 126 (Gordon Ashton ed., 2012).

13. See, e.g., Mental Capacity Act 2005, c. 9, § 2(1) (Eng.); N.Y. MENTAL HYG. LAW §81.02 (4)(III) (McKinney through L.2013, chapters 1 to 340); CAL. PROB. CODE § 1828.5(a).

14. In 2012, 375 people in Ireland had their legal capacity removed and were placed under wardship. Only seven of those people were reported as being placed under wardship for reasons
The most obvious human rights violation perpetrated by the functional approach is its facially discriminatory nature. Article 12 of the CRPD requires respect for the legal capacity of people with disabilities on an equal basis with others. Discrimination is defined in Article 2 of the CRPD as “any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.” Functional approaches that permit legal capacity denial only to individuals with cognitive impairments are facially discriminatory and interfere with the right to equal recognition before the law, guaranteed in Article 12.

If a functional approach were made facially neutral by eliminating the requirement of “impairment,” it would allow for the denial of legal capacity to any individual perceived to not understand the nature and consequences of her actions. Non-disabled people may realize what a high standard this is only when faced with having to meet it themselves—yet, as a society, we have continued to apply this high standard to individuals with cognitive disabilities. Due to stigma related to disability, there would still be a high risk of this system being discriminatorily applied to individuals with disabilities. Furthermore, even a facially neutral functional test of capacity that adequately deals with the stigma of disability would not adhere to Article 12 in its entirety. Article 12 calls for not only the respect for legal capacity on an equal basis but also places an obligation on states to provide access to the support necessary for the exercise of legal capacity. This requires the replacement of substituted decision-making regimes with supported decision-making ones.

The monitoring body of the CRPD has deemed substituted decision-making regimes incompatible with Article 12 of the Convention. Although the


17. An example of such an approach, which uses the criterion of “impairment of, or a disturbance in the functioning of, the mind or brain,” is the functional test of mental capacity in the Mental Capacity Act 2005, c. 9, § 2(1) (Eng.).

18. The type of functional test that is used varies by jurisdiction and not all use the term “impairment.” As discussed, England and Wales use this term, whereas the Irish Assisted Decision-Making (Capacity) Bill 2013 contains an assessment of “mental capacity” which does not include a diagnostic step of identifying an impairment in the functioning of the mind or brain.


20. See, e.g., Consideration of Reports Submitted by States Parties Under Article 35 of the Convention: Concluding Observations, Tunisia, Committee on the Rights of Persons with
Committee on the Rights of Persons with Disabilities has not yet provided a conclusive definition of substituted decision-making regimes, a tentative proposal has been made in the Committee’s Draft General Comment on Article 12. In this document, the Committee states that a substituted decision-making regime is a system where: (1) legal capacity is removed from the individual, even if just in respect to a single decision, (2) a substituted decision-maker can be appointed by someone other than the individual, and, (3) any decision made is bound by what is believed to be in the objective “best interests” of the individual as opposed to the individual’s own will and preferences. The Committee’s Draft General Comment also states that “functional tests of mental capacity . . . that lead to denials of legal capacity violate Article 12 if they are either discriminatory or disproportionately affect the right of persons with disabilities to equality before the law.”

Instead of systems of substituted decision-making, the CRPD calls for support to exercise legal capacity. In a legal system that follows the support paradigm, there would be no denials of legal capacity; instead, it would be accepted as a universal attribute. Supports for exercising legal capacity would be offered to the individual, but not imposed. These supports could include relatively minor accommodations, such as accessible information and additional time to make a decision, or more formal measures, such as supported decision-making agreements nominating one or more supporters to assist the individual in making certain decisions and communicating them to others. “Facilitated” decision-making would be available where someone could be appointed to make a decision on behalf of another individual as a last resort. Safeguards would be in place to ensure that the decision fully respects the individual’s “rights, will and preferences,” as far as they can be ascertained. Facilitated

