

BEYOND GUARDIANSHIP: SUPPORTED DECISION-MAKING BY INDIVIDUALS WITH INTELLECTUAL DISABILITIES

BRIEFING PAPER FOR ROUNDTABLE DISCUSSION

I. INTRODUCTION AND FRAMING THE ROUNDTABLE

BACKGROUND

People with intellectual disabilities are currently subject to guardianship (in some states called conservatorship, tutelage or committee) under state law. Guardianship deprives people with intellectual disabilities of their ability to make their own decisions, and of legal recognition of those decisions. A guardian (conservator, tutor or committee) is appointed by a court to make some or all decisions for the person, based on “substituted judgment,” taking into account what the person wants or would have wanted. If the guardian does not know what the person wants or would have wanted, the guardian can make a decision based on his or her view of the person’s “best interests.” The current state of guardianship law is briefly discussed at Point II, *infra*.

Disability is a natural part of the human experience that does not diminish the right of individuals with intellectual disabilities to live independently and to exert control and choice over their own lives. The ability to steer one’s own course—whether characterized as self-determination, liberty, the pursuit of happiness or freedom of choice—is a fundamental value in American law. In the context of the guardianship construct, people with intellectual disabilities have frequently been denied opportunities to communicate and make personal decisions because decision-making is taken out of their hands and assigned to other individuals who, ostensibly, make choices on their behalf. This includes exercising choice and control over the type and intensity of services and supports needed to participate in the community, and the authority to control their own resources.

In the language of human rights, guardianship deprives a person of “legal capacity,” which means not only that s/he no longer has the right to *make* decisions, but that s/he is not a person who will be *recognized* as a legal actor, that is, a person whose decisions *are entitled to legal recognition*. Indeed, the 1987 Associated Press report that triggered the modern guardianship

reform movement said guardianship “unpersons” an individual. The current understanding or construction of guardianship—to protect a vulnerable, “incapacitated” person by giving another legal decision-making power—is now challenged, as a matter of human rights law, by Article 12 of the Convention on the Rights of Person with Disabilities (CRPD), adopted by the United Nations in 2008. The CRPD is a truly groundbreaking document that was the result of activism and participation by the disability rights movement, and that moves the context of disability from a medical or social model to a human rights model. Article 12 of the CRPD states that *all persons* have full legal capacity, which means that they have the right both to make their own decisions and to act on and have those decisions legally recognized.

Article 12 requires states to provide the support necessary for persons with disabilities to make their own decisions, a concept called “supported decision-making.” While this concept may be new for most lawyers and adult guardians, advocates and providers in the disability rights movement will find it resonates with practices such as person-centered planning and the goals of self-determination and dignity. Relevant United Nations entities and the Committee that reviews member states’ treaty compliance have declared that Article 12 requires states to abolish guardianship laws based on surrogate decision-making (through either the principles of “substituted judgement” or “best interest”), in favor of a system of supported decision-making.

More than 110 countries have ratified the CRPD. Many have begun efforts to reform their existing guardianship or wardship laws, as well as to rethink and reform the legal definition of “capacity.” These efforts involve considering models of supported decision-making to the extent they exist, and adapting or inventing models that fit each nation’s particular legal systems and cultures. For example, the European Union has ratified the CRPD, as well as funded 17 “Dream Fellows” to study and propose changes in member states, with Ireland at the forefront of this work. At the direction of its Justice Ministry, the Center for Disability Studies at the National University of Ireland-Galway has convened a variety of nongovernmental organizations (NGOs) to create a set of “Principles” for a new statute to replace Ireland’s 1857 Wardship Law. (See supplemental materials sent via email). And, NGOs in Canada have been working for more than two years on draft legislation for the Province of Newfoundland and Labrador. Most recently, the Russian Constitutional Court found Russia’s plenary guardianship law unconstitutional and in violation of the CRPD, and has directed the Russian legislature to come up with a new law by next spring. The

Mental Disability Advocacy Center, which litigated the Russian case, has prepared a report to assist Russian lawmakers. (See supplemental materials sent via email).

The United States *signed* the CRPD shortly after President Obama took office; signature requires a state not to engage in activity that violates the Convention. Although the CRPD has not yet been *ratified* by the Senate—as required by our Constitution—it cleared the Foreign Relations Committee with a strong, bipartisan majority. Advocates are optimistic about the prospects for ratification. Ratification would require the United States to (1) recognize the legal capacity of all persons, including those with intellectual disabilities, and (2) engage in “progressive implementation” of Article 12, including the obligation to provide supports for decision-making.

If ratified, the CRPD does not automatically become the law, nor does it immediately invalidate existing state guardianship laws.¹ However, ratification would create both the opportunity and obligation to move from a legal system that measures and judges “mental capacity”—and that, upon a finding of “incapacity,” appoints a guardian to make substituted or best interest decisions for the person under guardianship—to a system that affirms the legal capacity of persons with intellectual disabilities and provides them with the supports necessary to make their own decisions and have those decisions legally recognized.

