

A Discussion of Legal Capacity in the Draft Convention on Disability

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By

Clarence J Sundram,
President, Mental Disability Rights International

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1. Background and Context

In the last century alone, there have been at least 24 International Human Rights Conventions adopted by the international community, aside from specialized and regional treaties. These conventions have addressed the special vulnerability of various groups who have experienced serious violations of their human rights. They have addressed problems such as slavery, genocide, treatment of prisoners of war and of civilians in a time of war, racial discrimination, torture and other cruel, inhuman and degrading treatment.

A consistent theme in these Conventions is their concern with exploitation of persons and the rights of particularly disadvantaged people like children, women, racial minorities, and prisoners and detainees. What is interesting is that none of these Conventions focus specifically on disability although people with disabilities (and especially people with mental disabilities) have been subjected historically to some of the most systematic and egregious violations of their human rights:

- They have been subjected to arbitrary detention, sometimes for a lifetime, without any legal process;
- They have been subject to peonage and forced labor in institutions for most of the 20th century;
- They have endured forced sterilization, being chained to walls and confined in cages;

- They have had fewer rights than prisoners of war and persons charged with crimes. POWS, for example, have been entitled since 1949 to daily outdoor exercise of at least one hour, but a similar right was not recognized for civilly committed psychiatric patients in New York until the 1990s and it took a lawsuit to gain recognition of this modest right;
- They have been subject to physical abuse and sexual exploitation;
- They have been deprived of basic health care, and many have died from preventable conditions like malnutrition and hypothermia; and
- They have been subjected to torture, and cruel and inhuman and degrading treatment including living in squalid conditions in institutions, being subjected to the use of painful and noxious aversives, unmodified ECT, and the misuse of restraints and seclusion for days on end.

But none of these conditions, which have existed in institutions all over the world and are well known, has caused them to be a subject of a human rights convention. For a long time, there was the view that existing human rights treaties and the Universal Declaration of Human Rights covered everyone, and thus there was no need for a more explicit set of protections.

The Universal Declaration of Human Rights clearly says that *all* human beings are born free and equal in dignity and rights. And it says equally clearly that *everyone* is entitled to all the rights and freedoms set forth in this declaration, without distinction of any kind. But as with other groups who are part of “everyone,” including notably women and children, history and experience have shown the need for additional and more specific recognition and protection of their rights.

A theme of this paper is that despite this nominally inclusive language in the UDHR and in the International Covenants of Civil and Political Rights, and Economic, Social and Cultural Rights -- which together comprise the International Bill of Rights— people with disabilities, and especially people with mental disabilities are among the most ignored groups when it comes to protection through law. There are tens of thousands, if not hundreds of thousands of people who are locked up, sometimes for life, without any legal process whatsoever and with no opportunity to win their release. They are often confined in conditions that threaten their lives, health and safety on a daily basis and that strip them of every shred of human dignity, notwithstanding the lofty words in the Universal Declaration of Human Rights.

Despite the very progressive ideas embodied in the Universal Declaration of Human Rights, one must remember that it was a product of its time. One of the problems with the Universal Declaration of Human Rights was that, like other generic human rights documents, many people and governments thought it could not possibly have been meant to apply to everyone, including people with disabilities.

As just one example of the assumed exclusion of people with mental disabilities from generic protections, it is useful to recall other significant developments in the immediate aftermath of the Second World War. Among the many revelations that horrified the world were the stories that emerged about the experiments done by the Nazis and the Japanese on human beings, many of whom were POWs or other captives (surgery without anesthesia; autopsies on live human beings, etc.). As a reaction to these revelations, the Nuremberg Code of 1947 was adopted. The first Principle in the Nuremberg Code reads:

The voluntary consent of the human subject is absolutely essential. This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, overreaching, or other alternative form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision.

This essential human rights protection was ultimately incorporated into the International Covenant on Civil and Political Rights, which is binding international law for the 152 states which have ratified it. Article 7 states: “No one shall be subjected to torture or cruel, inhuman or degrading treatment or punishment. In particular, *no one* shall be subjected without his free consent to medical or scientific experimentation.”

Notwithstanding this plain language, in the context of research protection, the widespread view in the research community apparently was that this statement could not have been meant to include people with mental disabilities. Thus, respected researchers in respected institutions, some a stone's throw away from the United Nations headquarters in Manhattan, continued to perform experiments at high levels of risk upon persons with mental impairments, without any consent at all and certainly not voluntary informed consent. Much of this research had no intended benefit for the mentally disabled human subjects. They were simply human guinea pigs. What is revealing is that this wasn't done only in secret; they published their findings and methods in some of the most respected professional journals, apparently never thinking that they were violating the human rights of their captive human subjects.¹

¹ See, generally, Clarence J. Sundram, *In Harm's Way: Research Subjects Who Are Decisionally Impaired*, J. HEALTH CARE L. & POLICY, Vol. 1, 36-65 (1998).

Even today, the federal regulations in the United States governing human subject research have special safeguards for children, pregnant women, and prisoners –due to the inherently coercive environment of prisons. However, despite repeated recommendations by Presidential Commissions,² at present convicted criminals have better recognition in law of their special vulnerability to coercion in human subject research due to their institutionalization than do people who are institutionalized due to mental disability. Human rights for everyone are not the same as human rights for people with mental disabilities.

Generic recognition of human rights for *all* people has been insufficient to bring people with mental disabilities under the same umbrella because there had been a long history in society of regarding them as a separate class, with separate and lesser human rights. Worse, the abuses to which people with mental disabilities have been exposed have generally not been recognized as violations of human rights even by organizations that are engaged in human rights work.

In 2004, a conference of the WHO/PAHO seemed to recognize this. In the Montreal Declaration on Intellectual Disabilities, the International Conference on Intellectual Disability reconceived the language of the UDHR to assert:

1. *Persons with intellectual disabilities*, as other human beings, are born free and equal in dignity and rights.

² National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, REPORT AND RECOMMENDATIONS: RESEARCH INVOLVING THOSE INSTITUTIONALIZED AS MENTALLY INFIRM (DHEW Publication No. (OS) 78-0006 [1978]; President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, SUMMING UP: THE ETHICAL AND LEGAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH (March 1983)

II. Capacity is a key barrier to the enjoyment of rights.

Even for those rights that have been explicitly articulated in the International Bill of Rights and other documents and declarations of rights, lack of capacity is often identified as a key barrier to the actual enjoyment of these rights by persons with mental disabilities. Although a finding of incapacity and a displacement of the ability to exercise rights is supposed to be an exceptional determination, permissible only after exacting procedural and substantive safeguards have been satisfied,³ in reality the transfer of personal rights to guardians and other personal representatives is often too easy, too informal and too complete, and yet often fails to offer the protection of the individual which this bargain is supposed to assure.