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22. Id. at ¶ 21.
23. See, e.g., Consideration of Reports, Tunisia, supra note 19 at 4; Consideration of Reports, Spain, supra note 19 at 5.
24. Draft General Comment on Article 12, supra note 20 ¶ 8.
25. Id. at ¶ 25(g).
26. For an example, see supported decision-making agreements under the British Columbia Representation Agreement Act. Representation Agreement Act, R.S.B.C. 1996, c. 405 (Can.).
decision-making would be used only as a last resort when others cannot determine the will and preference of the individual after exhausting all efforts.29

II.
The Support Model in Practice: Positive Reform Trends

When the law recognizes an individual’s competency to make her own decisions there are broad effects. Legal recognition of an individual’s power to make decisions fosters capability development across many areas of life. Amita Dhanda argues that “capability development can happen only if every human being is accorded the opportunity to so live life as to realize his or her own inner genius.”30 The legal recognition of an individual as competent to make decisions also affirms the power of choice, thereby enabling individual development.31 The support paradigm fosters social solidarity without sacrificing the recognition of equal legal capacity. By offering the choice of assistance, the supported decision-making paradigm removes the illusion that legal capacity can be exercised only through self-sufficiency. This opens the door for a societal dialogue about the interdependence of all individuals.32

The paradigm of support adapts to a sliding scale of abilities,33 rather than being a binary model of capacity or incapacity as many substituted decision-making models are.34 It does not create a separate category of people who are “legally incapacitated” with regard to some or all decisions—which has been argued to amount to institutionalized discrimination and subordination.35 This categorization of individuals, whereby there is one category of persons whose

30. See Dhanda, supra note 1, at 436.
33. See, e.g., Bach & Kerzner, supra note 27.
34. See S. Herr, Self Determination, Autonomy, and Alternatives for Guardianship, in THE HUMAN RIGHTS OF PERSONS WITH INTELLECTUAL DISABILITIES 440 (Stanley S. Herr et. al., eds., 2003); Dhanda, supra note 1, at 433, 459–60.
35. Minkowitz, supra note 1 at 406.
decisions are recognized and another category of persons whose are not, is fraught with pitfalls, and can be profoundly disempowering for the group of people labeled “incapacitated.” The support paradigm requires that the system begins with the assumption that all individuals have a decision-making ability and then determines what support each individual needs in augmenting that ability and expressing her preferences. In this system, no labels are needed; instead, the goal is merely to determine what type of support an individual might need.

When an individual is faced with challenges in exercising her legal capacity, according to the support paradigm, the solution is not forced intervention or substituted decision-making. Instead, in a supported decision-making system, outside assistance for decision-making should generally be minimal and based on the needs of the individual. The individual is the center of the decision-making process and the support person is not permitted to utilize her judgment in place of the individual’s judgment. Rather, the support person is merely an interpreter of the will and preferences of the individual.

There are some people who require almost complete outside support for decision-making, such as those with impairments that significantly affect communication. For people in this situation, the support person should, to the fullest extent possible, still enable the individual to exercise her legal capacity. This may mean a variety of things, including spending time learning the individual’s communication methods (e.g., movements of the eyelids, hand squeezing, and smiling), researching past communications, and any other means to ascertain the individual’s desires and decisions. The support person should try to ascertain, by any means available, the wishes of the individual. If it is not possible to discover the wishes of the individual, the support person should make a decision not based on what she believes are the best interests of the individual but instead on what she believes to be the individual’s true wishes. Even where communication is minimal or difficult to interpret, the support


40. Id.
person must search for indications of the individual’s will and preferences—
including speaking to those who know the person well, considering the person’s
values and belief systems, and taking into account any previous expressions the
person may have made about her wishes which could be applied to the present
situation.

There are many different possible forms of supported decision-making
systems. However, because substituted decision-making regimes dominate
modern legal frameworks, there are very few clear, functioning examples of
what a supported decision-making system should look like.41 States must
establish supported decision-making systems that conform to their particular
cultural and political landscapes.