OUR TASK

This is a huge “paradigm shift” that will undoubtedly generate substantial opposition, most likely based in arguments about the need to protect (*parens patriae*) people with intellectual disabilities. Reform and compliance with the CRPD thus require changing the hearts and minds of political decision-makers and stakeholders, and moving from a more traditional model of disability to one grounded in human rights. Equally important, it requires proposals for creating supported decision-making models that are realistic in terms of the resources currently and/or foreseeably available. It is unlikely that state or federal governments in the United States will suddenly (and in a difficult economic environment) commit huge additional resources to provide—as Sweden has done—a personal ombuds to receive and investigate complaints for everyone who has an intellectual disability.

¹In fact, if the reservations, understandings, and declarations (RUDs) recommended by the Administration to be part of the Senate’s resolution are included, the CRPD will create no new obligations nor require changes to U.S. federal or state laws.

The purpose of this Roundtable is to explore and generate ideas and/or proposals in both of these areas. We propose beginning from a presumption of competence, promoting the rights, self-determination and independence of people with intellectual disabilities, emphasizing dignity and freedom of choice, supporting individuals with intellectual disabilities in the decision-making process and implementing the least restrictive options. We suggest exploring why parents and others seek guardianship and how we can formulate ways to satisfy their needs (real or perceived), to move as many persons out of the guardianship system as possible. Concurrently, and as a necessary precondition to shrinking the reach of the existing guardianship regime, we need to think about how to utilize or re-purpose existing resources to create a supported decision-making system that the law will recognize and honor.

We are a group of experts in a variety of disciplines, working in different parts of a system that deals with decision-making for, with, and by people with intellectual disabilities, and, most importantly, are self-advocates and people with intellectual disabilities. Our focus here is to move beyond guardianship and to promote supported decision-making by individuals with intellectual disabilities.

PROPOSED STRATEGY

Our goal is to begin the task of “getting from here to there” —from a system in which the law sees disabilities and removes legal capacity, to a system that fully supports the legal capacity and dignity of *all* people. At a recent international roundtable on legislative change, convened by the Institute for Research and Development on Inclusion in Society (Canada) and chaired by Michael Bach, attendees from the United States were encouraged to pursue a strategic, incremental model. That model would create and expand supports for decision-making to satisfy the needs of those who currently seek guardianship in order to keep the vast majority of persons for whom guardianship is sought out of the courts and the existing guardianship system. While such a model may not necessarily be what the Roundtable participants choose as worth pursuing (given our intention that this will lead to a larger national summit), it is offered as an opportunity to begin the conversation. Accordingly, we propose the following points for consideration in preparation for the Roundtable:

- What are the “entry points” at which persons with intellectual disabilities necessarily interact with third parties (e.g., financial institutions, healthcare providers, benefits providers) with regard to decisions, agreements and arrangements about their lives? Or, thought of another way, what are the key decision points in the lives of people with intellectual disabilities (for example, employment, finances, health, interpersonal relationships, personal safety, community living, etc.—the same decision points in the lives of most adults).
- How can third parties be satisfied with—and legally protected from liability for accepting and acting on—supported decisions that honor legal capacity, rather than substituted decisions made by a guardian empowered by the court system?
 - (1) If we use, for example, a representation agreement or some sort of advanced directive that requires less “capacity” than a power of attorney, or traditional healthcare proxy, what should the test be?
 - (2) What agency/entity (existing or to be created) should replace the court system in placing the imprimatur of legality on such agreements and/or directives?
- How do we nurture, facilitate and/or create support mechanisms to allow persons with intellectual disabilities to exercise their legal capacity?
 - (1) What models exist?
 - (2) What existing resources could we employ?
- How do we protect against abuse without returning to a model of protectionism that inhibits or denies legal capacity?
 - (1) Do we have any idea of how much abuse there actually is in the court system?
 - (2) What is the likelihood that a model of supported decision-making based on trusting relationships would create new or greater opportunities for abuse (cost-benefit, analysis)?

(3) What community organizations or entities could be utilized to provide oversight and protection?

- How can we use (or plan to use) the gains expected from this diversion/capacity building/re-legitimation project to change societal views and educational practices about the right of decision-making and legal capacity for all people?
- What research will be needed to evaluate the use and effectiveness of supported decision-making models?

II. WHERE WE ARE NOW: GUARDIANSHIP

Because parents have the legal power to make decisions for their children, generally until age 18, guardianship laws apply to adults who, under the applicable test, are found to lack “capacity.” Most states have only one guardianship statute, which covers both those who have lacked capacity since birth or childhood (most people with intellectual disabilities who are placed under such arrangements are seen to fall into this category), as well as adults who “lose capacity” as a result of dementia (including Alzheimer’s disease), brain injury, stroke, etc. Only five states have guardianship laws that are specific to people with intellectual disabilities. In New York, for example, the specialized statute covers the “mentally retarded” and “developmentally disabled.” (See New York’s Surrogate Court Procedure Act (SCPA) Article 17, <http://codes.lp.findlaw.com/nycode/SCP/17-A>).