An example illustrates this point. In one of the countries in which MDRI has been working, we considered a challenge in the domestic courts of inhuman and degrading treatment and conditions at a Neuropsychiatric Hospital, which included keeping two adolescent boys naked and in solitary confinement in six-foot by six-foot cells in unhygienic, inhuman and dangerous conditions. However, it became difficult to commence a legal action because, upon being admitted to the institution (abandoned by parents who could no longer manage hyperactive behavior), the director of the hospital became their legal guardian, authorized by law to make all decisions on their behalf. In order to sue the hospital on behalf of the persons being abused there, the legal authorization of the director of the hospital –the putative defendant in the case -- would be required. Thus, the informal process by which these patients were placed under total

³ Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care, adopted by the UN General Assembly Resolution 46/119 of December 17, 1991, Principle 1 (6).

guardianship affected their right of access to the courts to enforce other individual human rights which ostensibly protect them against inhuman and degrading treatment.

Guardians have used their powers to dispose of property; to consent to placements in institutions and to refuse to approve proposed discharges to the community; to consent to treatment with neuroleptic drugs, modified and unmodified electroconvulsive therapy, aversive therapy and the use of restraints and seclusion, including placement in cage-beds; and to approve medical and surgical care, participation in risky experiments, sterilization, organ donation, and do-not-resuscitate orders. Public guardians often have large caseloads and fail to visit their wards or seek their opinions about decisions that need to be made. Many guardianship systems have weak or nonexistent processes for periodic review and an accounting of the actions of the guardian. As a result, people who have been found to lack capacity and have had guardians appointed for them have had decisions made on their behalf with serious and sometimes permanent consequences, without having any voice in the decision or any ability to challenge it.

It is with this type of experience in mind that many people with disabilities and their allies have identified legal capacity as a central issue to be addressed in the draft Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities.⁴ This article of the Convention addresses the recognition of people with disabilities as persons before the law, which is a prerequisite to exercising and enjoying all the other rights articulated. At the Fifth Session of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities (Ad Hoc Committee), held in New

⁴ See, e.g., Inclusion Europe, *Equal Rights for All: access to rights and justice for people with intellectual disabilities*

York from January 24 to February 4, 2005, this issue was debated extensively along with the related issue of the right to recognition as a person before the law. The same issues continued to be debated at the Seventh Session (New York, January 16-27, 2006) and are scheduled to be a major subject of discussions at the Eighth Session of the Ad Hoc Committee scheduled for August 2006.

The current Working Text from the Seventh Session provides:

Article 12 Equal recognition before the law

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

[2. States Parties shall recognize that persons with disabilities have [legal capacity] on an equal basis with others in all fields and shall ensure that where support is required to exercise that capacity:

(a) The assistance provided is proportional to the degree of support required and tailored to the person's circumstances, that such support does not undermine the legal rights of the person, respects the will and preferences of the person and is free from conflict of interest and undue influence. Such support shall be subject to regular and independent review;

(b) Where States Parties provide for a procedure, which shall be established by law, for the appointment of personal representation as a matter of last resort, such a law shall provide appropriate safeguards, including regular review of the appointment of and decisions made by the personal representative by a competent, impartial and independent tribunal. The appointment and conduct of the personal representative shall be guided by principles consistent with the present Convention and international human rights law.]

OR: alternative:

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

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

2 ter. States Parties shall ensure that all legislative or other 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 periodic impartial and independent judicial review. The safeguards shall be proportional to the degree to which such measures affect the persons' rights and interests.]

3. 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.

While many drafting and terminology debates have arisen in the years of discussion about this article, there are four major interrelated issues which have been the subject of the most debate and disagreement. These are:

1. the definition of legal capacity;
2. a paradigm shift from a presumption of legal capacity to a declaration and recognition of legal capacity for everyone;
3. related to this, a recognition of supported decision-making models and the obligation of State Parties to provide supports as needed for decision-making; and
4. the continued availability of guardians and personal representatives.

I will discuss these in turn and provide a summary of the main arguments regarding these issues. I will then provide an overview of the law in the United States regarding capacity. Finally, I will conclude with some personal reflections on issues of capacity.

A. Definition of Legal Capacity

An indication of the difficulty that participants in the treaty deliberations have had in reaching consensus is illustrated by the inability thus far to agree on the definition of the

term “legal capacity.” Some delegations have recommended translating this term into native languages and interpreting it accordingly. According to the comments of delegates from the corresponding states in the Sixth Session, in Arabic, Chinese and Russian, the term legal capacity refers to the “legal capacity for rights” rather than the legal capacity to act. A background conference document prepared by the Office of the United Nations High Commissioner for Human Rights on legal capacity makes the distinction as follows:

Unlike the capacity to be a person before the law – which belongs to all human beings since the moment of birth and is lost only with death – the actual exercise of the capacity to act is subject to the possession of such additional requirements as the minimum age and the capacity to understand the meaning of one’s actions and their consequences. It is therefore acquired at the achievement of major age and may also require additional requirements, which vary according to the act performed (matrimonial capacity, capacity to own and administer property, contractual capacity, capacity to bring claims before courts, capacity for tortious liability, etc.). Moreover, the capacity to act – which is presumed in adult persons – can be limited or restricted when individuals become unable to protect their own interests. In these cases, the person remains the holder of substantive rights (e.g. the right to property or the right to inherit), but cannot exercise them (e.g. sell his/her property or accept an inheritance) without the assistance of a third-party appointed in accordance with the procedural safeguards established by law.⁵

Under consideration is whether to specify in this treaty “the capacity to act,” language which was not used in comparable articles in other conventions, such as the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW). The International Disability Caucus has argued that CEDAW, in guaranteeing women and men identical legal capacity, treats it as including capacity to act, for example, by concluding contracts. The IDC expressed concern that women and men with disabilities will have inferior rights to non-disabled women and men if equal capacity to act is not guaranteed in the convention. As things currently stand, there is a placeholder to return to this definitional issue later in the debate.

⁵ <http://www.un.org/esa/socdev/enable/rights/documents/ahc6ohchrlegalcap.doc>.

The World Network of Users and Survivors of Psychiatry advocated that the convention should unequivocally recognize that all persons with disabilities have legal capacity to act.⁶ Some may need help in exercising their legal capacity through supported decision making, but such needs do not justify displacement of the individual as the decision maker.⁷ In this respect, the Convention would be taking a significantly different view of legal capacity than contained in previous United Nations pronouncements, including the Principles for the Protection of Persons with Mental Illness, which clearly recognizes that legal incapacity exists and makes provision for how to deal with it.⁸ The 1971 Declaration on the Rights of the Mentally Retarded specifically recognizes "the

⁶ Professor Amita Dhanda, *Advocacy Note on Legal Capacity*, World Network of Users and Survivors of Psychiatry, wrote:

One of the arguments put forth for substituted decision-making is that a number of persons do not have the wisdom to exercise legal capacity. But legal capacity is about the freedom to make choices and not the wisdom of those choices. . . . Whenever any people are not accorded the freedom to make their own errors they are in effect not being allowed to develop in accordance with their own genius and it is this discrimination and deprivation that needs to be addressed in relation to persons with psychosocial disability. Dignity of risk and the right not to be protected are inherent rights of all adults.

