

Supported Decision-Making and the Human Right of Legal Capacity

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Abstract

The United Nations Convention on the Rights of Persons With Disabilities (CRPD) establishes a new paradigm of supported decision-making, rather than guardianship or substituted decision-making, for people with intellectual disability (ID). Article 12 of the CRPD guarantees every person's right to legal capacity—to make her/his own decisions and have those decisions legally recognized—and specifically requires governments to provide people with ID the supports they may need to exercise legal capacity. The Article describes the human rights regime and explores different forms of supported decision-making and legislative efforts to abolish guardianship. It calls for a paradigm shift in how we view people with ID, from inquiry into what a person cannot do, to supports necessary to enable her/him to make her/his own decisions, and the legal efforts necessary to ensure that such decisions are recognized by third parties including financial institutions, healthcare providers, and government agencies.

Key Words: *legal capacity, supported decision-making, human rights*

Supported decision-making, which is the topic of this Special Issue, is probably not a foreign term to most readers of this journal. No one who has grown up with, or worked with, concepts like person-centered planning, inclusion, community living, or self-determination will find the proposition that persons with intellectual disability (ID) should be supported in making their own decisions a startling idea.

You know that treatments and training techniques that focus on communication and behavior have proven effective in increasing the mental capacity of people with ID. Studies show that self-determination, including decision making, problem solving, goal setting, and attainment, if taught, can be learned by an individual with a disability to develop skills that promote independent decision making (Palmer & Wehmeyer, 2002). Research has also shown that individuals with intellectual and developmental disabilities (IDD) who are more self-determined have more positive postsecondary outcomes, including employment, independent living, and community inclusion (Association of University Centers on

Disabilities, AUCD, n.d.). Students with disabilities given access to transition services focused on self-determination and independent living skills are more likely to live independently, be employed, and exercise effective choice and decision making (Martinis, n.d.). As a leading psychiatrist has noted:

Brain maturation is facilitated through the richness of personal experiences at home, in school, and in the community as, to some extent, life experience sculpts the brain. Personal mastery of developmental challenges and tasks bring satisfaction to people with neurodevelopmental disabilities just as it does to typically developing children. Successfully completing a learning task or handling a social situation effectively produces its own intrinsic rewards. (Harris, 2010, p. 63)

Supporting people with ID to make their decisions makes them more successful as people in the world.

In the legal world, however, supported decision-making has taken on a near revolution-

ary complexion, as it relates to the newly emerging, at least in the United States, human right of legal capacity. What is this right? Where did it come from? What will implementation mean to existing legal structures? And, perhaps most challenging as well as most relevant, how do we get there from here?

The Current Regime: Guardianship and Substituted Decision-Making

For many years in this country, after a widespread transition from institutionalization of persons with ID, the preferred legal “remedy” for people seen as incapable of making decisions about their own lives has been the legal status of guardianship. Guardianship involves the state depriving an individual of decision-making ability, and substituting another person, the guardian, who has the legal right to make binding legal decisions for what is generally referred to as the *ward*. Whether the guardian employs a best interests test or tries to ascertain what the ward might want to do, it is the *guardian’s* decision, not the ward’s decision. This is *substituted decision-making*.

Guardianship is governed by state, as opposed to federal, laws. Most states have a single guardianship law that covers people with all kinds of cognitive disabilities, including, in particular, older persons with progressive cognitive decline, but also persons of all ages with intellectual and developmental disabilities. (In some states, the term mental retardation is still used in legal documents. In accordance with guidelines implemented by this journal, we will use the term intellectual disability even when a state retains the term mental retardation, unless doing so changes the intent of the narrative.) The five states with exceptions to the single guardianship law include California, Connecticut, Idaho, Michigan, and New York. These states have separate statutes specifically covering persons with IDD (Glen, 2014). Although individual state statutes may vary in their particulars, they are all relatively similar with regard to the deprivation of liberty they entail.

Prior to the 1980s, most states’ guardianship statutes (often referred to as *conservator* or *committee laws*) provided for the appointment of a plenary (full) guardian of either the person or property or both, based almost entirely or entirely on a diagnosis which might be as

indeterminate as “old age,” “organic brain syndrome,” or “feeble mindedness” in the case of persons with ID. Appointment of a guardian deprived the person under guardianship, now referred to as the ward, of all decision-making power, and frequently, as well, of such rights as voting, contract, and marriage.

The Reform Movement, 1987 – Present

Spurred by a series of exposés by the Associated Press in 1986, statutes across the country were reformed in a number of ways (Johns, 2014). Rather than being diagnosis driven, the imposition of guardianship was now to be based on a functional assessment, not dissimilar to the change in focus of diagnosis of “mental retardation” by the American Association on Mental Retardation (now AAIDD) in 1992. A guardian would be appointed only when a person was found to be incapable of caring for her/his personal or financial needs, lacked understanding of the problem, and could not appreciate the consequences of her/his incapacity.