Guardianship, sometimes called conservatorship, is the legal means by which one person is given the power to make decisions for another, and to have those decisions recognized and honored by third parties. Guardianship has its roots in Roman law, and in the fourteenth century English principle of *parens patriae*, that is, the power of the state, or the father, to protect its vulnerable citizens.

This basis in protection continues in guardianship laws today. Generally speaking, a petitioner asks a court (in some states, the probate court; in other states, the trial court of general jurisdiction) to appoint a guardian for someone because that person is unable to care for her/himself or to manage her/his property, or both. The petitioner may be a relative—in the case of

guardianship for persons with intellectual disabilities, the petitioner is usually a parent or sibling—a friend, a hospital or an institution in which the person resides, Adult Protective Services (APS), a public or private social services agency, or, in some cases, a creditor.

The test for whether a guardian should be appointed is set out in state law, and is usually a mix of medical conditions, cognitive abilities, functional abilities and harm that could result if no appointment is made. For example, the Uniform Guardianship and Protective Proceedings Act provides that the person “is unable to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or self-care. . . .” While statutes differ, often in practice medical testimony, or a diagnosis that the person carries, weighs heavily and may be the deciding factor.

If the court believes a guardian should be appointed it may, depending on the particular state and statute, appoint either a *plenary* (“full”) guardian, or a *limited* guardian whose powers are confined to those areas in which the person is found to lack capacity to make decisions. For example, a person may continue to make healthcare decisions and routine financial decisions, but not decisions about investments or sale of real property. Almost all state statutes include language allowing for limited guardianship, and many statutes prefer limited guardianship. However, in practice, plenary guardianship may be the more common result, due to the lack of fine-tuned capacity assessments, the lack of judicial time or will in crafting limited orders, the high cost of returning to court to modify limited orders if changes are needed, and concern that third parties may not recognize the limitations. In addition, guardianship arrangements, once in place, are difficult to modify or terminate, though an individual’s skills and decision-making abilities may continue to develop.

In the past, guardianship often meant the loss of all of a person’s civil rights—to vote, marry, etc. However, more modern guardianship statutes no longer include such dramatic and total deprivation of rights. A number of states specify “rights retained,” or provide that all rights are retained except those specifically removed in the order. And, unlike earlier statutes, modern guardianship laws provide a number of procedural protections—notice; a hearing; an opportunity to be heard; the right to be represented by counsel (if s/he can afford a lawyer, and can find one) including, in some instances, counsel paid for by the state; the right to cross examine; a heavier burden of proof than what is required in ordinary civil cases; and in some states, an independent

“court examiner” or “visitor” to advise the court. Moreover, most statutes provide that guardianship is the last resort, and that less restrictive options, such as advance directives and powers of attorney, should be considered first.

Despite these statutory improvements, in many cases, both the hearing and the assessment of capacity are perfunctory, the person whose liberty is at stake may not even be present, and the guardian may not take into account the person’s wishes and values. In short, guardianship reform has come far on paper, but the practice remains uneven, and in some cases, sorely deficient. (For guardianship language that has been adopted or used as a model in whole or in part in many states, see the Uniform Guardianship and Protective Proceedings Act,

<http://www.uniformlaws.org/Act.aspx?title=Guardianship> and Protective Proceedings Act; for state-by-state guardianship statutory charts, see the ABA Commission on Law and Aging’s website at

http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice.html).

Regardless, whether all of the procedural protections are observed, and whether a person still retains some or many rights at the end of the process, when a guardian is appointed, the individual still loses the power to make some or all decisions about her/his life—often where to live, who to associate with, how to spend her/his resources, what kinds of medical treatments to accept or reject, etc. Only the guardian is empowered to make those decisions, and, as to such decisions, third parties (e.g., healthcare providers, banks or other financial institutions, service providers, and governmental agencies) will—and legally must—honor the guardian’s decisions without reference to the wishes and preferences of the person under guardianship.

III. THE CHALLENGE: THE CRPD AND THE RIGHT TO LEGAL CAPACITY²

The right to equal recognition before the law, and its attendant right to legal capacity without discrimination on the basis of disability, is recognized in Article 12 of the CRPD. The

² This section is taken in part, with permission, from THE WORKING GROUP ON LEGAL CAPACITY AND SUPPORTED DECISION MAKING AND THE CANADIAN ASSOCIATION FOR COMMUNITY LIVING, A STATUTORY FRAMEWORK FOR THE RIGHT TO LEGAL CAPACITY AND SUPPORTED DECISION-MAKING FOR APPLICATION IN PROVINCIAL/TERRITORIAL JURISDICTIONS IN CANADA (Draft Sept. 2012).

inclusion of Article 12 is a major achievement that makes clear that people with disabilities have the right to control decisions about their lives with whatever kinds of support they require to do so, and that States Parties are obliged to establish the arrangements to make this possible. This includes enabling a person with significantly challenging disabilities to exercise control over decisions through the assistance of support persons who, in their relationship of personal knowledge and trust with the person, commit to interpreting and acting on that person's preferences and will as the basis of decision-making that involves third parties.

