

Supported Decision-Making

- Proxy Decision-Making: A Legal Perspective.....page 2
- Searching for workable alternatives to guardianship for vulnerable populations.....page 18
- Supported Decision-Making a Viable Alternative to Guardianship.....page 25
- The Support Model of Legal Capacity: Fact, Fiction, or Fantasy?.....page 71

Proxy Decision-Making: A Legal Perspective

WINSOR C SCHMIDT

INTRODUCTION

Last summer, Frederick C Hayes was admitted to the advanced-dementia unit at Jewish Home Lifecare, on West 106th Street. It was not an easy arrival. Hayes, a veteran of the Korean War, had been a trial lawyer for five decades. He was tall, and, though he was in his early eighties, he remained physically imposing, and he had a forceful disposition that had served him well in the courtroom. One of his closest friends liked to say that if things were peaceful Hayes would start a war, but in war he'd be the best friend you could have.

Hayes practiced law until 2010, when he went to hospital for a knee operation. While there, he was given a diagnosis of Alzheimer's disease. His combative tendencies had become markedly pronounced, and before arriving at Jewish Home he was shuttled among several institutions. Nobody could manage his behavior, even after Haldol, a powerful antipsychotic drug, was prescribed. In the advanced-dementia unit, he appeared to be in considerable discomfort, but when doctors there asked him to characterize his pain on a scale of one to ten, he insisted that he was not in pain at all. Still, something was clearly wrong: he lashed out at the nurses' aides, pushing them away and even kicking them. It took three aides to get him changed. (Mead, 2013: 92).

THIS NARRATIVE ABOUT an attorney with Alzheimer's disease provides a poignant reminder that a legal perspective on proxy decision-making in dementia is personal for many readers of this chapter. The law regarding proxy decision-making and dementia should do unto others what it would have done to its own practitioners.

A 'proxy' is '[o]ne who is authorized to act as a substitute for another', '[t]he grant of authority by which a person is so authorized' or, '[t]he document granting this authority' (Garner, 2009). 'Proxy decision-making' in dementia refers to (a) decisions made by an individual or entity authorized to act for a person with dementia, (b) the granting of authority by which the proxy is authorized to act, or (c) a document granting authority of a proxy to act for a person with dementia.

This chapter addresses major problems and questions about proxy decision-making in dementia from a legal perspective focusing on: proxy decision-making as a constitutional right; advance directives; family consent statutes; guardianship; and supported decision-making under the Convention on the Rights of Persons with Disabilities (CRPD). The chapter begins with proxy decision-making as a constitutional right.

PROXY DECISION-MAKING AS A CONSTITUTIONAL RIGHT

Proxy decision-making is arguably a constitutional right in American law. In *Cruzan v Director, Missouri Department of Health* (1990), the US Supreme Court recognized (a) the common law doctrine of informed consent generally encompassing ‘the right of a competent individual to refuse medical treatment’ (at 277) and (b) the ‘principle that a competent person has a constitutionally protected interest in refusing unwanted medical treatment’ (at 278). For an incompetent person, the Court concluded ‘that a State may apply a clear and convincing evidence standard in proceedings where a guardian seeks to discontinue nutrition and hydration of a person diagnosed to be in a persistent vegetative state’ (at 284). Chief Justice Rehnquist’s majority opinion noted that the Court was not faced with the question of whether a state is ‘required to defer to the decision of a surrogate if competent and probative evidence established that the patient herself had expressed a desire that the decision to terminate life-sustaining treatment be made for her by that individual’ (at 287: fn 12). However, Justice O’Connor’s concurring opinion providing the majority’s decisive fifth vote specifically emphasized that while the Court was not deciding whether a state must ‘give effect to the decisions of a surrogate decisionmaker’ (at 289), in her view ‘such a duty may well be constitutionally required to protect the patient’s liberty interest in refusing medical treatment’ (at 289).

Dissenting Justices Brennan, Marshall and Blackmun asserted that Nancy Cruzan ‘has a fundamental right to be free of unwanted artificial nutrition and hydration’ (at 302) and that Missouri’s ‘improperly biased procedural obstacles ... impermissibly burden that right’ (at 302). They agreed with the New Jersey Supreme Court in *In re Jobes* that

‘Family members are best qualified to make substituted judgments for incompetent patients not only because of their peculiar grasp of the patient’s approach to life, but also because of their special bonds with him or her ... It is ... they who treat the patient as a person, rather than a symbol of a cause’ (at 327–28).

The three dissenting justices observed that ‘A fifth of all adults surviving to age 80 will suffer a progressive dementing disorder prior to death’ (at 329). Regarding proxies, the dissenting justices prescribed:

A State may ensure that the person who makes the decision on the patient’s behalf is the one whom the patient himself would have selected to make that choice for him. And a State may exclude from consideration anyone having improper motives. But a State generally must either repose the choice with the person whom the patient himself would most likely have chosen as proxy or leave the decision to the patient’s family (at 328).

In closing, the dissenting justices quoted the famous warning by Justice Brandeis about good intentions: ‘Experience should teach us to be most on our guard to protect liberty when the government’s purposes are beneficent ... The greatest dangers to liberty lurk in insidious encroachment by men of zeal, well meaning but without understanding’ (at 330).

ADVANCE DIRECTIVES

In the aftermath of *Cruzan*, every state has statutory provision for advance directives including health care powers of attorney and living wills (ABA Commission

on Law and Aging, 2013). At the federal level, Congress enacted the federal Patient Self-Determination Act (PSDA) (1990). The PSDA requires American hospitals, skilled nursing facilities, home health agencies, hospice programmes and health maintenance organizations receiving Medicare and Medicaid to provide each patient with information about rights to accept or refuse treatment, to formulate advance directives, to document whether an advance directive is signed, to assure related state law is followed and to provide for education of staff and public about advance directives. A minority of countries in Europe have legislation permitting the nomination of a substitute decision-maker (World Health Organization and Alzheimer's Disease International, 2012).

Advance Directive Document Completion and Compliance

Despite state statutes and the federal Patient Self-Determination Act, the prevalence of advance directives has declined from 40% in the early 1990s after the PSDA (Aitken, 1999) to a range more recently of from only 28% (Moorman and Inoue, 2013) to about 33% (Morhaim and Pollack, 2013; Sharma and Dy, 2011). When patients have formal written advance directives, only 36% of the medical records included any mention of the subject, and the relevant document was filed in the medical records of only two of 618 patients (Teno et al, 1994). Teno and colleagues concluded: '[q]uite simply, as far as we could tell, advance directives were irrelevant to decision making' (1994: 27) by medical providers. Subsequent studies have reached the same conclusion that patient preferences do not impact treatment ultimately received (Danis et al, 1996). Advance directives are still physically unavailable to providers, and care remains inconsistent with patient instructions half the time (Collins et al, 2006).

Legal Remedies for Advance Directive Non-Compliance

In response to advance directive non-compliance, legal commentators advocate such remedies as wrongful living lawsuits (Lynch et al, 2008), declaratory actions or injunctions to enforce the advance directives and wrongful prolongation of life lawsuits (Saitta and Hodge, 2011). Government regulators and private litigants are resorting to the imposition of a range of sanctions ["one of the next frontiers in healthcare litigation" (Parker, 2006)] that are increasingly frequent and severe, including: (a) civil liability in battery, negligence and breach of contract through health care decisions statutes and POLST (Physician Orders for Life Sustaining Treatment) statutes, to section 1983 and the False Claims Act; (b) administrative sanctions from medical board discipline, health care facility inspections and Medicare conditions of participation; and (c) criminal sanctions from criminal penalties protecting advance directives integrity through clinician non-compliance with advance directives, to criminal false claims for unwanted treatment (Pope, 2013).

The related proxy decision-making mechanism of a power of attorney concerning the principal's property and finances has a significant problem with power of attorney abuse (Stiegel and Klem, 2008). The broad decision-making authority of the agent, lack of court oversight, accounting and monitoring and unclear agent

conduct standards make financial exploitation of a person with incapacity relatively easy. In addition to 21 recommended provisions in the Uniform Power of Attorney Act to protect against power of attorney abuse and promote autonomy (Stiegel and Klem, 2008), the common law extensively defines the agent's fiduciary responsibility and offers many remedies and causes of action for the 57% of principals who are competent when the financial power of attorney abuse occurs (Hughes, 2000). Solace for financially abused principals with incompetence seems more limited.

FAMILY CONSENT STATUTES

Where an individual has not completed an advance directive, proxy decision-making for health care may occur on the legal authority of family consent statutes. At least 44 states have family consent statutes (ABA Commission on Law and Aging, 2009). Family consent statutes generally authorize designated close family members in a prescribed hierarchy to provide health care decisions when a patient is incompetent and without an advance directive (Furrow et al, 2000). The typical family consent statutory hierarchy is: (1) guardian of the person; (2) spouse; (3) adult child; (4) either parent; (5) adult sibling; (6) adult grandchild (Furrow et al, 2000). Although conceptually similar to intestate succession, no state has the same hierarchy for family consent and for intestacy because in intestacy grandchildren take precedence over parents and siblings. Twenty-three states include a close friend in the hierarchy usually at the lowest level (ABA Commission on Law and Aging, 2009).