Guardianship was to be the “last resort,” that is, it could only be imposed if it were the “least restrictive alternative” available. Reform statutes purported to encourage autonomy and self-determination, and favored, or even required, guardianships tailored to the specific functional deficits of the allegedly incapacitated person, rather than plenary guardianships. In addition, reform statutes added a plethora of procedural protections including the right to a hearing, the right to present evidence and to cross examine, a higher burden of proof than that ordinarily utilized in civil proceedings, the right to counsel, and an extensive reporting requirement with periodic review of the guardianship by the appointing court (Glen, 2014, pp. 108–115).

Although these reforms were salutary, and doubtless made a difference for some number of persons with ID for whom guardianship was sought, the practice “on the ground” has differed widely from what is on paper. A 2007 study demonstrated that in approximately 90% of all cases, the result was a plenary guardianship (Teaster, Wood, Schmidt, & Lawrence, 2007). Monitoring has also proven problematic as court budgets decline and protection of persons placed under guardianship is hardly the highest priority. Even the appointment of guardians themselves has been shown to be a problem. In a 2010 study by federal Government Accountability Office, faux

petitioners with false Social Security numbers or unsatisfactory credit ratings were easily and unquestioningly appointed as guardians (Wood, 2014, p. 314).

Why Guardianship?

People seek guardianship for a variety of reasons, especially, for parents of children with ID, when their children reach the age of 18, often based on a suggestion or direction by the school in which the child is enrolled. All adults (legally defined as persons 18 and over) are considered to have full legal capacity: to make decisions and choices, to enter into contracts, to vote, to marry, and so forth. For parents who are concerned about their child's ability to make such choices, or to make "good choices," her/his 18th birthday becomes the time at which they seek the power of the state to maintain control over that child. As a result of this and other forces, according to data collected by the National Core Indicators Project, 58% of adults with developmental disabilities living in states that participated in the project are under plenary guardianship, and another 11% are under limited guardianship (National Association of State Directors, 2014, p.19).

Guardianship is premised on the idea of protection, and the state's ability to impose a guardian is derived from its *parens patrie* power. Because we know so little about what actually happens to people under guardianship, even such details as the number involved or whether such guardianships cover both person and property or are more limited (Wood, 2014, p. 313), it is hard to determine whether people under guardianship are actually safer than others; one might argue that the total power which the law gives to guardians creates the possibilities for isolation and vulnerability that lead to, or at least permit, abuse. What is clear, however, is that adults under guardianship are less than full citizens or, as Congress member Claude Pepper so memorably noted, have "less rights than a convicted felon" (Glen, 2014, p. 17).

Mental Versus Legal Capacity

Guardianship and the notion of capacity are inextricably bound. The basis of capacity for purposes of guardianship laws is *cognitive ability*, that is, in its simplest iteration, the ability to understand a set of facts or concepts, and to appreciate the consequences of actions taken

based on those facts. This is the traditional definition of *mental capacity*, and, until now, *legal capacity*, which is the ability to make decisions that are recognized by the law. Under current law, mental capacity and legal capacity have been understood as one and the same.

The relatively newly articulated human right of legal capacity is, however, completely disaggregated from the notion of mental capacity. That is, as a matter of human rights, every human being is deemed to have full legal capacity regardless of any disability, including disability in cognitive functioning, which she/he may have. Legal capacity means that every human being has a right to make her/his own choices and to have those choices legally recognized. One of the leading theorists of legal capacity, Gerard Quinn (2010), described the right as follows:

Legal capacity is the epiphenomenon. It provides the legal shell through which to advance personhood in the life world. Primarily, it enables persons to sculpt their own legal universe—a web of mutual rights and obligations voluntarily entered into with others...it allows for an expression of the will in the life world...[it] is entirely right to focus on issues like opening and maintaining a bank account, going to the doctor without hassle, buying and selling in the open market, renting accommodation, etc. This is how we positively express our freedom. This is how we can see legal capacity as a sword to forge our own way. (p. 10)

Where does this human right come from, and what are its implications for guardianship and the current regime of substituted decision-making?

The Human Rights Regime

Human rights emerged from the horrors of World War II, including, most significantly for the issue of legal capacity, the mass murder of more than 60,000 people with ID and mental illness. (Harris, 2010, p. 53). The countries of the world came together to form the United Nations in 1945, and in 1948 adopted the Universal Declaration of Human Rights (UDHR). The fundamental principles of human rights law, as enunciated by the UDHR (1948), are "the equal and unalienable rights of all members of the

human family” and “the dignity and worth” of every person (“Preamble”).