At the time the CRPD was being negotiated, the Office of the United Nations High Commissioner for Human Rights prepared a "Background Report" reviewing the concept of legal capacity, and arrived at a definition that is inclusive of those who may not act entirely independently in their decision-making. The definition makes clear that legal capacity is about having the recognized "power" to enter transactions, contracts and legally-regulated relationships with others. The report defined legal capacity this way:

Legal capacity includes the 'capacity to act,' intended as the capacity and power to engage in a particular undertakings or transactions, to maintain a particular status or relationship with another individual, and more in general to create, modify or extinguish legal relationships.³

For governments to fulfill their obligations under Article 12 requires what many have referred to as a "paradigm shift" in the usual approaches to protecting and promoting the right to legal capacity. Adults can no longer be required to demonstrate that they meet certain tests of mental capacity in order to have their rights to legal capacity equally respected and protected. The CRPD recognizes this right and the supports needed to exercise it as an obligation, under international law, of governments to create and honor what is called "supported decision-making." For people with intellectual, cognitive or psychosocial disabilities in particular, Article 12 is essential to self-determination and equality, which are fundamental calls of the disability rights movement. The legacy of centuries of confinement and exclusion based on the idea of "mental

³ OFFICE OF THE UNITED NATIONS HIGH COMMISSIONER FOR HUMAN RIGHTS, LEGAL CAPACITY: BACKGROUND CONFERENCE DOCUMENT (2005), available at <http://www.un.org/esa/socdev/enable/rights/ahc6documents.htm> (last visited Oct. 16, 2012).

incapacity” is that people with intellectual, cognitive or psychosocial disabilities are often considered to have lesser moral and legal status than other human beings. The result has been laws, policies and practices in every sector of society that deny equality on the basis of disability, whether through guardianship or through denial of the rights to vote (still the case in some countries), to make one’s own healthcare decisions, and to make decisions about where one will live and with whom and how one’s money and property will be managed.

In acknowledging that people can exercise their legal capacity in different ways, and with a range of supports, Article 12 provides new ground on which people with disabilities can retain and rebuild their self-determination. We understand Article 12 as a kind of “ramp” of accessibility for adults who have long been denied the right to equal recognition before the law and to the process of controlling decisions that affect their lives.

While many strategies are needed to fully implement Article 12, there is no doubt that substantial law reform is required. Moreover, no single piece of legislation currently exists anywhere that pulls together all the pieces needed to ensure a right to legal capacity. These include the supports to exercise this right, as Article 12 requires, and the roles and duties of government, other parties in the decision-making process, support networks and community agencies.

IV. STARTING PLACES AND SHARED UNDERSTANDING

The Canadian working group identified a number of starting places points or shared understandings for legislative reform, many or most of which are equally applicable to the work which this Roundtable seeks to begin. They are:

1. People exercise their legal capacity in different ways and may need a variety of supports to do so, as recognized in Article 12. These supports can take different forms including communication aids and devices, or personal supports like a supporter or support network to assist in making decisions.
2. Most people use informal support in making personal decisions. We draw on the support of family and friends in managing decision-making with financial institutions or doctors, for

example. All people make decisions, as adults, interdependently and we have a right to make decisions and enter agreements by ourselves, as long as we appreciate and understand the nature and consequences of these decisions.

3. However, some people are not recognized as fully capable to make decisions by those with whom they are seeking to establish formal contracts or agreements, precisely because they need others to assist them. In order to prevent substitute decision-making from being imposed, their supporters need recognition as fully appointed to participate in the decision-making process—not as substitute decision-makers, but as supporters. Legislation is needed that guides how such appointments are to be made and how the role of supporters is to be safeguarded and regulated.
4. For some people who cannot communicate in ways that most others understand, decision-making supporters may be required to interpret personal preferences as the basis for direction in decision-making. Their preferences and will, as understood by those closest to them, is the basis on which they will exercise their full legal capacity.
5. Some people will not be able to make decisions all by themselves, but Article 12 makes clear that their full legal capacity cannot be denied on this basis. One challenge is to figure out how to protect against some people being required to use decision-making supports and assistance, just because others—like a physician or financial institution—wish to protect their professional or contractual liability.
6. Creating inclusive and accommodating decision-making processes has largely not been recognized as a public policy issue. Individuals, supporters, healthcare, social service and financial institutions and governments will need assistance in figuring out how to enable people in different situations to be supported and accommodated in making decisions.
7. Many people will make planning arrangements, through an advance directive, or representation agreement or power of attorney, which gives another person authority to

make decisions for them if they become unable to for whatever reason. Such arrangements respect a person's self-determination, because h/she is deciding what should happen in their future. However, safeguards are needed to ensure that those appointed do not abuse or exploit the person, and that appropriate responses are made when this happens.