We argue that in order to ensure that states adopt the support paradigm of
legal capacity, some basic guarantees must be met. These include the
replacement of substituted decision-making regimes (including adult
guardianship, trusteeship, or mechanisms based on the functional approach to
removal of legal capacity) with supports to exercise legal capacity, including
supported decision-making. The introduction of supported decision-making in
parallel with the retention of substitute decision-making is not sufficient to
ensure compliance with Article 12 of the CRPD.42 Another key component of
the support model is the guarantee that supports must be offered to the
individual, but never imposed against her will. This paradigm may also allow for
emergency interventions where an individual’s life, well-being, or safety is at
risk of serious adverse effects. However, these interventions must be very
carefully designed to ensure that they are used only in exceptional cases with
appropriate safeguards and do not permit a return to “best interests” or substitute
decision-making.

III.
LEGAL CAPACITY LAW REFORM PROCESSES

Since the entry into force of the CRPD, many countries have initiated legal
capacity law reform processes, either in preparation for ratification of the CRPD
or following ratification. Three examples of such reform processes are briefly
outlined here to illustrate the multiplicity of approaches state parties can take to
tackle Article 12 of the CRPD.

41. For a discussion of the support paradigm of Article 12 and supported decision-making
mechanisms, see generally CTR. FOR DISABILITY LAW & POLICY, NUI GALWAY, SUBMISSION ON
42. Draft General Comment on Article 12: Advance Unedited Version, Committee on the
THE SUPPORT MODEL OF LEGAL CAPACITY

A. Ireland

Prior to ratifying the Convention, Ireland committed to reform its outdated substitute decision-making regime, known as the “ward of the court” system.\(^{43}\) The Minister for Justice, Alan Shatter, stated in parliament that Ireland would not ratify the CRPD until the necessary legislative reforms were completed: “Ireland does not become party to treaties until it is first in a position to comply with the obligations imposed by the treaty in question, including by amending domestic law as necessary.”\(^{44}\) When the present government came to power in 2011, its Programme for Government included a commitment to introduce a “Capacity Bill that is in line with the UN Convention on the Rights of Persons with Disabilities.”\(^{45}\)

In August 2011, the parliamentary Joint Committee on Justice, Defence and Equality (the Justice Committee) called for submissions from interested parties on the content of what was then referred to as the Mental Capacity Legislation.\(^{46}\) In response, the Centre for Disability Law and Policy and Amnesty Ireland co-chaired a coalition of organizations and individuals in the fields of intellectual disability, mental health, and older people. This group came together to discuss whether a joint approach to legal capacity reform could be developed across their interest groups. The result was the publication of a set of Essential Principles for Legal Capacity Reform in April 2012, which set out ten key principles that legislation should adhere to in order to comply with Article 12 of the CRPD.\(^{47}\) Many of the groups involved presented at oral hearings convened by the Justice Committee in February 2012.\(^{48}\) The Justice Committee subsequently published a report based on the oral hearings, requiring a shift away from the “best interests” model of substitute decision-making and endorsing the support model of legal capacity toward an approach that respects the will and preferences of the individual.\(^{49}\)

\(^{43}\). Lunacy Regulation (Ireland) Act 1871, 34 Vict., c. 22.


\(^{47}\). AMNESTY INT’L, IRELAND & THE CTR. FOR DISABILITY LAW & POLICY, supra note 29.


The Assisted Decision-Making (Capacity) Bill was published in July 2013. It presents an interesting mix of supports (including the option of entering binding assisted decision-making agreements\textsuperscript{50} and co-decision-making agreements\textsuperscript{51}) and substitute decision-making (such as decision-making representatives\textsuperscript{52} and informal decision-makers\textsuperscript{53}), but continues to be premised on the individual reaching a certain standard of mental capacity as a prerequisite for retaining legal capacity with respect to a given decision. The definition of capacity does not include a diagnostic step (i.e., impairment in the functioning of the mind or brain). On the one hand, this makes it less obviously discriminatory, but on the other hand, any of the forms of decision-making prescribed under the Bill may occur only where the individual considers that her capacity is either “in . . . question” or “shortly [may] be . . . in question,”\textsuperscript{54} which seems to imply that the main group of individuals affected by the legislation will be those with impaired decision-making ability and especially persons with cognitive disabilities.