The Universal Declaration of Human Rights (1948) first recognized what now have become the *universal values*:

Human rights are inherent to all and the concern of the whole of the international community. Drafted by representatives of all regions and legal traditions, the UDHR has stood the test of time and resisted attacks based on “relativism.” The Declaration and its core values, including nondiscrimination, equality, fairness and universality, apply to everyone, everywhere and always. (“The Universal Declaration of Human Rights,” n.d., “Universality,” para. 1)

Unlike the “negative rights” conferred by the U.S. Constitution with which we may be more familiar (i.e., *freedom from* government interference in a variety of areas—speech, assembly, religion, bearing arms, etc.), or by “rights” created by statutes like the Americans with Disabilities Act of 1990 (ADA), human rights exist solely by virtue of the fact that one is born human. They are said to be inalienable, indivisible, inderivative, and interrelated. That is, each depends on all the others, and none can permissibly be taken away by any law or any government. As acknowledged upon the 60th Anniversary of the UDHR:

The Declaration represents a contract between governments and their peoples who have a right to demand that this document be respected. Not all governments have become parties to all human rights treaties. All countries, however, have accepted the UDHR. The declaration continues to affirm the inherent human dignity and worth of every person in the world, without distinction. (“The Universal Declaration of Human Rights,” n.d., “Enduring Relevance,” para. 2)

Human rights also provide a powerful tool for education and advocacy. Two leading commentators note, “Human rights norms have power to work change through non-legal mechanisms. . . . [They] trigger belief changes by providing information to societies about the human rights ideas with the attendant effect of serving as educational tools for altering social mores” (Lord & Stein, 2008, pp. 474–475).

The Convention on the Rights of Persons With Disabilities

The UDHR (1948) specifically grants the right to legal capacity to all persons on equal basis. Article 6 provides: “Everyone has the right to recognition everywhere as a person before the law.” Recognizing, however, that there are at least five “vulnerable” groups that may require special protection or measures to ensure their human rights, the United Nations has adopted four additional treaties that make specific provision for members of those groups to exercise and enjoy their rights (older persons are the last vulnerable group without a special convention, but efforts are currently ongoing within the United Nations structure for the creation and adoption of the convention on their behalf; Akinpelu, Flynn, Laurin-Bowie, Lewis, & Rosenthal, 2011). These treaties are the Convention on the Elimination of All Forms of Racial Discrimination (CERD, 1969), the UN Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW, 1979), the UN Convention on the Rights of Children (CRC, 1990), and, most recently, the UN Convention on the Rights of Persons with Disabilities (CRPD, 2007).

The CRPD is unique among these conventions because of the unprecedented participation of persons with disabilities at every stage, including drafting (Dhanda, 2006–2007). It represents a decade of efforts by governments, international agencies and institutions, and the disability rights community domestically and internationally, the latter under the slogan, “Nothing About Us Without Us!” It is understood to provide an authoritative interpretive lens to other international human rights instruments; as such, it is important to understand, it creates no new rights but rather provides the conditions for implementation of already existing human rights.

The General Principles of the CRPD are contained in Article 3 and include respect for inherent dignity, individual autonomy *including the freedom to make one’s own choices*, and independence of persons; full and effective participation and inclusion in society; and accessibility (CRPD, 2006). Article 5 requires State Parties (signatories and ratifiers of the Convention) to prohibit all discrimination on the basis of disability and to guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.

The Right of Legal Capacity

The specific right of legal capacity for persons with ID is set forth in Article 12 of the CRPD (2006). Entitled “Equal Recognition Before the Law,” it provides as follows:

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

It is important to reiterate that this right of legal capacity for persons with disabilities, including ID, is not a “new” human right, but one that goes back to the adoption of the UDHR in 1948. The right to legal capacity without discrimination before the law for all person discrimination has now been recognized for more than half a century, including, at least theoretically, the United States, which was an original signatory of the UDHR.

The Role of Supported Decision-Making

What is new in the CRPD, however, is the specific obligation on governments (States Parties) to provide the supports that are necessary for people with intellectual and/or cognitive impairment to exercise the right of legal capacity. This is, obviously, where supported decision-making

comes in. In the legal context, supported decision-making is not the *end*, but rather the *means* to the end of the human right of legal capacity.

Supported decision-making has been described in materials created by the United Nations to assist in understanding the CRPD. Among those materials is the First General Comment (First Comment) of the Committee on the Rights of Persons With Disabilities (the Committee), the body created by the CRPD to interpret the document and to monitor compliance by its signatories. The First Comment provides:

“Support” is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity. For example, persons with disabilities may choose one or more trusted support persons to assist them in exercising their legal capacity for certain types of decisions, or may call on other forms of support, such as peer support, advocacy (including self-advocacy support), or assistance with communication. (Committee on the Rights of Persons With Disabilities, 2014, para. 17)

The Comment also notes that:

For many persons with disabilities, the ability to plan in advance is an important form of support. ... States parties can provide various forms of advance planning mechanisms to accommodate various preferences, but all the options should be non-discriminatory. Support should be provided to a person, where desired, to complete an advanced planning process (Committee on the Rights of Persons With Disabilities, 2014, para. 17).