At least nine states authorize a physician in the surrogate consent hierarchy (ABA Commission on Law and Aging, 2009) despite significant ethical and other problems with surrogate decision-making for patients by physicians (Schmidt, 2011; White et al, 2007). Surrogate decision-making by physicians: (a) does not impart 'adequate safeguards to [assure] that decisions for these patients [critically ill patients lacking decision-making capacity and surrogates] are fair and consistent' (White et al, 2006: 2058); (b) is based subjectively and erroneously on such criteria as 'the patients' anticipated quality of life, [the physician's] own perception of what was in the patients' best interest, and concerns about appropriate resource allocation' (White et al, 2006: 2057); (c) judges patient quality of life systematically lower than patients themselves judge quality of life (Pearlman and Uhlmann, 1988); (d) chooses less assertive treatment for marginally housed or homeless patients than the patients choose (Norris et al, 2005); (e) presents physician conflict of interest and absence of due process for the patient (White et al, 2006); and (f) 'may result in similarly situated patients receiving different levels of treatment' (White et al, 2006: 2058) because of significant variations in physician beliefs about limiting life-sustaining treatment.

Designating a physician as a patient's surrogate decision-maker seems almost as wrong as the discredited US practice of naming a psychiatric or other institution as a patient's guardian, a practice often still occurring in many other nations (Perlin, 2013). Such practice is not only 'a conflict of interest *per se* and terribly wrong', but 'If the patient's guardian is the institution wishing to medicate the person over the person's wishes, it becomes an absurdity to consider this a fair or equitable process' (Perlin, 2013: 1165, 1167).

Medical literature documents conflicts of interest when physicians provide a proxy consent decision for their own patients, a colleague's patients or a patient of the physician's hospital (White et al, 2012; White et al, 2006). There is also concern that 'depending on the reimbursement structure of the ... hospital, there may be a systematic bias in favor of either overtreatment or undertreatment of these patients [incapacitated patients without surrogates]' (Meier, 1997; White et al, 2006: 2057). Such conflicts of interest, over-treatments and under-treatments suggest a risk of 'false claims' for Medicare and Medicaid reimbursement under federal and state 'fraud and abuse' statutes (Furrow et al, 2000; Furrow et al, 2012; Schmidt, 2011). Physician surrogate financial benefit from these conflicts of interest and self-referrals seems highly problematic.

Physicians rarely receive sufficient training in capacity evaluations to know when a proxy decision is appropriate (Dudley and Goins, 2003). Since only 15 states train or examine professional guardians through professional guardian licensing, certification or registration (Schmidt et al, 2011), physicians also rarely receive any or any adequate training or certification in guardianship and legal proxy decision-making.

GUARDIANSHIP

Guardianship is discussed in detail in chapter twenty-eight.

A legal guardian through a judicial guardianship proceeding is the proxy mechanism available for individuals with dementia and incompetence who do not have either an advance directive or a willing and responsible family member making health care decisions by the authority of a family consent statute. Guardianship is a product of the *parens patriae* authority and responsibility of the state as sovereign to serve as general guardian or 'super guardian' for such people with legal disabilities as children and persons with mental illness or with intellectual disabilities.

Incidence of Guardianship

The reported incidence of guardianship ranged from one in every 1785 (.056%) for Florida in 1977, to one in every 1706 (.059%) for six states (Delaware, Minnesota, North Carolina, Ohio, Washington and Wisconsin) in 1979 (Schmidt, 1981). In 1995, the total number of people under guardianship in the United States was half a million (Schmidt, 1995). By 2008, the median annual incidence of incoming adult guardianship cases was 87 per 100,000 (.087%) for 14 reporting states (Uekert and Van Duizend, 2011). The total number of people under guardianship from four reporting states (Arkansas, District of Columbia, Ohio, Vermont) in 2008 was an average of 664 per 100,000 (0.6%), or 1.5 million adults under guardianship nationally (Uekert and Van Duizend, 2011). Compared with .087% of the US adult population under guardianship in 2008, the percentages of international populations adjudicated with guardianship and trusteeship orders ranged from 0.444% in Alberta, Canada in 2003, to 0.459% for Israel, 0.625% for Austria, 0.721% for Ontario, Canada, 0.850% for Switzerland and 1.345% in Germany (Kroch, 2009).

There are approximately 80,000 people under guardianship in Hungary and 300,000 people under guardianship in Russia (Perlin, 2013).

Unmet Need for Guardianship

One of the biggest social problems with guardianship as a proxy decision-making device is the extent of unmet need for legal guardians. A 1983 survey in Florida discovered 11,147 identifiable persons reportedly in need of a public guardianship, defined as ‘the judicial appointment and responsibility of a public official ... to serve a legal incompetent, the “ward”, who does not have willing or responsible family members or friends to serve as guardian’ or resources to employ a professional guardian (Schmidt and Peters, 1987: 70). A 1988 study of elderly nursing home residents in Tennessee identified 364 nursing home residents in need of plenary guardianship of person and property (Hightower et al, 1990). A 2002 survey estimated a need for 1425 public guardianships in Virginia (Teaster and Roberto, 2002). A Bar Association task force report calculated 4265 Washington state residents in need of public guardianship services in 2005 (Public Guardianship Task Force, 2005). A multi-year, multi-method follow-up study confirmed between 4000 and 5000 Washington residents qualified for a public guardian in 2009 and 2011 (Burley, 2011a). Most recently, there are 305 individuals in need of plenary public guardian services in North Dakota (Schmidt, 2013).

The consequences for individuals with incompetency without guardians are substantial. Of foremost importance, without a guardian, individuals with incompetency lack a proxy to provide protection and individual decision-making. Economically, ‘Without sufficient appropriate guardianship services, significant health care costs are incurred through inappropriate institutionalization, insufficient deinstitutionalization, excessive emergency care, and lack of timely health care’ (Schmidt, 2012: 15–16).

Cost-Effectiveness of Guardianship

If a public guardian was available, half of Florida’s legally incapacitated public mental patients without a guardian would be immediately dischargeable (Schmidt and Peters, 1987). Four hundred un-discharged patients awaiting appointment of guardians cost the Greater New York Hospital Association \$13 million (Schmidt, 1996). Appropriate public guardian services for 85 patients in Virginia saved \$5.6 million in health care costs in one year (Teaster and Roberto, 2003). Patients without capacity and without a surrogate have a median intensive care unit (ICU) length of stay that is twice as long as other ICU patients (White et al, 2006). Appropriate public guardian services saved Florida \$3.9 million in health care costs in one year (Teaster et al, 2009). Appropriate public guardian services in Washington state resulted in: (a) a decrease in residential settings’ average costs that exceeded the cost of providing a guardian within 30 months in 2008–2011; (b) a decrease of an average of 29 hours in personal care hours needed each month for public guardian clients, compared with an increase in care hours for similar clients without a guardian; and (c) 21% of clients with a public guardian improved in self-sufficiency in the

previous three months (Burley, 2011b). The Vera Institute of Justice Guardianship Project in New York City saved a \$2,500,026 in net Medicaid cost-savings for 111 guardianship clients in 2010 (Guardianship Project, 2010).

Guardianship Outcomes

Although there are calls for evaluation of legal intervention strategies such as guardianship and adult protective services for persons with dementia (Kapp, 2001), systematic outcomes studies of guardianship and other adult protective services are generally lacking (Wilber, 1997). For example, the authoritative National Research Council report on elder mistreatment research concluded that, 'no efforts have yet been made to develop, implement, and evaluate interventions based on scientifically grounded hypotheses about the causes of elder mistreatment, and no systematic research has been conducted to measure and evaluate the effects of existing interventions' (Bonnie and Wallace, 2003: 121). A more recent review determined 'Little evidence is available that supports any intervention to prevent elder abuse' (Daly et al, 2011: 362).

Nonetheless, the few systematic outcomes studies of guardianship are important and instructive. The first such study, a quasi-experimental design conducted by Blenkner and colleagues through the service, research and advocacy leading Benjamin Rose Institute in Cleveland, discovered that the experimental group receiving enriched protective services including guardianship had a higher rate of institutionalization and mortality than the control group, as well as failing to have deterioration or mortality forestalled (Blenkner et al, 1971; Bloom et al, 1974). The Blenkner study design and conclusions were questioned (Dunkle et al, 1983), and a reanalysis by other researchers suggested that the mortality findings came from initial group differences not controlled by the random sampling, but the reanalysis confirmed the institutionalization tendency (Berger and Piliavin, 1976).