A detailed discussion of the legislation is outside the scope of this Article, but it is important to note that even in the substitute decision-making provisions of the Bill, intervenors are obliged to act in conformity with the guiding principles of the Bill, which include respect for the will and preferences of the individual (albeit with the qualifier that this should be done only when “all practicable steps have been taken”).\textsuperscript{55} It is also significant that “best interests” does not appear as a principle for guiding decision-making under the Bill.

The definition of capacity set out in Section 3 of the Bill reveals that the underlying premise of the legislation is that a certain standard of mental capacity is a prerequisite for the recognition of an individual’s legal capacity\textsuperscript{56}—a premise which is not, in our view, compatible with the CRPD’s interpretation of Article 12. Nevertheless, legal recognition of the various supports necessary to exercise legal capacity (such as assisted decision-making and co-decision making) is provided in the Bill,\textsuperscript{57} which is certainly a positive step forward.

\textit{B. Canada}

In the Canadian Province of Newfoundland and Labrador, the Minister for Justice, Felix Collins, made a commitment to reform at a symposium in 2011.\textsuperscript{58}

\begin{itemize}
\item \textsuperscript{51} \textit{Id.} at § 18.
\item \textsuperscript{52} \textit{Id.} at § 24.
\item \textsuperscript{53} \textit{Id.} at § 53.
\item \textsuperscript{54} \textit{Id.} at § 2 (see definition of “relevant person”).
\item \textsuperscript{55} \textit{Id.} at § 8.
\item \textsuperscript{56} \textit{Id.} at § 3.
\item \textsuperscript{57} \textit{Id.}
\item \textsuperscript{58} \textit{See Securing Citizenship and Legal Capacity for All, CANADIAN ASS’N OF CMTY. LIVING
Collins committed to work collaboratively with community actors to develop model legislation for legal capacity reform in the province, which could be subsequently used as an example of good practice for other Canadian provinces and jurisdictions outside of Canada. Subsequently, a working group, which included Article 12 scholars Michael Bach and Lana Kerzner, developed a policy document that was submitted to the provincial government in early 2013.

While the contents of the submission have not yet been made public, it is expected that it will build on the existing work of Bach and Kerzner, who in 2010 proposed to the Ontario Law Commission that legislation to support the exercise of legal capacity and comply with Article 12 of the CRPD could recognize three key ways to exercise legal capacity:

1. The first is where an individual is legally independent and requires only minor accommodations, such as accessible information, in order to make and communicate a decision.
2. The second is a formal supported decision-making arrangement, where the individual makes an agreement with one or more supporters about the areas of decision-making with which she would like assistance, while retaining full legal capacity.
3. The third is facilitated decision-making, which applies as a last resort when the person is not legally independent or in a support arrangement. In this case, a facilitator will attempt to interpret the will and preferences of the individual and make a decision that she believes in good faith represents the wishes of the person.

C. India

In India, the draft Rights of Persons with Disabilities Bill 2011 and the proposed amendments to the National Trust Act (establishing a support organization for persons with disabilities with high support needs) envisage a shift to universal legal capacity and supports to exercise legal capacity to replace substituted decision-making. The 2011 Bill proposes the abolition of plenary

59. Id.
61. Bach & Kerzner, supra note 27.
62. Id. at 83.
63. Id. at 84-90.
64. Id. at 91-94.
guardianship, and the transition of all those currently under plenary guardianship to a newly established limited form of guardianship, based on “joint decision making which operates on mutual understanding and trust between the guardian and the person with disability.” In this new system, guardians are under a legal obligation to closely consult with persons with a disability to determine their will and preference. While the principles in this system reflect a move towards the support model, we are concerned that it may function as a substituted decision-making regime in violation of Article 12.