The Impact of Article 12 on Guardianship

Critically for the current regime of guardianship, in its First General Comment, the Committee on the Rights of Persons with Disabilities (2014) has stated unequivocally that all laws imposing substituted decision-making, including guardianship laws, violate article 12 of the CRPD (para. 7).

The CRPD, whether or not ultimately ratified by the United States, will not necessarily invalidate existing guardianship laws. When the United States ratifies conventions and treaties, it generally attaches *RUDs*, (Reservations, Understandings, and Declarations), including, with regard to the

CRPD, that it will have no effect on existing U.S. law. And, of course, without ratification, the CRPD and Article 12 have even less force. But, the CRPD is a political as well as a legal document and it has inspired advocates for people with ID to begin serious efforts to significantly limit or abolish guardianship laws in the United States. This effort is aided and encouraged by the more enthusiastic adoption of Article 12 and its principles by many of the 150 countries that have now ratified the CRPD.

Examples From Other Countries

The European Union (EU) itself, as well as all of its member nations, ratified the CRPD; in an effort to implement and to meet its obligations, the EU funded 17 “DREAM (Disability Rights Expanding Accessible Markets) Fellows” to work specifically on the guardianship laws of each of the member states so as to ensure legal capacity to all persons (Glen, 2012, p. 158). In Ireland, the DREAM Fellow was housed in the National University of Ireland/Galway Center on Disability Law and Policy, which met with relevant groups of stakeholders for over a year before developing “Principles and Key Issues for Capacity Legislation.” Those Principles include the following:

The law must protect people’s rights to make decisions about all aspects of their lives. . .for example, healthcare, finances, relationships and when and with whom to live. Reasonable accommodations should be made to help the person understand the decision. Different ways of providing information must be explored (including sign language, alternate communication, flexibility with regard to time and location for delivering information, etc.). There should be a range of advocacy supports including state appointed advocates statutory powers, as well as other forms of individual advocacy (e.g., citizen advocacy, peer advocacy, self-advocacy support). Decisions made by someone else is a last resort when all supports have been considered and are unworkable (facilitated decision making). It should only apply for specific decisions for the length of time necessary for that purpose.

New legislation has been proposed or passed in a number of countries including Australia (Wallace, 2012), the Czechoslovak Republic (Mental Disability Advocacy Center, MDAC, 2014, p. 48),

and India (Flynn & Arstein-Kerslake, 2014, pp. 145–146). A major effort to bring legal capacity to the laws of countries in Eastern Europe has been launched by the MDAC headquartered in Budapest. Central to all of these efforts, and to the reform or repeal of traditional guardianship laws, is a clear understanding and appreciation of supported decision-making.

The Canadian Framework for Supported Decision-Making

The primary authors of proposed legislative reform in Canada, Bach and Kerzner (2010), explain:

Where people do not have the requisite decision-making abilities on their own to understand information and appreciate the nature and consequences of a decision, even with accommodations and supports, we propose . . . that they should retain their full legal capacity where decision-making can be managed through a “supported decision-making status.” This involves a trusted individual or network of individuals, assisting the individual in decision making. Support can be provided in a variety of ways including interpretation and plain language support, as well as assistance in representing the person to others who may not understand his or her ways of communicating. Effectively, supported decision-making distributes decision-making abilities required for competent decision-making processes across an individual and her/his supporters, as directed by the individual’s will and/or intention, and thus results in individual’s decision-making capability in the sense defined above. (p. 24)

Bach and Kerzner go on to provide useful outline for the kinds of supports that are necessary to enable legal capacity for persons with ID. They begin by defining three main types of supports:

- Supports to assist in formulating one’s purposes, to explore the range of choices and to make a decision.
- Supports to engage in the decision-making process with other parties to make agreements that give effect to one’s decision, where one’s decisions require this.
- Supports to act on the decisions that one has made, and to meet one’s obligations under any agreements made for that purpose. (p. 73)

They then describe six separate areas in which various kinds of supports can be utilized. They are

- **Life planning:** These are day-to-day decisions including where to live, or how to be supported, whether or not to accept certain medications, and so forth, and the larger defining decisions of a person's life path.
- **Independent advocacy:** This is the support and advocacy that may be necessary to assist an individual in expressing her/his wishes and informing other parties of her/his rights, and the other parties' duties to respect those rights and accommodate accordingly.
- **Communicational and interpretive:** Individuals with significant disabilities often utilize unique forms of communication and may require augmentative and alternative communication systems including signing, gestural, and vocalization systems, computer-assisted and electronic devices, as well as nonelectronic communication output needs. They may also require interpretive assistance for intake and processing of information from other parties.
- **Representational supports:** In the relatively rare and extreme case, the need is to represent an individual to the world where planning supports, advocacy, and communicational interpretive services are not enough for other parties to understand a person with a severe intellectual disability sufficiently to enter agreements with her/him. Representational supports require that individuals who have a knowledge of the person, born out of a relationship of trust and understanding of her/his unique way of communicating, and who, through shared life experience, have come to understand who the person is, what she/he values and wants or dislikes or rejects, can "represent" the individual to the world and assist the person by carrying out the intellectual processing required to translate intentions and wishes into actual decisions and agreements with others;
- **Relationship-building supports:** For individuals with significant intellectual and cognitive disabilities, who have no family or friends to provide the kinds of supports previously described, significant efforts are required to develop trusting relationships based on shared life experience and personal knowledge that can eventually provide the necessary representational supports.
- **Administrative supports:** These are required to enter into many agreements with others that give effect to one's decisions, such as completing arrangements for a loan or purchases, including the use of individualized and direct funding to enable people with disabilities to purchase their disability-related supports and services. (pp. 75–82)