⁷ Minkowitz, T. *No-Force Advocacy by Users and Survivors of Psychiatry*. Wellington: Mental Health Commission (2006)

⁸ Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care, adopted by the UN General Assembly Resolution 46/119 of December 17, 1991, Principle 1 (6).

Any decision that, by reason of his or her mental illness, a person lacks legal capacity, and any decision that, in consequence of such incapacity, a personal representative shall be appointed, shall be made only after a fair hearing by an independent and impartial tribunal established by domestic law. The person whose capacity is at issue shall be entitled to be represented by a counsel. If the person whose capacity is at issue does not himself or herself secure such representation, it shall be made available without payment by that person to the extent that he or she does not have sufficient means to pay for it. The counsel shall not in the same proceedings represent a mental health facility or its personnel and shall not also represent a member of the family of the person whose capacity is at issue unless the tribunal is satisfied that there is no conflict of interest. Decisions regarding capacity and the need for a personal representative shall be reviewed at reasonable intervals prescribed by domestic law. The person whose capacity is at issue, his or her personal representative, if any, and any other interested person shall have the right to appeal to a higher court against any such decision.

See also WHO, *Mental Health Care Law: Ten Basic Principles* (Geneva, 1996).

right to a qualified guardian when this is required to protect his personal well-being and interests."⁹ Similarly, the Declaration of the Rights of Disabled Persons in 1975 begins with a definition of the term "disabled person" as someone "unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and/or social life, as a result of deficiency, either congenital or not, in his or her physical or mental capabilities."¹⁰

The passionate and impassioned advocacy of people with disabilities, with the support of the International Disability Caucus, has resulted in a progressive strengthening the recognition of legal capacity in the draft treaty in each of the sessions of the Ad Hoc Committee. Nevertheless, sufficiently serious disagreements remain to the point that the most recent draft contains two alternate versions of portions of the article on capacity.

At the conclusion of the Seventh Session, the Chair summarized that with respect to Article 12, there was general agreement on a need to signal a paradigm shift towards a support model where everyone is entitled to exercise legal capacity. It was also agreed that some measures are required in the Article to safeguard this support. However, there was a range of views on what degree of prescription should be provided on these

⁹ Declaration on the Rights of Mentally Retarded Persons, paras. (1), (5) & (7). G. A. res. 2856 (XXVI) of 20 December 1971. The Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons With Disabilities, (AG/RES. 1608, 7 June 1999), specifically provided that:

If, under a state's internal law, a person can be declared legally incompetent, when necessary and appropriate for his or her well-being, such declaration does not constitute discrimination.

Id. Para. 2 (b).

¹⁰ Declaration on the Rights of Disabled Persons, Para. (1). G.A. res. 3447 (XXX), 30 U.N. GAOR Supp. (No. 34) at 88, U.N. Doc. A/10034 (1975).

measures. In particular, there was no consensus on whether to include some reference to personal representatives.¹¹

B. Presumption versus Declaration of Legal Capacity

In some respects, this issue is tied to the definition. If legal capacity is defined as meaning the ability to be the holder of rights rather than the ability to exercise these rights, it is not much more than recognizing the right to be a person before the law – a proposition for which there seems to be a broad consensus. However, if defined as advocated by a number of groups to mean an ability to exercise rights either independently or with support, the universal recognition of capacity is far more controversial. Related to such recognition is a rejection of the idea that capacity can be interrupted and displaced, and that the rights of the individual may be exercised by a duly appointed substitute decision maker when this happens.¹²

Advocates of a universal recognition of capacity rely heavily on the supported decision-making model to explain how capacity can be exercised by everyone.

C. Supported decision-making

As the supported decision-making model referenced in the draft treaty is a major innovation, it is important to understand what this is. The brief reference in the treaty document does not provide adequate explanation of how this model actually works. A good exposition of this model in relation to the treaty and its development occurred

⁷ Chair's Closing Remarks, Seventh Session, <http://www.un.org/esa/socdev/enable/rights/ahc7chairclose.htm>.

¹² The concept of interrupted capacity was adopted in the Montreal Declaration on Intellectual Disabilities, PAHO/WHO Conference on Intellectual Disability, Adopted in Montreal, Canada, October 6, 2004.

during the Third Session where the report of the Canadian Association on Community Living Task Force on Alternatives to Guardianship [hereinafter Task Force] was presented.¹³

The first hallmark of the supported decision-making model is reliance on a network of friends, family and other allies to help a person make and express decisions. The paradigm is one of interdependence rather than independence, proceeding from an understanding that most people make significant decisions with the help and advice of friends and family. Consistent with this approach, the issue of decision-making capacity of the individual is never raised, evaluated, professionally assessed or determined. It is assumed.¹⁴ The model relies on the competency of the decision-making process as a whole, rather than focusing solely on the capacity of the individual with a disability.

The second hallmark of this approach is informality. There are no formal processes to determine if a person needs help or in what area. The decision itself may be the subject of review in some cases but not over the issue of capacity to make the decision.

The Task Force report summarized the support decision-making model as follows:

¹³ http://www.worldenable.net/rights/adhoc3meet_guardianship.htm

¹⁴ *Id.* Part III.

This model is based on the following assumptions and principles:

- (i) All adults have the right to self-determination and the right to make decisions affecting their lives with the support, affection and assistance of family and friends of their choosing.
- (ii) Every individual has a will and is capable of making choices.
* * *
- (ix) No individual should be assessed to determine his or her “competency.” Only individual decisions should be reviewable by an outside party to determine (a) whether the will of the person is being respected; (b) the decision has not been made under undue influence; or (c) the persons providing support are not benefiting from the decision without the knowledge and permission of the person receiving support..

This model is based on values and principles which recognize that personal autonomy can be expressed interdependently; every person has a will and is capable of making choices, personal support in its many forms, must enable the individual; the state has an obligation to provide resources, to ensure that those who are isolated are (re)connected with others in their communities; the interests of third parties must not lead to an infringement of personal rights; and no individual should be assessed to determine his or her competency. (sic)

* * *

For those without support who require assistance with decision-making, a mechanism should be available to provide support on an interim basis. Where a person's wishes cannot be interpreted or ascertained, limited residual authority should rest with the court to make a decision.