8. There is likely a small group of people with significantly challenging disabilities who cannot act independently and who are not able to communicate in ways others understand or can act upon. Some way of stepping in to facilitate the making of needed decisions in order to prevent substantial harm to the person or others is required in these situations. This type of "facilitated" decision-making should be distinguished from "supported" decision-making, or "representative" decision-making where an adult appoints a power of attorney or other legal representative to act for them under certain circumstances. As well, safeguards are required to ensure such forms of assistance are time-limited, monitored, and result in the most autonomy-enhancing and community-based approaches to support.
9. Government has an essential role to play in protecting adults who are abused, victimized or exploited by those around them. However, adult protection systems need to be designed in ways that assure protection and intervention when needed, but do not override the rights of adults to make their own, sometimes risky decisions. At the same time, inputs are needed to assist adults in situations of neglect and abuse to regain their self-determination through supportive relationships with others or any other means as soon as possible.
10. Given the range of supported decision-making arrangements that people will have in place, especially with the aging of the population, governments must create new authorities to help people develop and manage these arrangements. In addition, authority is needed to adjudicate among parties where there are disputes about decision-making processes.
11. Governments must play a role in funding community agencies to assist people in creating decision-making arrangements that enable them to act on their right to legal capacity. Moreover, governments have a role to provide specific decision-making supports when

there is a demonstrated need and to promote broader public awareness about the right to legal capacity.

V. ENTRY POINTS

It is important to understand why people currently are placed under guardianship, so that alternatives that do not deprive persons with intellectual disabilities of their legal capacity can be generated. While there may be many reasons, a major impetus is in interactions with third parties and/or institutions that may, based on the perceived need to protect and liability concerns, insist on guarantees for the decisions made by persons identified as having an intellectual disability, solely because of that disability.

Legal capacity is lived in everyday life, in the many transactions and agreements we all make. The right to “living independently and being included in the community” recognized in Article 19 of the CRPD, for example, relies on people being able to enter these agreements—whether to rent an apartment, open a bank account, get married, or direct their healthcare and disability supports. These rights and values are protected by U.S. law, including the Americans with Disabilities Act (ADA) as interpreted by the U.S. Supreme Court in the *Olmstead v. L.C.* decision,⁴ the Rehabilitation Act, and the Developmental Disabilities Assistance and Bill of Rights Act of 2000. Many of the other rights recognized in the CRPD also rely for their full realization on people with disabilities being able, and supported as necessary, to make decisions in their lives. This means that doctors, bankers, service agencies, support networks, family and community members all have responsibilities to promote and enable decision-making processes that are inclusive, supportive and accommodating of people with disabilities.

The challenge for law reform is to craft legislation that makes clear the duties and responsibilities of all these actors, recognizes the systematic powerlessness and exclusion of many people in decision-making about their lives, and creates the right balance of rights, responsibilities and liabilities to enable people to lead and live good lives in the community in pursuit of their own life paths.

The issue, therefore, is not only to identify the “entry points” for these transactions and

⁴ 527 U.S. 581 (1999).

agreements, but also to craft ways—short of guardianship, but legally validated— to allow persons with disabilities to exercise their legal capacity. Not only do we need to find, develop and facilitate support systems, we also need to have legislation that creates legal recognition for them.

VI. SUPPORTS

REASONABLE ACCOMMODATIONS

People need different kinds of supports in different situations, and based on their particular abilities and disabilities. People with intellectual disabilities must have an equal opportunity to meaningfully participate in the decision-making process. This may include the provision or modification of devices, services and practices or procedures as necessary to support their ability to make choices, identify preferences and exert control over their own lives. In many instances, the supports necessary are relatively minor and can be provided by the person or entity involved in the transaction. Although “reasonable accommodation” is a requirement of the ADA in employment settings under certain circumstances, it has been less widely used for persons with intellectual disabilities and, of course, does not begin to cover all of the transactions and agreements in which they may participate. Thus, the Roundtable should examine how to ensure that financial institutions, healthcare providers and others involved in decision-making processes meet their legal obligations to provide accessible information and processes and accommodations consistent with current law and the CRPD (e.g., plain language documents; adequate time for reading, or being read to, and for comprehension, etc.) This extends to providing supports and accommodations to assist adults in exercising their legal capacity in a legally independent manner.

RECOGNIZING SUPPORT AGREEMENTS

Where greater support is necessary, legislation is necessary to recognize supportive arrangements that aid persons with intellectual disabilities in making decisions, or to choose others to make decisions on their behalf. “Representation agreements” like those utilized in British Columbia, are one possible model for the creation and legal recognition of such arrangements. (See supplemental materials sent via email for a description of the British Columbia model). Drawing on this model, the Canadian working group has proposed as follows:

Establishing Supported Decision-making Arrangements

Legislation should provide for adults to establish formalized supported decision-making arrangements, which involve an adult having access to other people to assist in decision-making and be recognized in their role by others involved in the decision-making process: An adult should be able to appoint a decision-making supporter or supporters and make an agreement with them to assist in decision-making for certain decisions or types of decisions.