The results of the 'landmark' Blenkner study were not 'revisited in an epidemiologically rigorous fashion' until 30 years later by Lachs and colleagues (Lachs et al, 2002: 734). The research question for the Lachs study was 'whether APS [adult protective services] use for abuse and self-neglect is an independent predictor of NHP [nursing home placement] after adjusting for other factors known to predict institutionalization (eg, medical illness, functional disability, and poor social support)' (2002: 735). The research discovered that

the relative contribution of elder protective referral [including 'pursuit of guardianship'] to NHP is enormous ['4- to 5-fold risk conferred by elder mistreatment and self-neglect, respectively'] and far exceeds the variance explained by other variables such as dementia, functional disability, and poor social networks (Lachs et al, 2002: 736-38).

The clinicians and APS clients acknowledged that dramatic quality of life improvements often resulted from nursing home placement but thought it 'remarkable that controlled studies of differential outcomes of APS have not yet been conducted' (Lachs et al, 2002: 738). The literature review showed 'no systematic attempt to evaluate program outcomes or to examine unintended consequences of APS intervention. Given the findings of the present study, APS should be subjected

to rigorous evaluation research' (Lachs et al, 2002: 738). While the need for adult protective services may seem as self-evident as child protective services, 'the positive benefits of APS intervention must be scientifically documented, to justify the possible risk of negative outcomes such as institutionalization' (Lachs et al, 2002: 738).

Contrary to recommendations (Kapp, 2001), systematic evaluation of guardianship and adult protective services outcomes for people with dementia are generally lacking. The few available studies (Blenkner et al, 1971; Lachs et al, 2002) show that such legal interventions contribute very much more to the likelihood of institutionalization than dementia itself. Nursing home admission is expected by age 80 for 75% of people with Alzheimer's compared with 4% of the general population (Arrighi, et al, 2010), with two-thirds of people dying with dementia doing so in nursing homes compared with 20% of cancer patients and 28% from all other conditions (Mitchell et al, 2005). Alternative approaches to guardianship for people with dementia seem imperative.

Procedural and Accountability Issues

In addition to the risk of negative outcomes with guardianship, there are myriad well-documented procedural issues beyond the scope of this chapter, such as: mandatory abuse and neglect reporting; petitioner conflicts of interest; right to counsel and legal counsel for indigents; right to jury trial; right of cross-examination; standard of proof; right to appeal; clinical evidence quality; preservation of civil liberties; emergency guardianship with too little due process (Schmidt, 1995; Schmidt, 2012; Teaster et al, 2010). Some of the biggest concerns about guardianship as a proxy decision-making tool most recently include: lack of oversight and active monitoring of guardians and guardian annual reports; lack of criminal background checks and credit checks of guardians; lack of guardian licensing, certification or registration; too high guardianship staff-client ratios; and non-compliance with guardian visitation-of-ward standards (Government Accountability Office (GAO), 2010; Schmidt, 2012; Schmidt et al, 2011).

Legally incompetent dementia patients who do not have either an advance directive or a willing and responsible family member making health care decisions by the authority of a family consent statute are dependent upon the kindness and fiduciary duties of a guardian. Procedural laxity and nominal accountability are intolerable in the context of guardianship (Schmidt, 1995).

CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The problems with proxy decision-making mechanisms like advance directives, family consent statutes and guardianship have generated the need for 'a dramatic paradigm shift from the medical or social welfare model of disability that focuses on diagnosis and inability to the human rights model that focuses on capability and inclusion' (Kanter, 2009: 572). The paradigm shift and human rights model are represented in the Convention on the Rights of Persons with Disabilities (CRPD, 2006).

For the purposes of proxy-decision-making and expansion of the rights of people with dementia under international law, Article 12(2) regarding equal recognition before law provides that ‘States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life’. Article 12(3) addresses the overarching problem of how to deal with the circumstances of individuals with disabilities who cannot exercise legal capacity without assistance: ‘States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity’. Paragraph (j) of the Preamble records the States Parties ‘Recognizing the need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support’. Article 19 recognizes the ‘equal right of all persons with disabilities to live in the community’ with assurance in paragraph (b) that ‘Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community’.

The CRPD forces abandonment of substituted decision-making paradigms that treat persons with disabilities as objects of protection and take away rights, and replaces them with supported decision-making paradigms that treat persons with disabilities as persons with autonomy, independence and dignity and which add a profusion of rights (Kanter, 2009; Perlin, 2013). The CRPD is consistent with arguments that substituted decision-making in American guardianship constitutes illegal discrimination under the American with Disabilities Act (Salzman, 2010) and violates the Supreme Court’s integration mandate in *Olmstead v LC* (1999): ‘Unjustified [institutional] isolation ... is properly regarded as discrimination based on disability’ (at 598).

Supported decision-making is defined as ‘a series of relationships, practices, arrangements, and agreements, of more or less formality and intensity, designed to assist an individual with a disability to make and communicate to others decisions about the individual’s life’ (Dinerstein, 2012: 10). Salzman (2011) advocates the study of existing supported decision-making models to determine best practices that:

- (1) maximize the individual’s responsibility for and involvement in decisions affecting his or her life;
- (2) ensure that the individual’s wishes and preferences are respected;
- (3) ensure legal recognition of decisions made with support or by the individual’s appointed agent;
- (4) provide the most appropriate qualifications and training for support persons, and standards for carrying out support responsibilities;
- (5) create the most efficient and effective mechanisms for funding support programs (including the possibility of volunteer support services);
- (6) have the most effective mechanisms for oversight and monitoring to ensure that the support relationship does not result in harm to the individual and protects against conflicts of interest, undue influence, or coercion of the individual needing support;
- (7) create standards for appointment of a substitute decision-maker that ensure that an individual is divested of decision-making rights only to the extent and for the time period that is absolutely necessary (2011: 328–29).

The key elements of a supported decision-making system adopted at the General Assembly are:

1. Promotion and support of self-advocacy.
2. Using mainstreaming mechanisms for the protection of the best interests of a person.

3. Replacing traditional guardianship by a system of [gradually implemented] supported decision-making.
4. Supporting decision-making.
5. Selection and registration of support persons [including ‘obligatory and regular training’].
6. Overcoming communication barriers.
7. Preventing and resolving conflicts between supporter and supported person [including addressing ‘the question of the liability and insurance of the supporter’].
8. Implementing safeguards.
(Inclusion Europe, 2008: 3–5)

Article 12(4) of the CRPD is quite specific about safeguards relating to enjoying legal capacity on an equal basis through supported decision-making:

State Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.

Examples of supported decision-making configurations including legislation exist in Canada, Germany, Norway and Sweden (Dinerstein, 2012). The Canadian provinces of Alberta, British Columbia (Representation Agreements, Enduring Powers of Attorney, registration), Manitoba, Quebec, Saskatchewan (Surtees, 2010) and Yukon Territory have legislation recognizing a form of supported decision-making. Common elements in Canada include: (1) emphasis on ‘the person with disability’s autonomy, presumption of capacity, and right to make decisions on an equal basis with others’; (2) the person with disability’s intent can serve as a basis of a decision-making process that does not involve removal of the person’s decision-making rights; and (3) individuals with disabilities often need decision-making assistance ‘through such means as interpreter assistance, facilitated communication, assistive technologies and plain language’ (Dinerstein, 2012: 10–11).

In the United States, the court in *Matter of Mark CH* (2010) ruled that state interventions like guardianship are subject to annual reporting by the guardian and review (monitoring) by the court as a matter of fundamental due process and international human rights law through the Supremacy Clause and Article 12 of the CRPD. In *Matter of Dameris L* (2012), the court held that, as a matter of substantive due process and international human rights through Article 12(3) of the CRPD, substituted decision-making by guardianship cannot be imposed until supported decision-making by ‘family, friends and professionals’ (at 579) is ‘explored and exhausted’ (at 580).

In addition to the challenge of heeding the call for research and evaluation of such strategies as supported decision-making for persons with dementia (Kapp, 2001; Then, 2013) formalized in Article 31 of the CRPD, the need for legal counsel is a significant ‘red flag’ of concern (Perlin, 2013). A national Associated Press investigation of 2200 randomly selected guardianships found that the proposed ward had no

representation by an attorney in 44% of cases (Bayles and McCartney, 1987). The number of states with a statutory right to counsel in guardianship proceedings has grown slightly from 22 states in 1981 to 25 states in 2005 (Teaster, et al, 2010). The Second National Guardianship Conference recommended:

28. Counsel always [is] appointed for the respondent and act as an advocate rather than as guardian *ad litem*.

29. The Wingspread Recommendation regarding the role of counsel as zealous advocate be amended and affirmed as follows: Zealous Advocacy—In order to assume the proper advocacy role, counsel for the respondent and the petitioner shall: (a) advise the client of all the options as well as the practical and legal consequences of those options and the probability of success in pursuing any one of these options; (b) give that advice in the language, mode of communication and terms that the client is most likely to understand; and (c) zealously advocate the course of actions chosen by the client (Wingspan, 2002: 601).