Importantly, no new entrants to limited guardianship will be permitted as this system is purely transitional for those currently under plenary guardianship. Limited guardianship did not exist prior to the new Bill. Individuals under limited guardianship will be supported to develop skills to enable them to transition out of limited guardianship into more progressive supported decision-making arrangements. The 2011 Bill envisages that all those currently not under plenary guardianship (i.e., new entrants to the system) will be provided with supported decision-making options instead of being placed into limited guardianship. The Bill also provides for a review of limited guardianship by the appropriate authorities designated by the government to establish whether this new system is effective in assisting “such persons with disabilities in establishing suitable support arrangements to exercise their legal capacity” and thus enabling them to transition out of limited guardianship.

D. Summarizing the Legal Capacity Reform Processes

These law reform processes and others developing throughout the world, including pilots of supported decision-making models, indicate positive steps


68. Id. at § 19(3).

69. The Rights of Persons with Disabilities Bill 2011 mandates state authorities to provide assistance to persons who have exited plenary guardianship to move to support arrangements other than limited guardianship. Id. § 20(1)(b). Draft amendments would grant funding for programs to train limited guardians on informed consent and arriving at decisions in accordance with the will and preference of the individual. Draft National Trust Act Amendments 2011, supra note 66, at Ch. IV, § 11(2)(e)(ii- iii).

70. The Rights of Persons with Disabilities Bill 2011 mandates state authorities to “establish or designate one or more authorities to mobilize the community and create social networks to support persons with disabilities in the exercise of their legal capacity.” The Rights of Persons with Disabilities Bill 2011, supra note 67, at § 20(1). This Bill eliminates plenary guardianship by stating that “any act, order or proceedings which has the effect of denying the legal capacity of a person with disability in any matter or which questions the legal capacity of a person with disability on the grounds of disability shall be void.” Id.

71. Id. at § 20(1)(c).

72. Id. at § 9(2)(ii).

73. MARGARET WALLACE, OFFICE OF THE PUBLIC ADVOCATE (SOUTH AUSTRALIA),
toward the replacement of substitute decision-making regimes with the support model of legal capacity. However, it should be acknowledged that none of these examples represent a flawless reform process, and that in each case certain political compromises may be made, for example, in terms of the scope of the legislative reform. Legal capacity is a fundamental issue at the core of our legal frameworks, and, consequently, legal capacity reform will have a knock-on effect on many areas of law (family law, inheritance and property law, marriage, consent to sex, and consent to medical treatment to name just a few). While acknowledging the limitations of any law reform process, the above examples demonstrate that law reform plays a vital role in ensuring the principles of Article 12 are enshrined in domestic legal frameworks. These examples also point toward changes in the ways in which people with disabilities interact with the law and receive support to exercise their legal capacity.

IV.
LEGAL CAPACITY REFORM AND THE COURTS

Both legislative reform and strategic litigation can play a role in securing the rights in Article 12. Legislative reform is particularly critical for the right to support in exercising legal capacity. The positive obligations that the right carries make it difficult to imagine how supported decision-making could be implemented and formally recognized without statutory language. It is absolutely critical that legislative safeguards are in place to ensure that supports to exercise legal capacity respect the “rights, will and preferences” of the individuals using the support.74 It is equally important to abolish substituted decision-making laws and discriminatory denials of legal capacity.

Particularly in common law jurisdictions, the precedential power of case law can also effectively chip away at the substituted decision-making edifice.75 Strategic litigation may be powerful for establishing negative obligations on states, such as the duty to refrain from discriminatory denials of the right to legal capacity. Such litigation has already proven influential for the duty to refrain from certain interferences with the correlating rights to a fair trial.76 private

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75. For a discussion of progressing legal capacity law through litigation see Oliver Lewis, Advancing Legal Capacity Jurisprudence, 6 EUR. HUM. RTS. L. REV. 700, 700-14 (2011).

life,77 and liberty.78 However, strategic litigation also has the potential to be a tool for the recognition of positive obligations, such as the right to supports to exercise legal capacity.