Bach and Kerzner's work may prove especially useful constructing models or templates for supported decision-making pilot projects going forward.

Supported Decision-Making in the United States and Elsewhere

At this moment there are few examples of supported decision-making systems in support of legal capacity in existence in the United States. A small pilot program in Northampton, Massachusetts represents a collaboration between the Center for Public Representation and Nonotuck Resource Associates (Center for Public Representation, n.d.). Disability Rights New York, the Policy and Advocacy agency (P&A) for New York State, is in the planning process for one or more pilot projects on supported decision-making as an alternative to guardianship, or as a means to restore the rights of persons currently under guardianship. A project of the Florida Developmental Disabilities Council is in the second year of an effort to restore the rights of persons currently under guardianship through teaching self-determination skills, including an iteration of supported decision-making (Florida Developmental Disabilities Council, 2014).

A newly constituted National Center for Supported Decision-Making has been funded by a 5-year grant from the Agency for Community Living (ACL), awarded to Quality Trust (see Blanck & Martinis, this issue), which will be partnering with the University of Kansas and the Burton Blatt Institute at Syracuse University, among others. Because ACL includes within its umbrella both the Agency for Intellectual and Developmental Disabilities (AIDD) and the Agency on Aging (AOA), the Center intends to deal with supported decision-making for both populations. The Request for Proposal explained that the purpose of the Center was to

document and disseminate successful decision-making practices; conduct research to fill data and information gaps; develop training materials and provide technical assistance to ACL networks on SUPPORTED DECISION-MAKING issues, including youth transition; develop a strategy that measures and demonstrates the impact of supported decision-making on the lives of people with I/DD and older Americans; design and commence implementation of a small grants demonstration program that awards funding to four to seven community organizations . . . ; and develop a clearinghouse of existing materials and resources, academic work and practices, success stories, and newly-developed research and training

materials, to be made available to the general public. (Department of Health and Human Services, 2014, *Executive Summary*)

More robust and developed efforts to replace substituted decision-making with supported decision-making have occurred in places that may seem unlikely, such as Bulgaria (Bulgarian Center for Not-for-Profit Law, BCNL, 2014). Under the leadership of the BCNL and in partnership with the Association of Families With Autism, 20 persons, some of whom have been institutionalized for most of their lives, have been given (a) assistance in developing networks of supporters who are facilitated in helping them create a vision of the lives they wish to lead, and (b) the steps they need to take to attain that vision. The BCNL pilot, which also includes 20 persons with psychosocial disabilities, was created to aid in the development of new legislation that would abolish the existing system of guardianship and replace it with the human right of legal capacity and supported decision-making in accordance with Article 12 of the CRPD (BCNL).

Requirements for Legal Recognition of Supported Decisions by People With Intellectual Disability

Although supported decision-making, which focuses on the person and her/his choices, is essential to legal capacity, in order for a person's decisions to be legally recognized, it is also necessary to consider the third parties with whom she/he will interact. When a person with an ID wishes to open a bank account, sign a lease, or direct some medical procedure, the right of legal capacity dictates that her/his choice must be honored. In the absence of specific legislation, however, third parties like financial institutions, landlords, or healthcare professionals may refuse to recognize that the person has capacity because of their concern that they may become liable for any transaction they enter into with her/him.

The primary means for dealing with this aspect of legal capacity thus far has been through the use of *representation agreements* by which the person with an ID names a person or persons to assist her/him in making decisions. These agreements presume capacity on the part of the person with the ID, define the areas in which the supporter will assist in making decisions, and

impose a duty of loyalty and trust on the supporter. The agreements may be filed in a central registry and, either by custom or law, become binding on third parties whose good faith reliance on such agreements relieves them of any subsequent liability. This is basically the system in effect in British Columbia, although third parties are not yet legally required to accept the agreements (Representation Agreement Act of 1996). Clearly, for full implementation of legal capacity, it will be necessary to enact legislation imposing the obligation of recognizing choices made by supported decision-making on third parties.