As a practical matter, it is necessary to decide what procedure will be used to make an appointment (or execute a representation agreement) that will be legally recognized, that is, have the official imprimatur that allows third parties to rely on it without fear of subsequent liability. Here, it is useful to think of how it might be possible to move this outside of the courts, whether simply through the registration of representation agreements, or by some more official review and imprimatur of agreements and/or support arrangements. What existing entities, if any, might be appropriate to bestow approval that translates to adequate guarantees for third parties? What existing entities might be re-engineered for this purpose? What new entity might it be practical to create? And, having identified the *place* where recognition will be legally guaranteed, what are the standards that should be applied to ensure against coercion or abuse? This question is addressed in VII, *infra*. The British Columbia model provides one possibility.

HIGHER LEVELS OF SUPPORT

The Canadian working group operated from the presumption that representation, or similar agreements or appointments, may not be possible for everyone with disabilities, and has proposed a model for “facilitated” decision-making. (For their treatment of this issue, see section taken from Canadian statutory framework referenced in footnote 2, in supplemental materials sent via email). One possibility is to import the language of “facilitated decision-making” into existing guardianship statutes for those relatively few people who could not otherwise be kept out of guardianship, *or* to amend guardianship statutes to require consideration and exhaustion of all forms of supported decision-making *before* guardianship could be imposed (a least restrictive

alternative approach).

CREATING AND FACILITATING SUPPORTS FOR DECISION-MAKING

Many people with intellectual disabilities are already in relationships of trust and support with family members and/or friends that enable them to make and act on their decisions themselves or to enter into representation or similar agreements that, where recognized, ensure their legal capacity. For many others, however, the necessary relationships are not in place, or may be subject to a model of dependency and paternalism.

Article 12 of the CRPD makes clear that the state has an obligation to ensure access to supports people may require to exercise their legal capacity. Legislation should take its guidance from Article 12.3 in particular and provide for community-based delivery of supports, which should include:

- Individual planning, service coordination and referral
- Independent advocacy
- Communication and interpretive assistance
- Facilitating a support decision-making arrangement
- Peer support
- Relationship-building assistance
- Administrative assistance
- Any other support or accommodation considered necessary to assist the adult in exercising control over her/his decisions, or to provide the adult with the conditions needed to develop or regain decision-making capabilities and to exercise his or her right to legal capacity.

Given the current economic situation, and the unlikelihood that new, publicly funded resources will be available in the foreseeable future, we need to look at existing resources—government funded, private, charitable, volunteer networks, etc., as well as existing, effective person-centered planning tools that can be adapted to individual circumstances.—with an eye to how they can be re-purposed or re-directed or more widely shared to help identify

and provide the supports necessary to assist persons with intellectual disabilities in making decisions, and/or providing circles of trust and responsibility from which such persons can delegate some or all of their decisions, or decisions in a particular area (i.e., healthcare).

There is another aspect to this task: educating families and others in close relationships to persons with intellectual disabilities to see them as *able*, as well as legally entitled, to make their own decisions with the appropriate support. Here, the experience of self-advocates and service providers experienced in moving clients to self-determination will be a valuable resource.

The special education system must also be engaged in developing and expanding teaching decision-making skills to students with intellectual disabilities. Such instruction should begin as early as possible and should also include educating parents or other caretakers about such tools, so as to foster, rather than inhibit, children's ability to make decisions in the broadest range of their life experience. Best practices in special education and child psychology can be critical resources in this enormously important aspect of the project.

VII. PREVENTING ABUSE

Given the overarching framework of the shift from surrogate (substituted judgment and best interest) decision-making to supported decision-making, and the need to use options less restrictive and more supportive of self-determination than the traditional guardianship system, the possibility of exploitation and/or abuse remains, and appropriate protective mechanisms are needed.⁵ The key is to design mechanisms that avoid overprotection and recognize individual preferences, choices and “the dignity of risk,” while setting appropriate safeguards against coercion and malfeasance.

⁵ As Michael Bach and Lana Kerzner have noted, “An important component of any decision-making regime would be the inclusion of a high level of review and oversight to address . . . concerns about abuse and undue influence. Bach and Kerzner, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity* 15, 37 (Oct. 2010), available at <http://www.lco-cdo.org/disabilities/bach-kerzner.pdf> (last visited Oct. 16, 2012). They point, however, to a recent United Nations report on issues of older persons from a global perspective that “calls for addressing elder abuse and other issues within a proactive human rights approach, and recommends a new international human rights mechanism for that purpose” *id.* See UNITED NATIONS, HUMAN RIGHTS COUNCIL, ADVISORY COMMITTEE, WORKING PAPER, CHINSUNG CHUNG, THE NECESSITY OF A HUMAN RIGHTS APPROACH AND EFFECTIVE UNITED NATIONS MECHANISM FOR THE HUMAN RIGHTS OF THE OLDER PERSON (Jan. 2010), available at <http://www2.ohchr.org/english/bodies/hrcouncil/advisorycommittee/session4/documentation.htm> (last visited Oct. 16, 2012).