* * *

An external review process must be able to review specific decisions which may be questioned, and to review individuals providing support when those individuals are challenged. Adult protection legislation must impose duties on the state to implement measures to protect individuals who are victims of various forms of abuse or neglect.¹⁵

The Task Force recognized that in order for third parties to be reassured that they could rely on decisions expressed through the supported decision-making process as being legally valid and binding, legislation would be necessary to address how someone is recognized as a supportive decision maker and what steps must be taken to give legal validity to specific decisions. Here again, the Task Force rejected traditional approaches such as powers of attorney and advance directives which require a threshold of capacity to execute such documents. Instead, the Task Force suggested legal recognition of support providers selected through a less formal means including (1) a witnessed designation in writing identifying the persons who will be providing support; (2) indicating verbally or otherwise, in the presence of witnesses, a desire to have someone act as a supporter; or (3) by having independent witnesses execute an affidavit providing

¹⁵ *Id.* Executive Summary.

the basis for recognizing the existence of a trusting relationship between the individual with a disability and persons providing support.

While the Task Force went to considerable lengths to find creative ways to preserve autonomy through support relationships, it also recognized the risk of abuse and exploitation. It suggested that there may need to be limitations regarding the types of decisions which will be possible under the support decision-making model, including decisions which would offend human dignity, citing as examples sterilization and experimentation. Finally, the Task Force also appreciated that there may be circumstances in which it is impossible to determine the wishes of the person concerning important matters such as commencing or discontinuing medical procedures. In these circumstances, the Task Force recommended that there be limited residual authority in a court to make such decisions.

Although this report of the Task Force was prepared in 1992 and the concept of supported decision-making has been recognized in the statutes of Canadian provinces,¹⁶ no province has as yet completely abandoned the availability of traditional substituted decision-making procedures when support networks are not available or the person is found to lack decision-making capacity in one or more areas.¹⁷ The creation of a

¹⁶ See, for example, Adult Protection and Decision Making Act, Yukon Territories, http://www.canlii.org/yk/laws/as/2003c.21/20041124/whole.html#_Toc61931380; The Vulnerable Persons Living with a Mental Disability Act of Manitoba, CCSM v. 90, <http://web2.gov.mb.ca/laws/statutes/ccsm/v090e.php>.

¹⁷ *Id.*

For purposes of this Act, a person is incapable of personal care if the person is not able to understand information that is relevant to making a decision concerning his or her own health care, or his or her own physical, emotional, psychological, residential, educational, vocational or social needs, or similar needs, or is not able to appreciate the reasonably foreseeable consequences of a decision or lack of a decision.

The Vulnerable Persons Living with a Mental Disability Act of Manitoba, Division 3, Substitute Decision Maker for Personal Care.

substitute decision maker also requires evidence of the capacity of the person supported to enter into such an agreement. The statute in the Yukon Territories, for example, provides that: “An adult may enter into a supported decision-making agreement if they understand the nature and effect of the agreement.”¹⁸

Some of the parties advocating for stronger language in the treaty to recognize supported decision-making seem not to have appreciated the limits of this model as it currently exists in Canadian provinces. As discussed in more detail in the section below, the idealized view of supported decision-making as suitable in all cases leaves unanswered how risks to different groups covered by the proposed treaty will be managed, especially when it is not possible to ascertain the wishes of the person, and the subject matter of the decision is an important one affecting the health, safety or welfare of the individual.

D. Guardians and Personal Representatives

One of the most significant disagreements is over the continued availability of guardianship or other substituted judgment processes and a recognition that there may be circumstances where individuals do not have the capacity to act. While there seems to be a general recognition that guardianship programs have often failed to provide adequate protection of individual rights, both over the person and their property, delegates divided over whether to devise better safeguards and oversight for guardianships or to eliminate

See also, A Guide to the Substitute Decisions Act, Province of Ontario, 2000 (<http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/pgtsda.pdf>); Yukon Territories Decision-Making Support and Protection to Adults Act, S.Y. 2003, c. 21, <http://www.canlii.org/yk/laws/as/2003c.21/20041124/whole.html>.

¹⁸ Adult Protection and Decision Making Act, Section 6.

such programs entirely and replace them with a supported decision-making model. This model was advocated by Canada, with support from the European Union, Australia, the United States, Norway, Costa Rica, Liechtenstein and nongovernmental organizations such as Inclusion International and the International Disability Caucus.¹⁹

The Canadian proposal would delete paragraphs 2 (a) and (b) from the working draft and replace them with:

2. States Parties shall recognize that persons with disabilities ~~have~~ enjoy ~~[legal capacity]~~ on an equal basis with others in all aspects of life. ~~fields and shall ensure, to the extent possible, that where support is required to exercise [that capacity] [the capacity to act]~~

2bis. States parties shall take appropriate legislative and other measures to facilitate access by persons with disabilities to any support they may require in exercising their legal capacity, as well as to provide appropriate safeguards to prevent abuses in the provision of support.

The deletion of subparagraphs (a) and (b) from the Working Text removes the type of periodic review and oversight found with guardianship programs, as well as any reference to the appointment of a personal representative as a matter of last resort.

The International Disability Caucus advocated the addition of a new paragraph 3 and 4 to read as follows:

3. States Parties shall ensure that persons with disabilities are entitled to use support to exercise legal capacity, and that such support meets the person's requirements, does not undermine the rights or freedoms of the person, respects the will and preferences of the person, and is free from conflict of interest and undue influence.

4. States Parties shall enact legislation and devise suitable procedures to facilitate access to, while preventing abuse of, supported decision-making.

¹⁹ While each of these parties endorsed the proposal, there were variations in the specificity of the language some of them proposed. See, *Comments, proposals and amendments submitted electronically*, Seventh Session, <http://www.un.org/esa/socdev/enable/rights/ahcstatabkgrnddocs.htm>. Michael Bach, *Securing Self-Determination: Building the Agenda in Canada*, TASH Newsletter, June/July, 1998. See also, *Community Living Ontario, Position On Supported Decision-Making*, available at www.communitylivingontario.ca/policies/decision.HTML

This language is consistent with the paradigm shift towards self-determination in the supported decision-making model. It takes the emphasis on self-determination and supported decision-making, contained in the Montréal Declaration on Intellectual Disabilities,²⁰ much further by eliminating any reference to circumstances under which a person's capacity to act may be legally displaced.²¹ The International Disability Caucus expressed their vociferous objection to language in the working text regarding the appointment of personal representatives as a last resort. "The International Disability Caucus affirms that Supported Decision Making is the only paradigm for legal capacity that upholds the principles articulated in Article 2 of this Convention."²²

The rejection of guardianship and personal representatives under any circumstances in the proposals described above were opposed by delegates from several countries including Kenya, India, Serbia-Montenegro, Russia and Qatar, as well as by the National Association of Community Legal Centers of Australia, and People with Disabilities of Australia. These groups generally supported the chairman's text which encourages supported decision-making but provides a mechanism for substituted decision-making with procedural safeguards as a last resort.