We have not yet seen the full application of Article 12 in a judicial decision. However, the importance of the rights and obligations in Article 12 of the CRPD is permeating the minds of the judiciary in domestic courts of first instance,79 as well as in regional human rights courts.80 Courts at many different levels and jurisdictions are actively challenging the antiquated regimes of substituted decision-making and discriminatory legal capacity denial. Two notable examples are the groundbreaking decision by the New York County Surrogate’s Court in 2012,81 and the ever-expanding body of cases at the European Court of Human Rights (ECtHR).82

In Matter of Dameris L.,83 the New York County Surrogate’s Court interpreted New York law to essentially include a right to supported decision-making.84 Building on prior decisions,85 the court used the CRPD as a lens through which to analyze Article 17A of the New York Surrogate’s Court Procedure Act (SCPA). Article 17A is inconsistent with Article 12 CRPD in a variety of ways. It allows for the denial of legal capacity and the imposition of a guardian based on the discriminatory basis of the existence of disability.86 Moreover, it provides very few due process protections and does not include any language on support.87 Although the scope of Dameris L. does not allow for a


78. See, e.g., Shtukaturov, supra note 76, at ¶ 108; Stanev, supra note 76, at ¶ 132.


80. Such as the European Court of Human Rights. See supra notes 76-78.


82. See, e.g., Stanev, supra note 76, at 46.

83. Dameris, 38 Misc. 3d at 570.

84. Id. at 576. The presiding judge in the case has recently written on the rights in the CRPD. See Kristin Booth Glen, Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship and Beyond, 44 COLUM. HUM. RTS L. REV. 93 (2012).


87. See generally id.
holistic examination of the human rights violations under 17A, the court was able to succinctly acknowledge the suspect nature of the legislation.

In the case, Dameris, a twenty-nine-year-old woman, had previously consented to being placed under the co-guardianship of her mother and husband. Dameris could take care of many of her daily needs, but the court found that she needed assistance with financial and medical affairs. Through the help of social services, family, and neighbors, Dameris and her family created a stable home and supportive environment for Dameris and her decision-making. It is significant that the court was involved in this case for three years, from the time that Dameris’ mother first petitioned the court for guardianship in 2009.

Although the law did not require it, in accordance with the principles of Article 12, the court sought Dameris’ consent for her placement under guardianship. The court also encouraged the development of a support network for Dameris and her family. Additionally, the court appointed several monitors for the progress of the family and provided the family with translation services for interactions with the court because the family is primarily Spanish speaking. The court ultimately found in Dameris L. that Dameris was no longer in need of the guardianship, which it terminated.\textsuperscript{88}

This case demonstrates the power of courts to promote human rights norms in rulings, even in the United States, which has not ratified the CRPD and is generally resistant to embracing international human rights law within its borders.\textsuperscript{89} In a jurisdiction that is bound by the CRPD and is upholding a support paradigm compliant with Article 12, guardianship and other forms of substituted decision-making would not be available as in Dameris. Instead, legislation would empower the relevant court or tribunal to provide for supports for the exercise of legal capacity. The court or tribunal would also act as an oversight mechanism to safeguard individuals in supported decision-making and ensure that their will and preferences are fully respected.

In a series of cases, the ECtHR has also been inching its way toward the protection of the rights enumerated in Article 12. The ECtHR’s task is to interpret the European Convention on Human Rights (ECHR),\textsuperscript{90} which is binding in all countries that are members of the Council of Europe.\textsuperscript{91} Not all of these countries have ratified the CRPD and the ECtHR is not bound by the

\textsuperscript{88} Dameris, 38 Misc. 3d at 570.