In its *Call to Action* to the EU and its members, MDAC (2013) suggests what legislation promoting supported decision-making in furtherance of the right of legal capacity might contain. Such law, it writes, “must establish structures” that

- recognise the right to legal capacity;
- respect the will and preference of the individual;
- provide the opportunity to challenge and modify support arrangements;
- recognise that supported decision-making is built on relationships of trust;
- assign clear roles to supporters to provide information to help the person with a disability to make choices, and to assist the person to communicate these choices to third parties (such as banks, doctors, employers, etc.);
- accommodate for individuals who communicate unconventionally;
- prevent and remedy exploitation, violence and abuse, as outlined in Article 16 of the CRPD;
- carefully structure and monitor these provisions and safeguards to ensure that they do not over-regulate the lives of the individuals utilising them and become invasive and burdensome; and
- ensure that third parties give legal recognition to the role of support people and to decisions made with support. (p. 27)

There is currently an interesting example of draft legislation that would ensure legal capacity for persons with ID in certain areas relating to health care choices. The Autism Self Advocacy Network (ASAN) has drafted *An Act Relating to the Recognition of a Supported Healthcare Decision-Making Agreement for Adults With Disabilities*, and has simultaneously created educational materials and a toolkit to accompany the draft statute which would provide “immunity from suit for health care providers who act consistently with a supported health care decision-making agreement [as provided for in the Model Act]”

(*Model Legislation*, Sec. 8, 2014a; *Transition to Adulthood*, 2014b). As another example, the Texas Guardianship Reform and supported decision-making Group has developed a draft bill that would recognize supported decision-making agreements across a range of contexts, including healthcare and financial decision making. (Crane, 2014, p. 24)

Barriers to Acceptance and Adoption of the Right of Legal Capacity

Although the mandate of the CRPD is clear and there are many examples around the world of legislative change or efforts towards such change away from guardianship and towards supported decision-making, it is enormously difficult for most people to get their heads around the entirely new concept of legal capacity. The perceived connection between cognitive capacity and legal capacity runs very deep. People find it hard, if not impossible, to imagine how a person who does not communicate in any traditional way, and who clearly has significant ID, could ever make meaningful choices, much less that those choices might have legal significance. This is why the move to legal capacity and supported decision-making has so often been referred to as a *paradigm shift*.

The Relevance of Paradigm Shift to Legal Capacity

Looking at the origin of the term paradigm shift provides a useful antidote to this widespread disbelief. In his book *The Structure of Scientific Revolutions*, Thomas Kuhn (1962) coined the phrase to describe that moment at which a community (in his case the scientific community) looks at a body of well-settled evidence and sees that evidence in an entirely new way. That shift, or pivot, or new “lens” in looking at what we think we already know, is what is necessary in order to understand and afford persons with ID the right and dignity of legal capacity. One historical analogy is, I think, especially helpful.

More than a century ago there was a group of people who society saw as clearly incapable of holding and exercising legal capacity. Because of their allegedly inherent inability, often disingenuously described as delicacy, fragility, or weakness, this group was deprived of the right to own property, to enter into contracts, to vote, to serve

as witnesses or jurors, to sue, to marry without permission, and so forth. Society, in the 18th century and before, saw such denial of legal capacity as entirely “natural” and appropriate. It was just the way world was, and few if any could imagine a world in which members of the group might exercise the full range of rights “on an equal basis with all other persons.” That group, of course, was women. Today we see those very same women quite differently. It’s all in the lens and the paradigm shift that changes that lens.

A practical example of the pivot or shifting lens may also be useful: A lawyer I know was appointed as a *guardian ad litem* in a proceeding in which the guardian, father of a 35-year-old man with ID whom we will call “John,” sought permission from the court to sign a consent for John to donate one of his kidneys to his brother on dialysis. The lawyer took as his responsibility to research existing law and apply it to the specific facts with which he was presented. He spent many hours in the library, discovering along the way that this situation would present a case of first impression. By analogy, however, he concluded that in order to give consent, John would, of necessity, have to pass the “understand and appreciate” test of traditional mental capacity.

He met with John several times, and although he was convinced of John’s desire to help his brother and to give up one of his own kidneys, he believed that John did not adequately understand what a transplant entailed or the risks he might be facing. Accordingly, using the lens of *mental capacity*, he recommended that judicial consent to the procedure be denied. As it turned out, the hospital had insisted on the court proceeding and a court order in the first instance, then determined that the entire enterprise was simply too risky and refused to perform the transplant, even if permitted by a judge.

In my conversation with this lawyer, I asked him to think about what it would mean to pivot, that is, rather than to ask what John could *not* do, to ask *what it would take* to enable John to make a decision to consent to a transplant with which he and the court could feel satisfied. Of course, there are many ways in which a person with ID can have medical procedures explained including models, drawings, or other visual aids. John might visit a hospital on one or more occasions to see what a stay might entail. John might speak with a person who had donated a kidney about his or her

experiences. These actions would have “supported” him in making a decision.