The Model Public Guardianship Act recommends further specification of the duties of counsel:

The duties of counsel representing an [alleged incapacitated person] at the hearing shall include at least: a personal interview with the person; counseling the person with respect to his or her rights; and arranging for an independent medical and/or psychological examination (Teaster et al, 2010: 167).

Counsel for all guardianship respondents would facilitate negotiation, settlement and achievement of the least restrictive supported decision-making for the alleged incapacitated person (Schmidt, 2012). In any event, the key to meaningful if not ‘emancipatory’ CRPD enforcement is the ‘right to adequate and dedicated counsel’, ‘vigorous, advocacy-focused counsel’, that is ‘free ... and regularized and organized’ leavened with sufficient ‘cause lawyers’ to accomplish the rights paradigm shift (Perlin, 2013: 1175, 1179, 1180).

In the dementia context, the human rights based model of decision-making is sometimes problematic. For example, assisted decision-making arrangements may not be suitable: guardianship is preferred in Alberta when adults with dementia cannot communicate or make decisions (Then, 2013). An attorney ethically shall otherwise maintain a normal client–lawyer relationship ‘as far as reasonably possible’ (Flowers and Morgan, 2013: 127) in the event of client diminished capacity while retaining the ability to take protective action like seeking appointment of a guardian when the attorney believes the client ‘is at risk of substantial physical, financial or other harm unless action is taken’ (Flowers and Morgan, 2013: 147; Law and Peck, 2013). If the right to a zealous, advocacy-focused counsel is not realized, then who remains to facilitate and achieve proxy decision-making and proxy decision-making procedure?

CONCLUSION

This chapter has provided a legal perspective on proxy decision-making. It began with the narrative about trial lawyer Frederick C Hayes, ‘the best friend you could have’ in a legal war, his admission to the advanced-dementia unit at Jewish Home Lifecare, his unmanageable behaviour despite a Haldol prescription, and his considerable discomfort. Despite knowledge that a person like Frederick C Hayes

with Alzheimer's is likely to spend 40% of their total disease years in the most severe stage (Arrighi et al, 2010), there is more to Mr Hayes' story.

An experienced 'support' person named Tena Alonzo stopped by to find Mr Hayes (a person who had 'trouble thinking', in her parlance) with his face

contorted in a grimace, writhing and moaning. She crouched next to him, asked him 'in a quiet, intimate tone' if he hurt anywhere, and moved her hand gently over his chest, abdomen, arms and legs: 'Do you hurt *here*?' His moaning stopped when her hand reached his stomach and he said, 'I hurt so bad'. She said, 'I promise you, we are going to fix this'. Ms Alonzo explained that it is hard for people with dementia to identify the source and experience of pain: 'All behavior is communication' (Mead, 2013: 92, 94).

The newer holistic approach articulated in this chapter focuses more on the way one feels rather than the way one thinks. In this model, medical care is less intrusive: there is more attention to a comfortable decline and less dependence on psychotropic medication. Supported decision-making is preferred to substituted decision-making.

Mr Hayes was placed on a higher dose of pain medication. He became more verbal, and he stopped making threatening gestures. The narrative about Mr Hayes concludes:

Frederick Hayes was unrecognizable from the man who had arrived at the unit, kicking and screaming, several months earlier. By observing his behavior carefully, nurses' aides had learned that he liked to watch television as a distraction while he was being changed or washed, and that it was important not to block his view of the set. Now that Hayes was receiving enough pain medication, he enjoyed it when the aides talked to him, and even responded to their jokes. His son told me, 'They understand how to get along with him. They know not to push too much'. Hayes particularly enjoyed being complimented; aides tell him he is a handsome man, which, in spite of everything, he still is (Mead, 2013: 101).

The approach taken in Mr Hayes' case seems to result in the maintenance of body weight, reduction in drug costs (Long and Alonzo, 2008) and reduction in pain (Long et al, 2010).

One would like to think that the care of Mr Hayes shows a kind of supported decision-making to which proxy decision-making in advance directives, family consent statutes, guardianship and the Convention on the Rights of Persons with Disabilities aspire.

REFERENCES

- ABA Commission on Law and Aging (2009) 'Default surrogate consent statutes'. Available at: www.americanbar.org/groups/law_aging/resources/health_care_decision_making.html.
- (2013) 'State health care power of attorney statutes: Selected characteristics'. Available at: www.americanbar.org/groups/law_aging/resources/health_care_decision_making.html.
- Aitken, P (1999) 'Incorporating advance care planning into family practice' 59(3) *American Family Physician* 605–12.
- Arrighi, HM et al (2010) 'Lethality of Alzheimer disease and its impact on nursing home placement' 24(1) *Alzheimer Disease & Associated Disorders* 90–95.
- Bayles, F and McCartney, S (1987) *Guardians of the elderly: An ailing system part I: Declared legally dead by a troubled system* (Associated Press) Available at: www.apnewsarchive.com.

- com/1987/Guardians-of-the-Elderly-An-Ailing-System-Part-I-Declared-Legally-Dead-by-a-Troubled-System/id-1198f64bb05d9c1ec690035983c02f9f.
- Berger, R and Piliavin, I (1976) 'The effect of casework: A research note' 21(3) *Social Work* 205–08.
- Blenkner, M, Bloom, M and Nielsen, M (1971) 'A research and demonstration project of protective services' 52(8) *Social Casework* 483–99.
- Bloom et al (1974) *Protective services for older people: Final report. Findings from the Benjamin Rose Institute study* (Cleveland, OH, Benjamin Rose Institute).
- Bonnie, RJ and Wallace, RB (eds) (2003) *Elder mistreatment: Abuse, neglect, and exploitation in an aging America* (Washington DC, National Academies Press).
- Burley, M (2011a) *Assessing the potential need for public guardianship services in Washington state* (Olympia, WA, Washington State Institute for Public Policy).
- (2011b) *Public guardianship in Washington state: Cost and benefits* (Olympia, WA, Washington State Institute for Public Policy).
- Collins, LG, Parks, SM and Winter, L (2006) 'The state of advance care planning: One decade after SUPPORT' 23(5) *American Journal of Hospice and Palliative Medicine* 378–84.
- Convention on the Rights of Persons with Disabilities (CRPD) (2006) (New York, NY, United Nations). Available at: www.un.org/disabilities/convention/conventionfull.shtml.
- Daly, JM, Merchant, ML and Jogerst, GJ (2011) 'Elder abuse research: A systematic review' 23(4) *Journal of Elder Abuse & Neglect* 348–65.
- Danis, M et al (1996) 'A prospective study of the impact of patient preferences on life-sustaining treatment and hospital cost' 24(11) *Critical Care Medicine* 1811–17.
- Dinerstein, RD (2012) 'Implementing legal capacity under article 12 of the UN Convention on the Rights of Persons with Disabilities: The difficult road from guardianship to supported decision-making' 19(2) *Human Rights Brief* 8–12.
- Dudley, KC and Goins, RT (2003) 'Guardianship capacity evaluations of older adults: Comparing current practice to legal standards in two states' 15(1) *Journal of Aging & Social Policy* 97–115.
- Dunkle, R et al (1983) 'Protective services reanalyzed: Does casework help or harm?' 64(4) *Social Casework* 195–99.
- Flowers, R and Morgan, R (2013) *Ethics in the Practice of Elder Law* (Chicago, ABA).
- Furrow, B et al (2000) *Health Law*, 2nd edn (St Paul, MN, West Group).
- (2012) *Health Care Reform: Supplementary Materials* (St Paul, MN, Thomson Reuters).
- Garner, B (2009) *Black's Law Dictionary*, 9th edn (US, West Group).
- Government Accountability Office (GAO) (2010) *Guardianships: Cases of financial exploitation, neglect, and abuse of seniors*. Available at: www.gao.gov/products/GAO-10-1046.
- The Guardianship Project (2010) *Summary of Medicaid cost-savings* (New York, Vera Institute of Justice, Inc).
- Hightower, D, Heckert, A and Schmidt, W (1990) 'Elderly nursing home residents' need for public guardianship services in Tennessee' 2(3–4) *Journal of Elder Abuse & Neglect* 105–22.
- Hughes, MM (2000) 'Remedying financial abuse by agents under a power of attorney for finances' 2 *Marquette Elder's Advisor* 39–48.
- Hurd, MD et al (2013) 'Monetary costs of Dementia in the United States' 368(14) *New England Journal of Medicine* 1326–34.
- Inclusion Europe (2008) *Key elements of a system for supported decision-making*. Available at: inclusioneurope.org/images/stories/documents/PositionPapers/Position_Supported_Decision_Making_EN.pdf.
- Kanter, AS (2009) 'The United Nations Convention on the Rights of Persons with Disabilities and its implications for the rights of elderly people under international law' 25(3) *Georgia State University Law Review* 527–73.