²⁰ PAHO/WHO Conference on Intellectual Disability, Adopted in Montreal, Canada, October 6, 2004.

²¹ The Montréal Declaration provided in paragraph 6(b) that:

Under no circumstance should an individual with an intellectual disability be considered completely incompetent to make decisions because of his or her disability. It is only under the most extraordinary of circumstances that the legal right of persons with intellectual disabilities to make their own decisions can be lawfully interrupted. Any such interruption can only be for a limited period of time, subject to periodic review, and pertaining only to those specific decisions for which the individual has been found by an independent and competent authority to lack legal capacity.

²² Report of the Coordinator to the Fifth Session, Draft Article 9 [the precursor to the current Article 12], IDC response, p. 7. <http://www.un.org/esa/socdev/enable/rights/ahcstata12fiscomment.htm>.

People with Disability Australia and the Australian National Association of Community Legal Centers commented:

A legal mechanism that will allow, as a last resort, the formal appointment of a person with the responsibility to make particular decisions on behalf of the person unable to make decisions for themselves is essential for the realization of the human rights of persons with disability. . . . In the absence of such a mechanism State Parties will be unable to ensure equality of access to medical and dental services for persons unable to consent to treatment, and will lack a crucial legal mechanism to protect particular individuals from abuse, neglect and exploitation – particularly where this is at the hands of persons in close personal relationship with them, such as a spouse, parent, or other family member. Although the support networks of an adult with severe disability should be empowered as much as possible to act in the interests of the person without having to resort to formal guardianship arrangements, it is unrealistic and dangerous to assume that persons with disability will always be protected by those closest to them.²³

²³ www.un.org/esa/socdev/enable/rights/ahcstatabkgrnddocs.htm. Similar opinions were expressed in Inclusion Europe, Equal Rights for All! Access to rights and justice for people with intellectual disabilities; Peter Bartlett, *Human rights? Of course . . . but what does that mean?* In NO-FORCE ADVOCACY BY USERS AND SURVIVORS OF PSYCHIATRY. Wellington: Mental Health Commission (2006). In comments filed during the Fourth Session, People with Disabilities Australia noted more specifically:

We acknowledge that in many parts of the world forms of adult guardianship (or trusteeship) have resulted in the denial of the legal and social personality of the individual with disability, and in the abuse and neglect of their human rights. However, the absence of decision-making and financial management arrangements for adults with cognitive disability has also resulted in extensive exploitation, abuse and neglect. This includes exploitation of the person's financial resources, sometimes even by family members; failure to perform beneficial medical and dental procedures on the basis that there is no one to consent or advocate for them; and, failure to protect against harmful or unnecessarily restrictive interventions, for example, non-therapeutic sterilization, polypharmacy, aversive behavior management procedures etc. We are therefore firmly of the view that appropriately safeguarded substitute decision-making and financial management arrangements are essential to protect and promote the rights of some people with disability. * * *

[T]his proposal for supported decision-making does not displace the need for formal supported decision-making and financial management arrangements for some people in some circumstances.

Comments, proposals and amendments submitted electronically, Fourth Session, www.un.org/esa/socdev/enable/rights/ahcstata12fscomments.htm.

III. Mental Disability and Capacity in the United States

This is a topic that could easily fill a treatise, as indeed it has.²⁴ In this section, I will attempt to summarize the key points dealing with mental disability and capacity. Under the system of government in the United States, each of the 50 states has substantial latitude to develop its own laws, and there is considerable variation among the states. What follows therefore should be seen as broad generalizations about the manner in which states deal with issues of legal capacity.

Historically, a diagnosis of a mental disability would operate to automatically deprive a person of decision-making autonomy. So-called “idiots” and “imbeciles,” like children and married women, had to rely upon others for the protection of their rights. Today, however, the prevailing law is to presume that everyone is competent. That presumption can be overcome by evidence of a lack of capacity to make specific types of decisions. At one time, a diagnosis of mental illness or mental retardation was a sufficient basis on which to involuntarily commit a person to a mental health facility. However, in the case of *O'Connor v. Donaldson*,²⁵ the United States Supreme Court ruled that involuntary commitment on the basis of mental illness alone violated the patient’s constitutional right to liberty.

A finding of “mental illness” alone cannot justify a State’s locking up the person against his will and keeping him indefinitely in simple custodial confinement

²⁴ Michael Perlin, *MENTAL DISABILITY LAW: CIVIL AND CRIMINAL* (Lexis Law Publishing, 1998–2003); Samuel Jan Brakel, John Parry, & Barbara A Weiner, *THE MENTALLY DISABLED AND THE LAW*. (American Bar Foundation, Chicago, Ill. 1985. 3rd ed.); Michael Perlin, *LAW AND MENTAL DISABILITY*, (Lexis Law Publishing, 1994).

²⁵ 422 U.S. 563 (1975).

In short, a State cannot constitutionally confine without more a nondangerous individual who is capable of surviving safely in freedom by himself or with the help of willing and responsible family members or friends.²⁶

Similarly, where once a determination to involuntarily commit a person to a mental facility was sufficient to overcome the presumption of competence, the modern approach is to look more critically at the person's decision-making abilities in specific areas of life. Courts are likely to look more carefully at the functional capacities of the individuals involved and examine how the mental illness or mental retardation affects their ability to make decisions. Thus, for example, involuntary commitment to a psychiatric hospital, by itself, is not sufficient to overcome a patient's decision-making autonomy to consent or refuse treatment, unless there has been a specific finding that the patient lacks the ability to make treatment decisions.

We conclude, however, that neither the fact that appellants are mentally ill nor that they have been involuntarily committed, without more, constitutes a sufficient basis to conclude that they lack the mental capacity to comprehend the consequences of their decision to refuse medication that poses a significant risk to their physical well-being. Indeed, it is well accepted that mental illness often strikes only limited areas of functioning, leaving other areas unimpaired, and consequently, many mentally ill persons retain the capacity to function in a competent manner.²⁷

When a person is adjudicated to be incompetent, there are a variety of legal tools available for decision-making.

A. Guardians

Traditional guardianships of the person and property transferred the responsibility for exercising decision-making to a guardian appointed by the court. These so-called

²⁶ *Id.* at 573-76.

²⁷ *Rivers v. Katz*, 67 N.Y. 2d 485, 493-94, reargument denied 67 N.Y. 2d 808 (1986).

plenary guardians completely displaced decision-making autonomy of their wards, except in areas that were so personal that the surrogate could not exercise decision-making rights (e.g. sexuality) or where the law prevented the exercise of authority.