CRPD. While the ECHR does include a non-discrimination clause, it has no specific right to equal recognition before the law. However, the court has interpreted certain restrictions on legal capacity as interfering with rights to privacy and family life, liberty, and a fair trial. Although the ECtHR cases to date have been tinkering only around the edges of violations related to the right to legal capacity, the court appears to be slowly heading in the direction of Article 12 of the CRPD. The ECtHR has found an interference with the right to a fair trial where an individual does not have standing to engage the judicial system except through her appointed guardian. It has also found that a deprivation of legal capacity can amount to a violation of the right to private life. Finally, the ECtHR has held that the right to liberty is violated when an individual is stripped of her legal capacity and a guardian consents to her placement in an institution against her will.

These findings all describe positive steps in the journey toward the protection of the right to legal capacity and equality before the law, set forth in Article 12 of the CRPD. Unfortunately, the ECtHR has not yet interpreted the ECHR to include the right to legal capacity on an equal basis with others. One way the court could accomplish this, if a future case were to allow it, is through a finding that the denial of legal capacity to persons with disabilities is a violation of the right to freedom from discrimination. This could be a very powerful holding. In order to find a violation of the right to freedom from discrimination in the ECHR, the discrimination must occur in relation to the enjoyment of another ECHR right. The discrimination can be direct or indirect. In order for a state to justify the discrimination, it must show that

92. The ECtHR is mandated to interpret only the ECHR. It is not bound by the CRPD because the CRPD binds only states and regional bodies that have signed and ratified the CRPD. The monitoring body for the CRPD is the UN Committee on the Rights of Persons with Disabilities.


94. Id. at art. 8.

95. Id. at art. 5.

96. Id. at art. 6.


98. Lashin, supra note 76, at ¶¶ 98-122; Shinkaturov, supra note 76, at ¶ 83.

99. Shinkaturov, supra note 76, at ¶¶ 108-09; Stanev, supra note 76, at ¶ 132.


101. Id.

there is an “objective and reasonable” justification which pursues a legitimate purpose and satisfies the proportionality test.\textsuperscript{103}

A violation of the right to freedom from discrimination would, therefore, require a preliminary finding that the denial of legal capacity is itself a violation of ECHR rights—for example, the rights to privacy\textsuperscript{104} and liberty.\textsuperscript{105} It would then require a finding that people with disabilities are actually being discriminatorily denied legal capacity, thereby being discriminatorily denied their ECHR rights to privacy and liberty. Statistics on deprivations of legal capacity can often provide evidence for this claim, as they can clearly show that people with cognitive disabilities are disproportionately denied legal capacity.\textsuperscript{106} \textit{Prima facie} evidence would consist of any laws that are facially discriminatory and require a finding of cognitive disability before depriving legal capacity.

The state may assert that there are objective and reasonable justifications to permit discriminatory denials of legal capacity of people with cognitive disabilities. For example, it may claim that denying legal capacity to persons with cognitive disabilities is justified in the interest of public safety, prevention of disorder or crime, or protection of health and morals. Evidence against these assertions is that legal capacity denials are profoundly marginalizing and create an underclass of individuals whose safety is jeopardized because they are left vulnerable to those controlling their legal capacity (guardians, conservators, institutions, and others) often without legal or other recourse.\textsuperscript{107}

In the alternative, the ECtHR may find that discriminatory legal capacity denials do pursue a legitimate aim but do not pass the proportionality test and are therefore not “objective and reasonable.”\textsuperscript{108} It should find that the aim is not “objective and reasonable” because the deprivation of legal capacity is a disproportionately harsh measure to achieve such an aim.\textsuperscript{109} Here, it should be emphasized that the right to legal capacity is an element of the right to equal recognition before the law, which is a civil right that is present in major human rights instruments.\textsuperscript{110} Therefore, the right to legal capacity should be of the