Under the current guardianship model, the court has the responsibility for oversight of guardians and conservators. Court monitoring varies, and may include the following requirements: an annual report and accounting submitted by the guardian; court review of the report/accounting; identification of problems or guardian malfeasance; investigators to verify the report and inquire into problems; and follow-up action by the court, including a hearing and possible modification of the order, fine or removal of the guardian. Additionally, adult protective services (APS) may receive and pursue reports of suspected abuse by guardians and other fiduciaries.

The protection and advocacy agencies (P&As) provide another source of protection and monitoring for the rights of people with disabilities, including individuals with intellectual disabilities. P&As, which operate in all 50 states, the District of Columbia, Puerto Rico and the U.S. Territories, as well as a Native American P&A, are authorized to provide legal representation and related advocacy services, and to investigate abuse and neglect of individuals with disabilities. National Disability Rights Network (NDRN) is the national membership association of the federally-mandated P&As. NDRN supports its member organizations by, among other roles, providing training and technical assistance, legal support and legislative advocacy regarding state guardianship law, which may include examples of abuse as a result of unnecessary guardianship or neglect as a result of a guardian's financial mismanagement.

In practice, courts often lack the wherewithal for full and effective oversight.⁶ APS, as well as the P&A system, are limited by resources. It is far from a perfect system, but theoretically there are at least measures to address malfeasance and exploitation by guardians acting as fiduciaries and surrogate decision-makers.

As an example of the multiple values to be weighed when considering how to effectively protect the rights of people with disabilities in the guardianship context, the Developmental Disabilities Assistance and Bill of Rights Act of 2000 states:

The goals of the Nation properly include a goal of providing individuals with developmental disabilities with the information,

⁶ See Naomi Karp & Erica Wood, *Guarding the Guardians: Promising Practices for Court Monitoring* (AARP Public Policy Institute, 2007), available at http://assets.aarp.org/rgcenter/il/2007_21_guardians.pdf (last visited Oct. 16, 2012); Naomi Karp & Erica Wood, *Guardianship Monitoring: A National Survey of Court Practices* (AARP Public Policy Institute, 2007), available at http://assets.aarp.org/rgcenter/consume/2006_14_guardianship.pdf (last visited Oct. 16, 2012).

skills, opportunities, and support to make informed choices and decisions about their lives; live in homes and communities in which such individuals can exercise their full rights and responsibilities as citizens; pursue meaningful and productive lives; contribute to their families, communities, and States, and the Nation; ... live free of abuse, neglect, financial and sexual exploitation, and violations of their legal and human rights; and, achieve full integration and inclusion in society, in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of each individual....

The CRPD clearly recognizes the need to prevent abuse, neglect and exploitation, including in the context of supported and facilitated decision-making. Article 12 states that “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.”

Article 16 provides for “Freedom from Exploitation, Violence and Abuse.” Specifically, it requires “States Parties . . . [to] take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse. . . .” Article 16 names three types of such measures. First, it recognizes that support should include “the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse.” Second, it states that, to prevent exploitation, violence and abuse, “all facilities and programmes designed to serve persons with disabilities [must be] effectively monitored.” Third, it addresses the need for services for victim recovery, rehabilitation and social reintegration.

The ability to live free of abuse and neglect is one important goal among multiple priorities, and has been recognized in key supported decision-making documents. The Mental Disability Advocacy Center also alludes to the need for safeguards against abuse.⁷ It states that “[t]o ensure supported decision-making works correctly and effectively in place of substituted decision-making under guardianship, a number of safeguards should be put in place to prevent and

⁷ Mental Disability Advocacy Center, *Supported Decision-Making: An Alternative to Guardianship*, available at http://www.globalmentalhealth.org/sites/default/files/MDAC%20Supported_Decision-making_An_Alternative_to_Guardianship.pdf (last visited Oct. 16, 2012).

remedy any forms of physical, emotional or financial abuse, or neglect, that may occur.”⁸

The Canadian Association for Community Living, in its *Statutory Framework*, provides perhaps the most well-considered approach to protection from abuse in its concept of designated “monitors.” It states:

Given that some people are at higher risk of neglect and abuse because of the nature of their disability, isolation, or other factors, some provision should be in place to enable ‘monitors’ of supported decision-making and representative decision-making arrangements to be appointed. An appointment should be made only on request by an adult, supporter, representative or where there are reasonable grounds to indicate that this safeguard is required to ensure the decision-making process with and around the adult maintains integrity. . . . A monitor would be independent and act to ensure supporters and representatives are fulfilling their statutory obligations.