The procedures for appointing, monitoring and removing guardians vary from state to state, as do the laws which limit the powers of plenary guardians to make decisions about certain subjects (e.g. sterilization, commitment to a psychiatric facility, electroconvulsive therapy, experimentation, termination of life supports, etc.). New York, for example, created alternatives like Committees of the Person to exercise powers over the person, and Conservators of Property to exercise power over the property of the ward.²⁸ Like a plenary guardianship, these devices also apply broadly to remove decision-making authority from the person for the areas they cover.

Guardians are required to act as fiduciaries and owe a duty of loyalty to act in the best interest of the ward. Thus, in the case of an institutionalized 27 year-old mentally retarded man, a Kentucky court refused to recognize the authority of his mother, acting as his Committee of the Person, to consent to a kidney donation to his non-mentally disabled brother who was dying of kidney disease.²⁹ The court ruled that the Committee did not have the power to subject her ward to the serious surgical techniques unless the life of the ward was in jeopardy.³⁰ Similarly, a court in Louisiana ruled that the parent-

²⁸ New York Mental Hygiene Law, articles 77 and 78.

²⁹ *Strunk v. Strunk*, 445 S.W. 2d 145 (KY. 1969).

³⁰ Ironically, the Court, which had the power to do what the guardian could not, then took it upon itself to authorize the surgery on the basis of testimony that the surgery would be beneficial to the mentally retarded donor brother because he was greatly dependent emotionally and psychologically upon the beneficiary brother, and would be adversely affected by his death. There is no discussion in the court's opinion of the almost impossible conflict of interest that the mother was placed in when appointed as the Committee of the mentally disabled son. As a mother, she was understandably concerned with the welfare of both her children. As the Committee, she owed undivided loyalty to the best interests of her mentally disabled son.

guardian of the a 17 year-old mentally retarded son could not give consent for a proposed kidney transplant to his 32 year-old sister, as there was no benefit for the ward in donating his kidney, and the court could not authorize the procedure.³¹

As in other countries, in the United States there have been reports of the abuse by guardians of the responsibilities given to them, violations of the rights of the ward, and a failure of the courts to adequately supervise the guardians they appoint.³²

In recent years, there has been a general trend away from the appointment of plenary guardians and increasing use of limited guardians who are granted specific powers to make decisions in specific areas while leaving unaffected the individual's decision-making ability in other areas. A new guardianship law in New York is an example of a more narrowly tailored approach to providing decision-making assistance only in those areas where it is needed. Article 81 of the New York Mental Hygiene Law replaces statutes dealing with Conservators of Property and Committees of the Person and offers flexibility in meeting the needs of persons who require surrogate decision-makers, without completely compromising their decision-making autonomy.³³ This statute stresses the use of the least restrictive alternative in determining the appropriate

See Robertson, *Organ Donations by Incompetents and the Substituted Judgment Doctrine*, 76 COLUMBIA LAW REVIEW 48 (1976), wherein that author states that the trend of approving intrafamily transplants began in 1957 with three unreported Massachusetts cases, and that since that time, Massachusetts courts have authorized transplants on numerous occasions involving legally incompetent donors. The author states that trial courts in other states have followed Massachusetts' example.

³¹ *In Re Richardson*, 284 So. 2d 185 (La App 4th Cir., 1973), application den (La) 284 So. 2d 338.

³² American Bar Association, Commission on the Mentally Disabled and Commission on Legal Problems of the Elderly, STEPS TO ENHANCE GUARDIANSHIP MONITORING (ABA 1991); Associated Press, *Guardians of the Elderly: An Ailing System*, (1987); American Bar Association, GUARDIANSHIP: AN AGENDA FOR REFORM (ABA 1988).

³³ NY Mental Hygiene Law, article 81.

relief to be granted, which must take into account the personal wishes, preferences and desires of the person, and afford the greatest amount of independence, self-determination and participation in all decisions affecting the person's life.

B. Surrogate Decision Making Committees

New York has also created another innovative approach to surrogate decision-making which dispenses with the need for appointment of guardians, committees or conservators. For persons with mental illness or mental retardation in residential facilities, who lack decision-making capacity to provide informed consent for major medical treatment, New York has created a Surrogate Decision-Making Committee program under which four-person panels of volunteers are authorized to receive relevant information and make the informed consent decision.³⁴ The invocation of the services of the Surrogate Decision Making Committee does not affect other decision-making rights of the individual.

C. Powers of Attorney

Many states now have laws recognizing durable powers of attorney, which survive incompetence, or which come into existence when the principal becomes incompetent.³⁵ This device allows individuals to choose their surrogate decision-makers and confer upon such decision-makers authority to make certain types of decisions on behalf of the principal. Thus, even if the principal subsequently becomes incapable of making decisions, the principal is able to retain a degree of control over decisions by

³⁴ NY Mental Hygiene Law, article 80; 14 New York Code of Rules and Regulations, Part 710. Clarence J. Sundram, *Informed Consent for Major Medical Treatment of Mentally Disabled People: A New Approach*, 318 NEW ENG. J. MED. 1368 (May 1988).

³⁵ See, e.g., NY General Obligations Law, section 5 – 1501.

determining in advance to entrust this responsibility with someone who can be counted on to respect his or her wishes.

With respect to health care decision-making, New York law provides for a specific tool to enable competent adults to ensure that their wishes concerning health care and treatment will be carried out if and when they are unable to make such decisions for themselves. The Health Care Proxy³⁶ recognizes the right of a competent adult to appoint someone he or she trusts to decide about treatment in the event of future decision-making incapacity. Unless specified otherwise, the person designated as the proxy has the same authority as the grantor would possess to decide about treatment. That authority encompasses the right to forgo treatment, including life-sustaining measures.

Although this law is intended to be used by competent adults, it also provides that all adults are presumed to be competent unless they have been adjudged incompetent or have had a plenary guardian previously appointed because they were determined not capable of making health care decisions. Thus, it has significant potential for use by people who have diagnoses of serious mental illness or mental retardation who have not been adjudicated as incompetent, and for whom witnesses to the execution of the proxy can attest that they are of “sound mind.”

D. Advance directives

Another device that is used in many states is an advance directive or a so-called “living will.” These typically address the individual’s preferences about life-sustaining medical treatment if that person is terminally ill and unable to make such decisions for themselves. Recording one’s preferences facilitates a subsequent recognition by a court

³⁶ NY Public Health Law, sections 2980-2994.

which seeks “clear and convincing evidence” of the patient’s will regarding life-sustaining medical treatment, and especially the termination of such treatment. Advance directives that have been expressed orally and consistently have also been respected by the courts.³⁷

Some states have enacted specific laws for mental health advance directives that permit individuals to make written declarations or to designate another individual as a proxy to make substitute decisions regarding the administration of neuroleptic medications and ECT.³⁸ A New York court recognized a patient’s right to refuse ECT based upon the patient’s expressed wishes while competent that such treatment should be refused.³⁹

Another general trend has been to emphasize the responsibility of the surrogate decision maker to make decisions using a substituted judgment standard, to give effect to the ward’s wishes and preferences to the extent they are known or can be determined and to do what the ward would do if capable of making the decision.