- Kapp, MB (2001) 'Legal interventions for persons with dementia in the USA: Ethical, policy and practical aspects' 5(4) *Aging & Mental Health* 312–15.
- Kroch, U (2009) 'The experience of being a dependent adult (ward) – A hermeneutic phenomenological study' (unpublished doctoral dissertation, University of Calgary).
- Lachs, MS et al (2002) 'Adult protective service use and nursing home placement' 42(6) *Gerontologist* 734–39.
- Law, R and Peck, K (2013) *Alzheimer's and the Law: Counseling Clients with Dementia and their Families* (Chicago, ABA).
- Long, CO and Alonzo, T (2008) 'Palliative care for advanced dementia: A model teaching unit – Practical approaches and results' 13(2) *Arizona Geriatrics Society Journal* 14–17.
- Long, CO et al (2010) 'Improving pain management in long-term care: The campaign against pain' 12(3) *Journal of Hospice & Palliative Nursing* 148–55.
- Lynch, HF, Mathes, M and Sawicki, NN (2008) 'Compliance with advance directives: Wrongful living and tort law incentives' 29(2) *Journal of Legal Medicine* 133–78.
- Mead, R (20 May 2013) 'The sense of an ending: An Arizona nursing home offers new ways to care for people with dementia' *New Yorker* 92–103.
- Meier, DE (1997) 'Voiceless and vulnerable: Dementia patients without surrogates in an era of capitation' 45(3) *Journal of the American Geriatrics Society* 375–77.
- Mitchell, SL et al (2005) 'A national study of the location of death for older persons with dementia' 53(2) *Journal of the American Geriatrics Society* 299–305.
- Moorman, SM and Inoue, M (2013) 'Persistent problems in end-of-life planning among young-and middle-aged American couples' 68(1) *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 97–106.
- Morhaim, DK and Pollack, KM (2013) 'End-of-life care issues: A personal, economic, public policy, and public health crisis' 103(6) *American Journal of Public Health* e8–e10.
- Norris, WM et al (2005) 'Treatment preferences for resuscitation and critical care among homeless persons' 127(6) *CHEST Journal* 2180–87.
- Parker, L (2006, December 19) 'In a crisis, do-not-revive requests don't always work' *USA Today*. Available at: http://usatoday30.usatoday.com/news/health/2006-12-19-do-not-revive-cover_x.htm.
- Patient Self-Determination Act 1990, 42 USC sections 1395 *et seq.*
- Pearlman, RA and Uhlmann, RF (1988) 'Quality of life in chronic diseases: Perceptions of elderly patients' 43(2) *Journal of Gerontology* M25–M30.
- Perlin, ML (2013) "'Striking for the guardians and protectors of the mind": The Convention on the Rights of Persons with Mental Disabilities and the future of guardianship law' 117(4) *Penn State Law Review* 1159–337.
- Pope, T (2013) 'Clinicians may not administer life-sustaining treatment without consent: Civil, criminal, and disciplinary sanctions' 9(2) *Journal of Health & Biomedical Law* 213–96.
- Public Guardianship Task Force (2005) *Report of the public guardianship task force to the WSBA elder law section executive committee*. Available at: www.wsba.org/Legal-Community/Sections/Elder-Law-Section/Guardianship-Committee.
- Saitta, NM and Hodge, SD (2011) 'Wrongful prolongation of life – A cause of action that has not gained traction even though a physician has disregarded a do not resuscitate order' 30 *Temple Journal of Science, Technology & Environmental Law* 221–38.
- Salzman, L (2010) 'Rethinking guardianship (again): Substituted decision making as a violation of the integration mandate of title II of the Americans with Disabilities Act' 81 *University of Colorado Law Review* 157–245.
- (2011) 'Guardianship for persons with mental illness – A legal and appropriate alternative?' 4 *Saint Louis University Journal of Health Law & Policy* 279–329.

- Schmidt, W (1981) 'Guardianship of the elderly in Florida: Social bankruptcy and the need for reform' 55 *Florida Bar Journal* 189–195.
- (ed) (1995) *Guardianship: Court of last resort for the elderly and disabled* (Durham, NC, Carolina Academic Press).
- (1996) 'Public guardianship issues for New York: Insights from research' 6 *Elder Law Attorney, New York State Bar Association* 31–37.
- (2011) 'Medicalization of aging: The upside and the downside' 13 *Marquette Elder's Adviser* 55–88.
- (2012) *Final report: A study of guardianship services for vulnerable adults in North Dakota* (Bismarck, ND, Human Services Committee, North Dakota Legislature).
- (2013) 'Guardianship for vulnerable adults in North Dakota: Recommendations regarding unmet needs, statutory efficacy, and cost effectiveness' 89(1) *North Dakota Law Review* 77–142.
- Schmidt, W, Akinci, F and Magill, S (2011) 'Study finds certified guardians with legal work experience are at greater risk for elder abuse than certified guardians with other work experience' 7(2) *NAELA Journal* 171–97.
- Schmidt, W and Peters, R (1987) 'Legal incompetents' need for guardians in Florida' 15(1) *Journal of the American Academy of Psychiatry and the Law* 69–83.
- Sharma, RK and Dy, SM (2011) 'Documentation of information and care planning for patients with advanced cancer: Associations with patient characteristics and utilization of hospital care' 28(8) *American Journal of Hospice and Palliative Medicine* 543–49.
- Stiegel, L and Klem, E (2008) *Power of attorney abuse: What states can do about it. A comparison of current state laws with the new Uniform Power of Attorney Act* (Washington DC, American Association of Retired Persons).
- Surtees, D (2010) 'The evolution of co-decision-making in Saskatchewan' 73(1) *Saskatchewan Law Review* 75–92.
- Teaster, P and Roberto, K (2002) 'Living the life of another: The need for public guardians of last resort' 21(2) *Journal of Applied Gerontology* 176–87.
- (2003) *Virginia public guardian and conservator programs: Evaluation of program status and outcomes* (Blacksburg, VA, The Center for Gerontology, Virginia Polytechnic Institute and State University).
- Teaster, P et al (2009) *The Florida public guardian programs: An evaluation of program status and outcomes* (Lexington, KY, University of Kentucky Graduate Center for Gerontology).
- (2010) *Public guardianship: In the best interests of incapacitated people?* (Santa Barbara, CA, Praeger Publishers).
- Teno, JM et al (1994) 'Do formal advance directives affect resuscitation decisions and the use of resources for seriously ill patients?' 5(1) *Journal of Clinical Ethics* 23–30.
- Then, SN (2013) 'Evolution and innovation in guardianship laws: Assisted decision-making' 35 *Sydney Law Review* 133–66.
- Uekert, BK and Van Duizend, R (2011) *Adult guardianships: A 'best guess' national estimate and the momentum for reform* (Williamsburg, VA, National Center for State Courts).
- White, DB et al (2006) 'Decisions to limit life-sustaining treatment for critically ill patients who lack both decision-making capacity and surrogate decision-makers' 34(8) *Critical Care Medicine* 2053–59.
- (2007) 'Life support for patients without a surrogate decision maker: Who decides?' 147(1) *Annals of Internal Medicine* 34–40.
- White, DB, Jonsen, A and Lo, B (2012) 'Ethical challenge: When clinicians act as surrogates for unrepresented patients' 21(3) *American Journal of Critical Care* 202–07.

- Wilber, KH (1997) 'Choice, courts, and competency: The coming of age of protective services research' 37(2) *Gerontologist* 272–74.
- Wingspan – The Second National Guardianship Conference (2002) 'Recommendations' 31 *Stetson Law Review* 595–609.
- World Health Organization and Alzheimer's Disease International (2012) *Dementia: A public health priority* (Geneva, WHO Press).

CASES

- Cruzan v Director, Missouri Department of Health*, 497 US 261 (1990).
- In re Jobes*, 108 NJ 394, 529 A.2d 434 (1987).
- Matter of Dameris L*, 38 Misc.3d 570, 956 NYS.2d 848 (Surr Ct NY Cnty 2012).
- Matter of Mark CH*, 28 Misc.3d 765, 906 NYS.2d 419 (Surr Ct NY Cnty 2010).
- Olmstead v LC*, 527 US 581 (1999).



Available online at
ScienceDirect
www.sciencedirect.com

Elsevier Masson France
EM|consulte
www.em-consulte.com



DOSSIER “ABUSE” / *Philosophical considerations*

Searching for workable alternatives to guardianship for vulnerable populations?



Quelles alternatives viables à la tutelle pour les populations fragiles?

T. Carney¹

The university of Sydney, Eastern avenue, Sydney, NSW 2006, Australia

Received 12 January 2015; accepted 21 February 2015
Available online 3 April 2015

KEYWORDS

Autonomy;
Vulnerability;
Supported
decision-making;
Law reform;
Guardianship

Summary The right of a person to make their own decisions but be protected from serious harm should cognitive capacity decline poses ethical and practical challenges for the law. The principle of supported decision-making enshrined by the UN Convention on the Rights of Persons with Disabilities 2006 has fuelled the search by law reform bodies for new statutory models or principles capable of better respecting autonomous choice and avoiding undue paternalism in the name of protection of the vulnerable. This paper selectively reviews some law reform models across the spectrum from guardianship and supported decision-making to durable powers of attorney or support. It argues that across these different legal settings there are shifting (and delicate) balance points to be found between competing ethical principles (such as autonomy and protection), adequate accountability and freedom from undue regulation, and “workability” (fidelity of practice to intended objectives).