\textsuperscript{104}European Convention on Human Rights, \textit{supra} note 90, art. 8.
\textsuperscript{105}Id. at 5.
\textsuperscript{106}See \textit{supra} note 14.
\textsuperscript{107}See Winick, \textit{supra} note 31, at 6–42, 41–42. For information on guardianship abuse in the United States see U.S. GOV’T ACCOUNTABILITY OFFICE, GAO-10-1046, GUARDIANSHIPS: CASES OF FINANCIAL EXPLOITATION, NEGLECT, AND ABUSE OF SENIORS (2010).
\textsuperscript{108}See, e.g., James, ¶ 75.
\textsuperscript{109}See, e.g., id. ¶ 50.
utmost importance and denial should be strictly scrutinized. Evidence could also be provided showing that the provision of support is more effective in creating citizens who are active participants in society and are at a lower risk of being significantly dependent on others or on government benefits.111

In order to fully protect the right to legal capacity, the finding of an ECHR violation must apply to denials of legal capacity that are discriminatory in either purpose or effect.112 It is not enough to only create facially neutral laws because they could have the effect of disproportionately denying legal capacity to people with cognitive disabilities. There is currently work being done by NGOs and academics to bring strategic cases before the ECtHR to encourage such a finding.113

CONCLUSION

The legal reforms underway throughout the world, in combination with strategic litigation related to the deprivation of legal capacity, demonstrate a growing trend in favor of the support model of legal capacity set out in Article 12 of the CRPD. Research and pilot projects on supported decision-making have shown how the viability of the support model and its effectiveness in protecting human rights outweighs current approaches based on substitute decision-making. This is due to the fact that the cornerstone of the support model is to enhance the autonomy of the person by respecting her will and preference.

Naturally, a system that attempts to move away from the paternalistic approach of substitute decision-making to rebalance autonomy and protection entails certain risks. Some argue that the risks that flow from universal recognition of legal capacity are too great.114 However, we argue that the support model simply seeks to restore to people with cognitive disabilities the “dignity of risk,” which we are all afforded in our daily lives. Everyone deserves the right to make risky, bad, or unwise decisions, once he or she has been given the relevant information and offered the support needed to make a particular decision. It should also be noted that the support model of legal capacity will require safeguards to prevent the exploitation and abuse of individuals using supports. The key difference between safeguards in the support model and those

111. Although very little research has been done in this area, the successful supported decision-making pilot program in South Australia is evidence of this. See WALLACE, supra note 73.
112. In Hugh Jordan v. United Kingdom, 2001 Eur. Ct. H.R. 327, the court found that “where a general policy or measure has disproportionately prejudicial effects on a particular group, it is not excluded that this may be considered as discriminatory, notwithstanding that it is not specifically aimed or directed at that group.”
114. This is based on the authors’ experiences of engaging in legal capacity law reform around the globe.
which have existed in substitute decision-making regimes is that safeguards for support are based on the core principle of respect for the individual’s will and preferences, no matter what level of decision-making ability she holds. For example, in a support model there must be an adjudication mechanism for challenging support people if they fail to respect the will and preference of the individual. In contrast, adjudication in most current substituted decision-making regimes focuses on “protecting” the individual and discovering what is in her “best interest,” with little importance placed on her will and preference. As set out in Section II, the support model does not preclude emergency interventions in exceptional circumstances to preserve the life, immediate safety, or well-being of the individual. However, further research is needed to determine a coherent basis for such interventions with appropriate safeguards to protect against a return to substituted decision-making regimes based on an objective-best-interests approach.

In order for the support paradigm of legal capacity to take root in legal systems universally, wider reform beyond the abolition of adult guardianship is required. This includes reform of criminal law (especially related to mens rea and consent), medical treatment, mental health law, and property law. However, a detailed consideration of these areas for reform is beyond the scope of this Article. Therefore, the arguments we present in favor of a support model of legal capacity are intended as a starting point for future research. The support model is possible and feasible and should be used as a framework for further discussions on legal capacity law reform.

115. This can be seen in case law from the England and Wales Court of Protection. See, e.g., Re E (Medical Treatment: Anorexia), [2012] EWHC 1639 (COP).