While surrogate decision-makers may make many decisions on behalf of incapacitated individuals, states may place limits on the types of decisions they can make. So, for example, in *Cruzan v. Director, Missouri Department of Health*,⁴⁰ the United States Supreme Court recognized that a competent person would have a constitutionally protected right to refuse lifesaving hydration and nutrition, but for an incompetent person

³⁷ *In Re Eichner*, 52 N.Y. 2d 363 (1981).

³⁸ Minn. Stat. section 253 B.03 (6d).

³⁹ *In Re Rose M*, 597 NYS 2d 544 (N.Y. Sup. Ct., 1991). More information about Advance Psychiatric Directives can be found on the web site of the Bazelon Center for Mental Health law (<http://www.bazelon.org/issues/advancedirectives/index.htm>)

⁴⁰ 497 U.S. 261 (1990).

such a right would have to be exercised, if at all, by some sort of a surrogate. Nancy Cruzan suffered anoxia following a car accident and progressed into an unconscious state. To ease feeding and further recovery, surgeons implanted a gastrostomy feeding tube and hydration tube with the consent of her then husband. Nevertheless, she ended up in a persistent vegetative state. Her parents asked the hospital employees to terminate the artificial nutrition and hydration, but they refused to do so without court approval. The parents then sought and obtained court approval, providing evidence that she had expressed the view, in conversations with a friend, that she would not want to live in this condition. The state of Missouri refused to recognize the substituted judgment of the parents and appealed the decision. The state required “clear and convincing evidence” of the patient’s own wishes for ending nutrition and hydration in such cases – a standard which the conversations with the friend did not meet -- and the Supreme Court upheld its right to do so.⁴¹

A different result was reached by the New York Court of Appeals in *In Re Eichner*, another case involving permission to terminate extraordinary medical treatment. In this case, however, the 83 year-old patient, a member of a religious order, had engaged in long and substantial religious and philosophical discussions with other members of his order concerning his beliefs and wishes regarding life-sustaining treatment. These discussions began in response to the widely publicized case of 19 year-old Karen Ann

⁴¹ *Id.*

Close family members may have a strong feeling -- a feeling not at all ignoble or unworthy, but not entirely disinterested, either -- that they do not wish to witness the continuation of the life of a loved one which they regard as hopeless, meaningless, and even degrading. But there is no automatic assurance that the view of close family members will necessarily be the same as the patient would have been had she been confronted with the prospect of her situation while competent.

Quinlan who was in a vegetative coma in New Jersey.⁴² In granting permission to terminate treatment, the court found clear and convincing evidence that this was the patient's personal desire.

These were obviously solemn pronouncements and not casual remarks made at some social gathering, nor can it be said that he was too young to realize or feel the consequences of his statement. (Citation omitted) That this was a persistent commitment is evidenced by the fact that he reiterated the decision but two months before his final hospitalization. There was, of course, no need to speculate as to whether he would want this particular medical procedure to be discontinued under these circumstances. What occurred to him was identical to what happened in the Karen Ann Quinlan case, which had originally prompted his decision. In sum, the evidence clearly and convincingly shows that Brother Fox did not want to be maintained in a vegetative coma by use of a respirator.⁴³

By contrast, until a recent legislative enactment, the New York Court of Appeals would not recognize a guardian's right to refuse life-saving blood transfusions for her profoundly mentally retarded adult son who had never been capable of expressing a view about the decision at hand. There was no "clear and convincing evidence" of the patient's own expressed wishes, and so the transfusions proceeded.⁴⁴

⁴² *In re Quinlan*, 70 N.J. 10, cert. denied sub nom. *Garger v. New Jersey*, 429 US 922 (1976).

⁴³ *In Re Eichner*, 52 N.Y. 2d 363, 380 (1981).

⁴⁴ *In re Storar*, 52 N.Y. 2d 363, cert. denied, 454 US 858 (1981); *In re Westchester County Medical Center ex rel. Mary O'Connor*, 72 N.Y. 2d 517 (1988). The United States Supreme Court expressed the rationale for leaning on the side of the preservation of life in such cases as follows:

The more stringent the burden of proof a party must bear, the more that party bears the risk of an erroneous decision. We believe that Missouri may permissibly place an increased risk of erroneous decision on those seeking to terminate an incompetent individual's life-sustaining treatment. An erroneous decision not to terminate results in a maintenance of the status quo; the possibility of subsequent developments such as advancements in medical science, the discovery of new evidence regarding the patient's intent, changes in the law, or simply the unexpected death of the patient despite the administration of life-sustaining treatment at least create the potential that a wrong decision will eventually be corrected or its impact mitigated. An erroneous decision to withdraw life-sustaining treatment, however, is not susceptible of correction.

Cruzan v. Director, Missouri Department of Health, 497 U.S. 261 (1990).

Other states, however, do apply a substituted judgment standard for the termination of life supporting medical care and the United States Supreme Court has let their decision to do so stand.⁴⁵ Subsequent to the New York court's ruling in *Storar*, discussed above, the New York Legislature enacted the Health Care Decisions Act for Persons with Mental Retardation, granting guardians full health care decision-making authority, including the authority to terminate life-sustaining treatment.⁴⁶ This statute establishes a decision-making standard requiring that guardians “base all health care decisions solely and exclusively on the best interests of the mentally retarded person and, when reasonably known or ascertainable with reasonable diligence, on the mentally retarded person’s wishes, including moral and religious beliefs.”⁴⁷

For those persons who never had decision-making capacity, or never indicated their wishes when capable of doing so, the responsibility of the surrogate decision maker, if authorized to act, is to use the best interest standard of what most reasonable, competent people in the community would do in the particular situation.

IV. Analysis/Commentary

The draft treaty takes a major step forward in emphasizing legal capacity and equality in the exercise of rights. It strengthens the legal standing of families and friends who support people with disabilities, and places new responsibilities upon governments to recognize, nurture and help make available such support networks to those who need them. By emphasizing the primacy of such arrangements, the draft treaty sends a strong

⁴⁵ *In re Quinlan*, 70 N.J. 10, cert. denied sub nom. *Garger v. New Jersey*, 429 US 922 (1976).

⁴⁶ N.Y. Surrogate Court Procedure Act, section 1750, subdivision (2) [2002].

⁴⁷ *Id.* Section 1750-b [2] [b].

message about the need to change prevailing practices in many states which create and recognize guardianships too easily, and permit these arrangements to usurp the autonomy of people with disabilities far more completely than necessary.