© 2015 Elsevier Masson SAS. All rights reserved.

MOTS CLÉS

Autonomie ;
Vulnérabilité ;

Résumé Le droit d’une personne à prendre ses propres décisions, tout en étant protégée contre les dommages graves causés par une baisse de la capacité cognitive, pose au droit des défis éthiques et pratiques. Le principe de prise de décision assistée consacré par la convention des Nations Unies relative aux droits des personnes handicapées 2006 a alimenté la recherche de nouveaux modèles ou principes pour mieux respecter le choix autonome comme éviter le

E-mail address: terry.carney@sydney.edu.au

¹ Emeritus Professor of Law, University of Sydney and Visiting Research Professor, University of Technology Sydney.

Prise de décision
assistée ;
Réforme ;
Tutelle

paternalisme excessif au nom de la protection des personnes vulnérables. Ce document passe en revue de manière sélective certains modèles de réforme du droit allant de la tutelle et la prise de décision assistée aux mandataires. Il fait valoir que dans ces contextes juridiques différents, les points d'équilibre se trouvent entre les principes éthiques (tels que l'autonomie et la protection), pratiques et encadrements formels mal régulés.

© 2015 Elsevier Masson SAS. Tous droits réservés.

Introduction

The search for workable ways of promoting the realisation of human autonomy while also providing avenues for protection against oppression exploitation and abuse has been ongoing for centuries.

The ancient common law jurisdiction of *parens patriae* to protect the person or property of vulnerable individuals such as children, the mentally ill or people with an intellectual disability had its origins in the royal court of 13th century Britain, though it turned out that the state was as much motivated by pragmatic interest in protection of its revenue as it was in the moral interests of the people themselves [1]. This tension between principle and pragmatism persists to the present day, no longer due so much to venal concerns of government (at least not beyond penny pinching reluctance to fund gold standard laws and policies) but due more to the frailties of human nature and the fragility of civil society processes for avoidance of abuse of the vulnerable.

The statutory successor to the common law principle of *parens patriae* and the protective wardship jurisdiction of superior courts (appointment of a so-called "committee" of the person or property of vulnerable people such as children, people with psycho-social disabilities or the aged) is the institution of adult guardianship, a model quite widely adopted in common law jurisdictions, as well as (with modifications) in Western Europe [2,3]. Children, once characterised as chattels rather than as individuals with legal personality and independent rights, were for their part presumed bereft of all legal capacity, and even today there are variations in the degree to which the law in advanced western countries respects the rights of mature minors to make their own decisions [4–6], though all of this is outside the scope of the present paper.

Vulnerability is a notoriously slippery notion ([7], pp 123ff, [8], pp 46–47), one which is arguably best portrayed as both relational and layered, rather than a fixed essence or individual status [9]. As Dennis Cooley ([10], this issue) eloquently outlines, the concept is open to many highly nuanced interpretations, and the risk of well-meaning over-protectiveness of the "vulnerable" is one which rises and falls across the life course. Ageism is a virulent disease of community perception or attitudes; a collective and discriminatory state of mind which has proven to be very resistant to change by way of laws outlawing mandatory retirement ages, discrimination in employment hiring, or presumptions of incapacity in life more generally [11–13]. Some of the lessons of behavioural research in explaining why laws misfire due to subconscious (latent or implicit) "perceptions,

attitudes, beliefs and actions" of those sought to be influenced by the law are nicely sketched by Vieira and Graser [14].

Avoiding over-protectiveness without leaving truly vulnerable adults at risk of abuse or exploitation arises in many settings, including: as subjects of research [15]; in the more mundane but much more prevalent use (though still only by a minority) of durable powers of attorney over finances, health or personal affairs [16,17]; in the more routine administrative powers such as representative payee appointments conferring proxy control over social security; and, in some jurisdictions, also in the statutory hierarchies of pre-authorised "default" proxy decision-makers for health [18,19]. Striking a balance between the real risk of elder abuse (put at around 5% of the relevant population) and cloying paternalism is difficult, though there is attraction in Jonathan Herring's "rights based" approach — based around duties to investigate and act on serious incursions on civil rights, while according greater respect for personal autonomy in other less "weighty" spheres [20].

What has added pertinence and urgency to discussion about such issues is the "equality principle" of Article 12 of the Convention on the Rights of Persons with Disabilities 2006, the rejection of capacity-tests as gate-keepers for support ([21], para 29 (i)), and the outlawing of provision for — or at the very minimum the "least restrictive" resort to — substitute decision-making interventions [22,23]. This has spawned law reform enquiries around the world, including most recently by the Victorian and the Australian Law Reform Commissions [24,25] and the Law Commission of Ontario [26,27] in the search to more fully realise a richer and more holistic understanding of the intrinsic capacity of personhood: as extending beyond cognition and rationality, to embrace recognition of the ability to express "will and preferences" ([23], pp 84–85, 91–94).

This paper touches on some selected issues which arise across this wide spectrum of models, though leaving aside for another time the rather peculiarly US approach of enacting "elder (or dependent adult) abuse" laws (further, [28]); an approach which often incorporates controversial obligations mirroring the approach taken to child abuse ([29,30], pp 28–30), raising as it does issues about the possible limits of reliance on law compared to other remedial or protective interventions [20]. Two ends of the spectrum of models in particular will be canvassed: the proxy decision-maker powers associated with traditional adult guardianship laws (and the alternative of supported decision-making) and the private planning options such as durable (i.e. enduring or lasting) powers of attorney.

It will be argued that across these different legal settings there are shifting (and delicate) balance points to be found between competing ethical principles (such as autonomy and protection), adequate accountability and freedom from undue regulation, and “workability” (fidelity of practice to intended objectives).

Vulnerability risks of paternalism at the “sharp end”: guardianship and supported decision-making?

Reforms to adult guardianship law in many countries from the 1980s onwards, in varying degrees, removed some of its more egregious features: such as plenary, indefinite (and sometimes effectively unreviewable) orders, favouring instead presumptively partial, time-limited and routinely reviewed orders [24,31]. But such reformed guardianship still retains its essential character of making a disempowering appointment of a proxy decision-maker, even where legislation strongly encourages consultation with and regard for the wishes of the person subject to such a more “personalised” order [32,33]. And there is evidence of a “social gradient” in utilisation of such orders, with a greater representation of people lacking the informal networks or “social capital” associated with living in higher socio-economic neighbourhoods [34].

Renovation of the concept of legal capacity — which serves as the main gate-keeping test of need for guardianship — was also but a small step forward ([35], pp 37–39), given the conceptual and other complexities of its common law development in respect of people at opposite ends of the life course [36]. Certainly the Weisstub Report in Ontario [37], by recognising the socio-legal character of capacity ([27], p 62), helped to bed down a “functional” approach to deciding whether a guardianship or other order was needed. However retention of capacity as the gate-keeper criterion is seen by the UN Committee on the CRPD ([21], para 29(i)) to be a violation of the equality principle of Article 12 of the Convention (also [22]). Arguably its retention may also compound stereotyping of groups such as the aged, or people with psycho-social disabilities ([38], pp 127–128 (a critique of the functional approach as constituting the “worst of both worlds”)). Such groups are more likely to be perceived by others as lacking capacity for autonomous choice, thus putting them at greater risk of paternal interventions based on their supposed vulnerability, leading many to support the UN Committee’s call for a complete switch to support for decision-making ([39–41]; but compare [42], pp, 40, 41). This may be much easier said than done, however.

Both Australia and Canada made interpretive reservations to the CRPD, stating that retention of substitute decision-making was acceptable as a last resort ([25], p 48, [27] p 119); and — despite much ink having been spilt by law reform bodies and academic commentators — Australia, the US and Britain have been slow to legislate supported decision-making when compared to say Canada and Sweden ([27], pp 126–130 (Canada), 130–31 (Sweden), [43], pp 110–111, [44]). However, that said, there is a rather disturbing lack of evidence about whether any of the already legislated supported decision-making models actually “work” in terms of realising their intended goals at all or

do so best for which disability types, or for which personal characteristics of those sought to be served [45,46] and similar reservations are held about informal schemes of support [47].

Anticipating Dennis Cooley’s focus on vulnerability, Margaret Hall [48] — in place of abandoning capacity as the gate-keeper for adult guardianship or legislated schemes of “supporters” — has proposed “replacing” capacity with measures hinging on removing or compensating against “vulnerability”. One part of the justification for doing so is the claim that traditional guardianship already empowers existing or creates new “relationships of responsibility” which are sufficiently stable and ongoing in character as to enable people to continue to function adequately (by searching out and seeking to close any gaps between personal ability and the current challenges or demands facing that person). This is certainly a promising line of thought in that vulnerability is arguably a more subtle and nuanced concept than is the case with functional capacity, and is more capable of reflecting the relational and situational aspects of living. However its very fluidity and subjectivity has led me to question its readiness yet to provide the required “bright line” discrimination between who is and who is not to be subjected to intervention, since it is “dubious that there is a line at all” ([18], pp 10–11).