Consideration of possible safeguards in supported decision-making raises a number of questions for Roundtable discussion:

1. The Mental Disability Advocacy Center notes that any safeguards against abuse “should not overprotect people with disabilities, but must respect the inherent dignity, individual autonomy—including the freedom to make one’s own choices—and independence of persons.”⁹ How would this balance play out in policy and practice?
2. How can we create practices that ensure an adult’s rights are enhanced to the greatest extent possible—developing support for the exercise of legal capacity as needed? How best to balance the need to intervene and protect with the obligation to enhance the supports required to assist a person in establishing or regaining self-determination through appropriate supported decision-making. (Canadian Association for Community Living, in *Statutory Framework*)
3. To what extent and how will there be any qualifications, standards and screening for those serving in a support role? The guardianship world only recently has begun to develop

⁸ *Id.* at 9.

⁹ *Id.*

standards of performance for guardians and conservators.¹⁰ What standard should apply to support roles? What different standards would be needed for different support roles?

4. Will a system of supported decision-making rely on individuals with disabilities to make complains or reports of problems, or will there be any system of routine or targeted checks to ensure against abuse by persons in support roles. What entity would conduct such checks and how?
5. Will persons in support roles regularly report to any specified authority? Should there be different reporting requirements for different support roles? Who will receive and review such reports? What actions could be taken as a result?
6. How will a supported decision-making system treat instances of conflict of interest? A family member often may be in a conflicted position as to finances, living arrangements, property and long-term plans of an individual. Article 12 of the CRPD states that measures concerning the exercise of legal capacity should be “free of conflict of interest.” How will this be sorted out, and how can any practices adopted be designed to reflect the preferences and choices of the individual with intellectual disabilities?
7. “Undue influence” is a subtle phenomenon that often is undetected, and may well affect an individual with disabilities. Undue influence “refers to a dynamic between an individual and another person. It describes the bending of one person’s will to the extent that the will of the perpetrator is substituted for that of the victim.”¹¹ It comes up in relationships based on trust and confidence, especially in situations of isolation. Indeed, Article 12 of the

¹⁰ SEE NATIONAL GUARDIANSHIP NETWORK, THE THIRD NATIONAL GUARDIANSHIP SUMMIT: STANDARDS AND RECOMMENDATIONS (Oct. 2011), *available at* <http://www.guardianshipsummit.org/wp-content/uploads/2011/11/Final-Summit-Standards-Recommendations-5-12-2.pdf> (last visited Oct. 16, 2012); NATIONAL GUARDIANSHIP ASSOCIATION, STANDARDS OF PRACTICE (3d ed., 2007), *available at* http://www.guardianship.org/documents/Standards_of_Practice.pdf (last visited Oct. 16, 2012).

¹¹ AMERICAN BAR ASSOCIATION COMMISSION ON LAW AND AGING & AMERICAN PSYCHOLOGICAL ASSOCIATION, ASSESSMENT OF OLDER ADULTS WITH DIMINISHED CAPACITY: A HANDBOOK FOR PSYCHOLOGISTS 15 (2008), *available at* <http://www.apa.org/pi/aging/programs/assessment/capacity-psychologist-handbook.pdf> (last visited Oct. 16, 2012).

CRPD states that “safeguards shall ensure that measures relating to the exercise of legal capacity . . . are free of undue influence.” How will a system of supported decision-making recognize, account for and protect against undue influence?

8. A “representation agreement” is an agreement between two parties, as is a power of attorney. Financial powers of attorney have been subject to considerable abuse, and have in fact been called “a license to steal.”¹² Yet, there is widespread recognition that durable financial powers of attorney, as well as healthcare powers of attorney, are valuable instruments to promote planning and empowerment. What safeguards could and should be built into representation agreements?
9. People with intellectual disabilities have a wide range of needs and circumstances. Article 12 of the CRPD recognizes that safeguards against abuse must be “proportional and tailored to the person’s circumstances. . . .” What will this involve? Where along the spectrum of possible safeguards against abuse is the ideal balance between too much oversight, which would be expensive, cumbersome, possibly invasive of rights in the exercise of capacity, *and* too little oversight allowing widespread abusive practices to flourish without remedy? Does this differ in different situations?
10. In cases where an individual has no family, friends or colleagues to serve as support—and thus the role falls to “strangers” unfamiliar with the person—are there any special or different oversight measures required?
11. Finally, if in some instances supported decision-making is incorporated into the existing—or a more reformed—guardianship system, how can we best move toward limited guardianships? How can individuals have ready access to the court system if needed? How can we best provide accessible information about less restrictive options,

¹² Loria A. Stiegel & Ellen Van Cleave Klem, *Power of Attorney Abuse: What States Can Do About It* (AARP Public Policy Institute 2008), available at http://assets.aarp.org/rgcenter/consume/2008_17_poa.pdf (last visited Oct. 16, 2012).

guardianship proceedings, rights of appeal and restoration? How can we protect against conflict of interest by appointed guardians?