In considering the draft treaty, a point that must be kept in mind is that issues of incapacity cover a wide variety of conditions that compromise the ability to make knowing, intelligent and voluntary decisions about matters that could have serious consequences upon rights, health, safety or welfare in many domains of life. These conditions can be temporary, as in the case of childhood or unconsciousness; episodic and intermittent, as in the case of serious mental illness; or permanent, as in the case of profound mental retardation and the late stages of Alzheimer's disease, AIDS dementia, Huntington's disease and other similar conditions.

The issues which affect each of these groups can also be significantly different. For example, while a person diagnosed with serious mental illness who is decisionally impaired may share with others similarly situated an inability to weigh the risks and benefits entailed in a particular decision, there are aspects of serious mental illness that can distinguish it from other impairing conditions.

The nature course of serious mental illness, including its onset, commonly in late adolescence or early adulthood, and its fluctuation from periods of acute psychosis to periods of relative remission, place particular demands and strains upon relationships with family and close friends. These strains in turn affect the acceptability, availability, and reliability of family surrogates in the decision-making process. Such strains and their effects are not found to the same extent with other cognitively impairing conditions which are either of a short-term nature (e.g. unconsciousness), a normal part of the

lifecycle (childhood), or which occur in an environment of stable family relationships (e.g. late stage Alzheimer's disease).

Attitudes towards a diagnosis of serious mental illness vary widely as well. Some people accept a diagnosis of mental illness, and report generally positive experiences with mental health treatment, and welcome and assist in efforts to improve the understanding of their illness and methods of treatment. Others challenge their diagnoses, see treatment as coercion, and report bad and abusive experiences in mental health facilities, which they see themselves as having survived. Some view their families as natural allies and the most reliable and enduring support system that represents their interests when they are unable to. Others see their families as adversaries who are allied with those who would coerce them into unwanted and unnecessary treatment. The views of attitudes of persons diagnosed with serious mental illness are not fixed and static, but may move to different points between these poles as their family relations, psychiatric condition, relationship with professionals, experiences with treatment and a variety of other influences affect them.

People diagnosed with serious mental illness are not the only ones who are vulnerable to natural support systems breaking down. Everyone who relies on a support system is vulnerable to changing circumstances, as people on whom they rely for assistance move on, change jobs, become ill, die or simply become unavailable when needed. To the extent that legal capacity is exercised through supported decision-making, the unavailability of the support network can also interrupt the ability to exercise legal capacity and decision-making.

Besides these issues, the present reality is that there are many thousands of people with mental disabilities who are isolated and abandoned in closed institutions, without access to support systems of any type apart from the institution staff. It is also an unfortunate reality that many people with such disabilities living in the community are equally isolated and lack reliable support networks.

The treaty needs to contemplate the fragility of these human relationships between persons with disabilities and members of their support networks, the reality that many people have no support networks and are unlikely to have them for some time into the future, and consider the safety net that must be available when a support network is not present to assist with decision-making. More fundamentally, in my opinion, there needs to be intellectual honesty in recognizing the widely varying circumstances in which people with mental disabilities find themselves when it comes to decision-making about important issues that affect their health, safety and welfare.⁴⁸

While many aspects of daily living require choice making that can be left to the individual with no great risk and no need for assessments of capacity or delegation of responsibility to surrogate decision-makers, as the seriousness of the issue at stake increases, the formality with which issues are examined should increase as well – e.g., regarding decision-making capacity, the ability to process information, awareness of options, absence of coercion, conflicts of interest, and the like,. The availability of some measure of independent review for important decisions that are made with the help of informal support networks seems indispensable. If this is to be meaningful however, the

⁴⁸ Clarence J Sundram, *A Framework for Thinking About Choice and Responsibility*, in CHOICE AND RESPONSIBILITY: LEGAL AND ETHICAL DILEMMAS IN SERVICES FOR PERSONS WITH MENTAL DISABILITIES, NYS Commission on Quality of Care, Nov 1994

availability of legal advocacy on behalf of the individual with a disability is essential. Without it, we are left to empty promulgation of rights without any means of enforcing them on behalf of their ostensible beneficiaries. The people most at risk are those with the least amount of personal support and those who are the most isolated.

The concept of legal capacity has historically had both positive and negative consequences. Much of the debate on the treaty has focused on the negative effects – the use of incapacity as a means of depriving people with disabilities of exercising rights including the protection against arbitrary detention, forced treatment and other human rights. But lack of legal capacity also is used to trigger the protective *parens patriae* role of government without which people with mental disabilities often have lived outside the protection of any law. Thus, to prevent them from being exploited, we have laws that make contracts entered into with someone who lacks legal capacity void or voidable at the option of the individual without capacity; to prevent exploitation, we have laws that make sexual relations with a person who lacks legal capacity a serious criminal offense; to preserve legal rights, we have provisions to toll statutes of limitations for commencing civil action during periods when an individual is not capable of exercising these rights. There does not seem to have been much attention paid during the treaty discussions regarding capacity on what will be lost by people with disabilities when the protections that flow from legal incapacity are eliminated as a result of the universal declaration of capacity, whether or not there is a realistic support network to help exercise that capacity.

There is no silver bullet. On either side of the mental capacity divide lie dangers to the individual. One only has to read a week's worth of intake reports at any adult protective services office to appreciate how much abuse, neglect and exploitation occurs

regularly at the hands of family and others one would think of as part of a natural support network for a person in need of some measure of decision-making assistance. At the same time, the same source would contain legions of reports of abuse, neglect and exploitation by persons who have been formally appointed as guardians or other personal representatives, despite the safeguards and oversight that are supposed to be a part of the legal process to prevent this from happening.

Abolishing guardianship and formal substitute decision-making is likely to increase dependence on natural support networks and also to increase risks when that network is itself the source of abuse, neglect and exploitation. But failing to emphasize the important role of genuine support networks is likely to permit more people to be pushed into guardianship systems that are insufficiently accountable and fail to maintain a decent respect for the autonomy and decision-making capacities of people who need some assistance.

This is not an either/or proposition. We need to do both -- to recognize the importance of real support networks, to encourage their development, to consider them the first and primary option when some measure of decision-making assistance is needed, and to maintain a reasonable level of vigilance over the manner in which supporters are recognized, decisions are made and given legal validity. For the cases in which such decision-making networks are not available, or one cannot ascertain with reasonable confidence the authentic voice of the person with a disability, we need the safety net of some form of substitute decision-making, whether exercised through a personal representative or a court. In either case, there need to be more robust safeguards to ensure care in determining the need to invoke this last resort, substantial scrutiny in

determining in whom to entrust this responsibility, clear standards for decision-making, an independent mechanism for ongoing and periodic vigilance over how this power is being exercised, and the availability of legal advocacy.