While this is obviously a concern where substitute decision-making orders are being issued, as under adult guardianship law (reformed or otherwise), any lack of clarity about who is covered does not entirely disappear under supported decision-making models either. For example Michael Bach’s and Lana Kerzner’s [49] three part conceptual model for implementing supported decision-making includes the option of “facilitated status” decision-making, in order to cater for people unable to make an autonomous decision either independently (“legally independent status”) or with assistance from a supporter (“supported decision-making status”) ([27], pp 124–25). Even if these three are arguably better thought of as points which are more fluid or capable of simultaneous enjoyment by particular individuals in certain situations ([23], pp 95–96), it still remains true, as Nandini Devi has argued, that “the facilitated decision-making status is similar to substituted decision-making because decisions are made on behalf of adults lacking the standard decision-making ability, even though it seeks to promote individuality and freedom.” ([41], p 802). Eilionoir Flynn and Anna Arstein-Kerslake recognise this, writing that the model is one which: “Does not prevent a representative from making a decision for another person who is not expressing her will and preferences in a way which anyone can interpret—rather, it requires representatives making such decisions to do so in a way which *attempts to draw out the imagined* will and preferences of the person”. ([23], p 94 (emphasis added)).

Not only does this mean that facilitated decision-making reprises the same fiction identified long ago by Louise Harmon as infecting other forms of substituted judgement [50], but as I have contended elsewhere, supported decision-making in this form may be almost identical to optimally operating guardianship: both functionally and in terms of public perception of the consultative and capacity-building roles of the supporter/guardian ([51], p 12, [52], p 62). While there are crucial educative benefits of opting to call

it facilitated “support” so far as changing popular culture and discriminatory perceptions are concerned, at the operational level, reformed guardianship and “facilitated” support may be something of a distinction without much of a difference.

That said, vulnerability certainly remains as one of the more crucial benchmarks for “assessing” the adequacy of legal arrangements in this context, including the supported decision-making alternatives to guardianship now so strongly espoused by the CRPD and its UN monitoring committee. Yet, as already mentioned, supported decision-making has been little legislated outside a few Canadian provinces. And it is lacking a sound evidentiary base to show that it is taken up when enacted, or that it achieves its declared objectives ([27], pp 123–24, [45,46,53]), let alone whether it might cater only to people with particular cultural characteristics like a preference for collaborative decision-making, or mainly appeal to those caring for people with intellectual disabilities ([27], pp 124, 135–36, respectively). Whether for this or other reasons, government reluctance to enact supported decision-making reforms seems endemic. By way of illustration, in the Australian State of Victoria (the first to legislate in that federation), the government accepted only the supported decision-making recommendation from the landmark report of its Law Reform Commission, rejecting its co-decision-making proposal ([24], paras 8.13–8.31; 8.78–87). Government then rather botched the introduction of supported decision-making in 2014 by calling such appointments “supportive guardianship” when made on application to the relevant tribunal, and a “supportive attorney” when made as a private planning appointment by the person themselves [18,54]. Although only the supportive attorney provisions were enacted prior to the dissolution of Parliament for a State Election in November 2014 where the Government was defeated, this package involved missteps with at least two unfortunate consequences.

Assessed in the light of Dennis Cooley’s vulnerability framework ([10] this issue), the first misstep under Victoria’s reform is the risk that the addition of supportive guardians or attorneys alongside their traditional counterparts will “net-widen” the reach of paternalist involvement in the lives of those affected (instead of “replacing” proxy decision-making orders with “support” orders, the total number under one or the other may increase). The second, surely almost inevitable risk, is that of *de facto* paternalism — that the public, compounded by the ill-chosen name of the new orders, will wrongly view holders of these appointments (which actually confer not a “shred” of any proxy powers) as holding the very same full set of proxy authority which the reform is seeking to replace [51,52].

Vulnerability and personal autonomy it seems make for unhappy bedfellows, as further highlighted when turning to briefly consider some of the private planning or more routine powers put in place in various jurisdictions.

Vulnerability risks of paternalism at the “mundane end”: enduring powers and default appointments?

Durable powers of attorney may seem an odd focus for attention given their ability to overcome the common law position

against recognising execution of an instrument projecting wishes beyond the point of loss of capacity. Such enduring powers of attorney over finances (such as property or money), the person (such as where a person resides or works) and health (such as consent to treatment) are a comparatively recent invention from the US (credited respectively to: Virginia in 1954; the 1969 Probate Code and a Californian durable health power in 1983: [51], p 2). At first blush, such instruments appear to be the perfect vehicle for projecting realisation of individual autonomy into the future; a future where a dementia, stroke, accident or other such episode may impair cognitive capacity. Non-binding “advance directives” which record the wishes, values or other guidance statements set down by an individual are a more fluid expression of the same sentiment [55], a flexibility with “wriggle room” attractions when balancing the accreted statement of the right to choose against unanticipated fresh challenges or conditions emerging due to say subsequent episodes of severe mental illness [56,57].

Yet as Kaiponanea Matsumura ([58], p 77) writes in the context of enforcement of “personal” contracts about issues such as surrogacy, it is the very projection of personality from a past time into a future time which renders the device controversial, at least when “core” aspects of personality are at stake, since the views, values and anticipated choices made by the present self may not equate with the “future” self or revised future preferences (see the empirical evidence of such shifts in: [19], pp 1005–1006). Of course there is a partial remedy available in those jurisdictions which permit a durable power to be challenged and either be modified or be terminated and replaced with a different order (such as guardianship) should it turn out to be inappropriate to current circumstances, such as due to abuse of the power [16,59]. Such avenues are less likely to work for the socially isolated lacking access to “concerned others” of course, since there will be few people inclined to set review in motion (or notify any statutory specialist ombudsman, or “office of the public advocate”, or adult protective service charged with taking action), even where cost and emotional barriers of initiating such review have been overcome. However in any event some would argue that such an ability to overturn or modify expressed choices defeats the purpose of a durable power, and that the original choice, if a genuinely autonomous one, should be allowed to stand, “for better or worse”.

Such pre-arranged private planning appointments, whether of proxy decision-makers or of the “supporters” so favoured by the UNCRPD because they avoid conferral of any proxy decision-making at law, also encounter other problems. Those problems include: low and differential take-up around race, ethnicity, education and other variables [17]; and minimal investment in any education or routine monitoring and accountability checks for appointees. Nor are these concerns easily addressed. There is likely to be further suppression of already low take-up levels on introduction of supposed protections against abuse such as official registration either on making such instruments or on their coming into force, as people react against making their declining capacity publicly known [16]. That said, the frailty of human nature and family disharmony being what it is, the very insulation of such appointments from outside scrutiny does serve to magnify the risks of their deliberate abuse

or unintentional misuse ([18], [20], p 187), giving pause for consideration of low-cost and practical (if partial) remedies such as Nina Kohn's proposal of insisting on consultation between principal and agent about any significant decisions ([60]; for a much wider application of such personal "empowerment" strategies see [61]).

Statutory enactment of a hierarchy of default proxy decision-makers (or in future perhaps also supporters) for anyone who may need one and who has not made their own appointment is able to solve the problem of low-take up, but it raises other concerns. Such universal coverage provisions are known to the law in other contexts of course, such as the aptly named "statutory will" governing inheritance for the sizeable minority of people (ranging between 10–20%) who die without having made a will [62]. In the present context the automatic health proxy is the illustrative model of such laws. These statutory default health care decision-maker laws operate in the form of a "hierarchy" of close relatives or others automatically authorised in advance to consent to basic medical or dental care of a person otherwise unable to give their own consent when their situation is not covered by the common law dispensation for a need for consent in an emergency (further, [19] (USA), [24], Ch 13 [59], pp 244–248 (Australia)). Yet such laws may rest on a fundamentally false premise: that "anyone" is ever capable of knowing the mind of another person, or of accurately "reading" their behavioural cues, no matter how well or how long they have known the other person. If it is sensibly conceded that such models actually seek out, not authentic will, but merely the "closest fit" in terms of congruent values and interests, the approach still rests on the assumption that the designated close family member actually "sufficiently shares" such values and interests to a sufficient degree for their reading of the person's past and present will to be accepted as a secure ethical foundation for the decision in question. This is an assumption already shown to be contradicted for many people, as demonstrated in a review of empirical studies by Nina Kohn and Jeremy Blumenthal ([19], pp 994–1000).