Rather than being questioned in the intimidating environment of a courtroom by someone he did not know and might not understand, there could have been a conversation in simple language, in a comfortable place, which would have permitted John to demonstrate, even under existing standards, that his wish to help his brother should be honored. This would have been an “accommodation” to his disability. As Bach (2014) has noted, it is the person’s will and preference plus support plus accommodation that equals legal capacity.

Simply by moving from what a person with ID lacks to the capabilities she/he possesses and asking what supports might be necessary to enable him/her to make her/his own decision, it is possible to make the transition from an outmoded view of mental capacity as legal capacity to the dignity of making one’s own decision with whatever supports are necessary—and to having that decision recognized. Dignity is a key concept here, and, although nowhere mentioned in our own Constitution, it is at the very heart of human rights, and, in particular, the human right of legal capacity.

Because we so often assume that people with ID, including those with the most significant deficits, are not able to make decisions, we invest little or no human capital in teaching them to do so. Our narrow vision perpetuates limitations on their opportunities for self-determination and dignity. The human rights lens of legal capacity, unbound to mental capacity, may permit us to move beyond this limitation. Granting the legal capacity to which they are entitled as a human right to persons with ID is a moral and ethical obligation, if not yet a legal one. Supported decision-making is the means to make this happen.

Some Hard Issues

Protection From Abuse

Even with a complete shift to the human rights lens, there are real and difficult questions about the full implementation of legal capacity. One of these surely is how persons with ID can be protected from abuse, exploitation, and/or violence under a supported decision-making regime.

Drawing directly on provisions of the CRPD (2014), Article 12(4) requires States Parties to “ensure that all measures that relate to the exercise

of legal capacity [supported decision-making] provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law.” Article 16 of the CRPD provides, with more explicit obligations, that “State Parties shall take all appropriate measure to prevent all forms of exploitation, violence and abuse,” and names four types of measures State Parties are required to undertake:

1. Ensuring assistance and supports, including provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse.
2. Monitoring all facilities and programs designed for people with disabilities by independent authorities.
3. Promoting the physical, cognitive and psychological recovery, rehabilitation and social reintegration of victims, including providing protection services.
4. Enacting legislation and policies to ensure that instances of exploitation, violence, or abuse against people with disabilities are identified, investigated and, where appropriate, prosecuted.

Legislative proposals to replace substituted decision-making with supported decision-making incorporate provisions for protection, generally focusing on the use of *monitors*. Flynn and Arstein-Kerslake (2014) wrote:

The key difference between safeguards for support models and those 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 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. (pp. 19–20)

The system in British Columbia depends on monitors who are chosen by the person with ID, and different monitors who can be chosen for different kinds of decisions (Representation Agreement Act of 1996). Under standard representation agreements, there are also limitations on the kinds of decisions representatives can make, including

refusing life-saving treatment on behalf of the individual, placing the individual in an institution, limiting the individuals contact with others, or consenting to treatment over the individual's objection. (Representation Agreement Act of 1996, Part I. p. 4)

Deficiencies of the Existing System

In thinking about protection, however, it may be important to remember as well the often-cited observation that “the great is the enemy of the good.” Although the kinds of monitoring systems currently in use or potentially available for supported decision-making may not provide perfect protection against all possible abuse, existing systems of guardianship monitoring are hardly an optimal model (Wood, 2014, p. 322).

In most jurisdictions, although guardianship statutes specifically provide for periodic reporting by guardians and review by courts, such reporting and review are haphazard or even nonexistent (Uekert, 2010). To the extent that review exists, it is generally directed at, and employs expertise about, the financial issues involved in guardianship of the property. Court personnel or lawyers who are paid to conduct reviews of reports filed by guardians seldom possess any expertise in issues related to personal needs, and receive no training in evaluating such issues as the kinds of overmedication a person under guardianship may be receiving, the kinds of assistance that are, are not, or should be provided, and most significantly, whether there is a need to continue guardianship or alternatively a series of supports which might permit its termination (Association of the Bar, 1994).

The total power given to a guardian is far more likely to lead to isolation and vulnerability, and thus potential abuse and exploitation, than participation in a network of supporters with whom a person has a relationship of trust. Diminished resources for the state court systems that administer guardianship suggest that, despite the admirable work of volunteers in some jurisdictions, the current system of protecting persons under guardianship in a substituted decision-making regime will only become less effective over time. Adherence to that system, simply because there is not yet extensive evidence of how a supported decision-making system could protect persons with ID, is an inadequate reason for continuing substituted decision-making and denying the right of legal capacity.

People With the Most Severe Disabilities

There is another “hard issue” which should be acknowledged. Many readers will doubtlessly respond to the apparently absolute right of every person to make her/his own decisions with their own experiences of persons with such severe disabilities that no amount of support would seem adequate to permit him/her to exercise legal capacity. Most advocates for Article 12 recognize that there is a small group of persons—perhaps 5%—for whom none of the current models of supported decision-making will be effective. As Gerard Quinn (2010) notes, “Human rights are meant to be deontological—which is a fancy way of saying counter –consequential. We of all people, should not be in the business of sacrificing 5% for the sake of 95% (p. 17). Even for this group, a human rights approach premised in Article 12 still prohibits substituted decision-making—a third-party making decisions based on her/his own perception of the person’s “best interest”—calling instead for *facilitated decision-making*. Article 12 recognizes that there may be situations where a person entirely lacks supports that make it possible for her/him to make and communicate a decision. As two of the leading figures working on legal capacity in Ireland have written, where facilitated decision-making is employed:

A 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 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. (Flynn & Arstein-Kerslake, 2014, pp. 141–142)

Article 12(4) also requires that where facilitated decision-making is employed, it must apply “for the shortest time possible” and be subject to independent and impartial review.

The difference between facilitated decision-making and substituted decision-making may seem purely semantic, but it is intended to be much more than that. In his helpful analysis Quinn (2010) writes:

What's worse: stretching a fiction (100% supports) to the point that is visibly at odds with reality—a factor only likely to be seized on by States acting out of abundant caution and enter declarations or reservations ring-fencing substitute decision-making - or, editing the obvious and then using our talents to lock in the exception and transform how decisions are “made for” people? (p.17)

He continues by emphasizing that for what may be 5% with such significant disabilities that the general supported decision-making model does not work, the paradigm shift to legal capacity adds an

obligation to divine the will if at all possible and create social embeddedness that allows some flash of the will to emerge. Human rights cannot accept social determinism. Because we believe in personhood we must believe that all have the potential to exert will in the world. Likewise, human rights cannot accept medical determinism. Medicine is not exempt from social determinants—its categories, its diagnoses are also socially bound. We cannot trade off the reality the decisions will be “made for” some people under the carpet in the hope of cementing into place the paradigm shift only for the majority. (pp. 17-18)

Moving Forward

In an excellent and comprehensive report on legal capacity and supported decision-making worldwide, Inclusion International (2014), a leading Disabled Persons Organization (DPO) sums up the project of what it calls “the right to decide” as follows:

For people with intellectual disabilities the realization of this fundamental right [legal capacity] will require: attitudinal change; transformations in the way supports are provided by governments and communities;

legislative reform; public policy transformation; and, the development and recognition and in law of supported decision-making networks and processes. Simply eliminating all forms of substitute decision making without providing the necessary support for decision making would in effect deprive people of intellectual disability of the power to make decisions. (pp. xii-xiii)

So how do we get there from here? From the legal standpoint, there are some ongoing efforts to specifically include supported decision-making as an alternative that must be attempted before guardianship can be imposed. These efforts are based in part on a widely cited decision by the New York Surrogate's Court in which guardianship for a person with ID who had developed a supported decision-making network was terminated as no longer necessary. *In re* guardianship of Dameris L., 38 Misc.3d 570 (N.Y. Surr. Ct. 2012).

The Uniform Law Commissioners, who write model statutes in a variety of areas, have formed a committee to consider revision of the Uniform Guardianship Procedure and Protection Act (UGPPA), which serves as the model for most state guardianship statutes; the issue of supported decision-making as a *least restrictive alternative* before guardianship can be imposed will be on the table (Glen, 2014, p. 20). ASAN continues to work to create legislation that will make supported decision-making part of the law.

At least as important as these legal efforts, and, in fact, critical to any success in the legal area, is the work of demonstrating that supported decision-making is a real alternative for persons with ID, including those with severe intellectual disability. Partly this requires targeted research into how supported decision-making actually works on the ground, its effects on persons making decisions, and the quality of the decisions themselves (Kohn, Blumenthal, & Campbell, 2013). The project, however, is ultimately to change “hearts and minds”; without people's belief that supported decision-making is feasible and realistic, there is no chance for meaningful legislative change.

It is likely that there are many, many examples of persons with ID who are not under guardianship, but who are supported by family or friendship networks making decisions that are recognized by third parties within their communities. The inspiring story of this issue's co-editor

Jenny Hatch, who lived successfully in the world with a network of supports *prior* to the imposition of guardianship (and who now thrives again in that network, the guardianship having been finally terminated) is the one example.

We need to collect those stories and to create new ones. We need projects that specifically test supported decision-making models, and projects in which persons under guardianship have their rights restored because a judge is persuaded that their supports are adequate to permit them to make their own decisions and have those decisions recognized as a matter of law. And, especially for those readers on the front lines of working with people with ID, it is necessary to imagine, design, revise, and perfect a variety of means by which appropriate supports can be provided to every individual according to her/his own specific needs.

This is where the expertise, experience, and knowledge of readers of this journal become critical. It is only through a partnership of advocates and self-advocates, educators, service providers, members of the legal profession (lawyers, judges, legal academics) and all the other professionals working in the field of intellectual and developmental disability that supported decision-making and the human right of legal capacity, so basic for human dignity, will become available to the most vulnerable among us.

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