Of course these schemes in any event are out of kilter with the CRPD in that they authorise proxy decision-making rather than anoint a "supporter", and are often complex and confusing to understand on the part of health practitioners called on to act on them. In Australia the VLRC report therefore recommended simplification of their expression in the form of free-standing powers distinguishing between different levels of seriousness of medical procedures ([24], Chap 13), while the ALRC urged their review against its template and principles of supported decision-making, without reaching any real conclusion about how or to what extent this transformation might prove possible ([25], paras 10.44–10.62, esp 10.60). Even if these concerns are overcome or are thought not to be a fatal objection, there is also the delicate balance required to be struck between the gravity of the matter and the risk of misuse or abuse, as weighed against the convenience and economy of such "off the peg" laws. Commonly for instance any such health powers are restricted either to low-risk, routine procedures or to more serious health matters (but excluding major or contentious issues such as irreversible procedures), while other checks and balances are often considered for inclusion, such as accountability or review avenues [18]. Even

so, some jurisdictions eschew the idea entirely, seeing the risk of blanket entrustment of powers to close family as too risky; as too lacking in faith in the nostrum about "blood being thicker than water" so to speak.

On a different tack, serious efforts have been made to translate CRPD principles into more workable forms of "support for" rather than substituted decision-making, including the work of the Australian Law Reform Commission, the Law Commission of Ontario and the Victorian Law Reform Commission, as briefly touched on above. Valiant attempts have been made to see ever more promising lights at the end of these tunnels (recently [38] pp 133–136 (discussing Irish, as yet unseen Newfoundland and Labrador, and Indian proposals)), including possible glacial progress under European human rights jurisprudence towards recognition of the equality principle of Article 12 of the CRPD ([38], pp 139–140 (only to give the equivalent of the parental answer to tired child travelers that "No, we're not there yet")).

However the reality is that most of these newly minted models are either untested, are under-utilised, or are lacking in sufficient detail to yet inspire confidence that they will work as intended [45,46,53]. Salvation may ultimately lie with these more visionary reforms, but for the moment it may be a matter of making the best of the messy inheritance of adult guardianship, durable powers, automatic health decision-making mandates, or representative payee and nominee powers.

Conclusion

So where does this leave us? Ideally no doubt we should strive for a set of individual, family, friendship network and civil society arrangements which facilitate enjoyment of maximum choice through respect for "autonomy, will and preferences" ([21], para 26), or to use the formulation of the Australian Law Reform Commission, which serve to embody and reflect the "will, preferences and rights" of people ([25], pp 64, 75–85 (proposed decision-making principle 3)), all the while without degenerating into hidden abuse, exploitation or self-interested paternalism.

As this selective review surely exposes, this aspiration is easy to state but hard to translate with confidence into accessible and workable laws. Certainly no one jurisdiction can sensibly be confident that its portfolio of legislation manages to both balance-off all the competing ethical principles and at the same time meet the socio-legal challenge of ensuring that this balance is retained "on the ground". Recent reforms are especially dubious in that regard, since what little evidence there is will likely present the initiative in rosy light at first; while reform proposals, whether from law reform bodies or academics, are by definition untested, however attractive in their theoretical design. That said, on the evidence to hand so far [24,25,27,31,63], Australia's suite of measures as found in most jurisdictions within the federation may come closest. This suite of measures includes its favourably evaluated model of tribunal adjudication of guardianship applications (and perhaps soon in Victoria, tribunal appointed as well as the recently enacted personal appointment of supporters: [54]) and usually also approval of research protocols for vulnerable research subjects; combined with its active and

comparatively well-funded Offices of the Public Advocate (including serving advocacy roles in protecting vulnerable individuals); and its array of durable powers, statutory default health decision-makers, and soon to be revamped representative payee provisions ([18] introducing authentic “supporters” [25]).

But as always in law reform which potentially makes incursions of individual autonomy or collective decision-making preferences in the name of protection against the risk to the vulnerable, great care needs to be taken to craft and evaluate the effectiveness of mechanisms which truly balance the competing ethical considerations in play.

Disclosure of interest

The author declares that he has no conflicts of interest concerning this article.

References

- [1] Neugebauer R. Treatment of the mentally ill in medieval and early modern England: a reappraisal. *J Hist Behav Sci* 1978;14(2):158–69.
- [2] Doron I. Elder guardianship kaleidoscope: a comparative perspective. *Int J Law Policy Family* 2002;16:368–98.
- [3] Blankman K. Guardianship models in the Netherlands and Western Europe. *Int J Law Psychiat* 1997;20(1):47–57.
- [4] QLRC. Consent to health care of young people. Brisbane: Queensland Law Reform Commission; 1996 [Report no 51].
- [5] Rozovsky L. Children, adolescents, and consent. In: Rozovsky L, editor. *The Canadian law of consent to treatment*. 2nd ed Toronto and Vancouver: Butterworths; 1997. p. 61–75.
- [6] Tan J, Jones D. Children’s consent. *Curr Opin Psychiatry* 2001;14:303–7.
- [7] Bennett B, Carney T. Vulnerability: an issue for law and policy in pandemic planning? In: Freeman M, Hawkes S, Bennett B, editors. *Law and global health - current legal issues*, 16. Oxford: Oxford University Press; 2014. p. 121–32.
- [8] Levine C, Faden R, Grady C, Hammerschmidt D, Eckenwiler L, Sugarman J. The limitations of “vulnerability” as a protection for human research participants. *Am J Bioeth* 2004;4(3):44–9.
- [9] Luna F. Elucidating the concept of vulnerability: layers not labels. *Int J Fem Approaches Bioeth* 2009;2(1):121–39.
- [10] Cooley D. Elder abuse and vulnerability: avoiding illicit paternalism in healthcare, medical research, and life. *Ethics, Medicine and Public Health* 2015;1(1), <http://dx.doi.org/10.1016/j.jemep.2014.09.003> [pre-print].
- [11] Doron I, Soden AM. *Beyond elder law*. Dordrecht: Springer; 2012.
- [12] Spencer C. Legal and legislative issues in protecting older adults in the workplace: an international perspective. In: Brownell P, Kelly J, editors. *Ageism and mistreatment of older workers*. Dordrecht: Springer; 2013. p. 145–64.
- [13] Neumark D, Button P. Did age discrimination protections help older workers weather the great recession? *J Policy Anal Manage* 2014;33(3):566–601.
- [14] Vieira ACA, Graser A. Taming the biased black box? On the potential role of behavioural realism in anti-discrimination policy. *Oxf J Leg Stud* 2014, <http://dx.doi.org/10.1093/ojls/gqu025> [pre-print].
- [15] Tomossy G, Weisstub D. The reform of adult guardianship laws: the case of non-therapeutic experimentation. *Int J Law Psychiatry* 1997;20(1):113–39.
- [16] Carney T. Abuse of enduring powers of attorney: lessons from the Australian tribunal experiment? *NZULR* 1999;18:481–508.
- [17] Mitchell LK, Pachana NA, Wilson J, Vearncombe K, Massavelli B, Byrne GJ, et al. Promoting the use of enduring powers of attorney in older adults: a literature review. *Australas J Ageing* 2014;33(1):2–7.
- [18] Carney T. Supported decision-making for people with cognitive impairments: an Australian perspective? *Laws* 2015;4(1):37–59.
- [19] Kohn NA, Blumenthal JA. Designating health care decisionmakers for patients without advance directives: a psychological critique. *Georgia Law Rev* 2008;42(4):979–1019.
- [20] Herring J. Elder abuse: a human rights agenda for the future. In: Doron I, Soden AM, editors. *Beyond elder law*. Dordrecht: Springer; 2012. p. 175–97.
- [21] Committee on the Rights of Persons with Disabilities. General Comment No. 1. Geneva: UN Committee on the Rights of Persons with Disabilities; 2014 [2014 19 May, eleventh session 31 March–11 April 2014].
- [22] Morrissey F. The United Nations Convention on the Rights of Persons with Disabilities: a new approach to decision-making in mental health law. *Eur J Health Law* 2012;19(5):423–40.
- [23] Flynn E, Arstein-Kerslake A. Legislating personhood: realising the right to support in exercising legal capacity. *Int J Law Context* 2014;10(1):81–104.
- [24] VLRC. *Guardianship: final report*. Melbourne: Victorian Law Reform Commission; 2012.
- [25] ALRC. *Equality, capacity and disability in Commonwealth laws: final report*. Sydney: Australian Law Reform Commission; 2014.
- [26] LCO. *Capacity of adults with mental disabilities and the Federal RDSP*. Toronto: Law Commission of Ontario; 2013.
- [27] LCO. *Legal capacity, decision-making and guardianship*. Discussion paper May 2014. Toronto: Law Commission of Ontario; 2014.
- [28] Chesterman J. Responding to violence, abuse, exploitation and neglect: improving our protection of at-risk adults. Canberra: Winston Churchill Memorial Trust of Australia; 2013.
- [29] Jirik S, Sanders S. Analysis of elder abuse statutes across the United States, 2011–2012. *J Gerontol Soc Work* 2014;57(5):478–97.
- [30] Kohn NA. A civil rights approach to elder law. In: Doron I, Soden A, editors. *Beyond elder law*. Dordrecht: Springer; 2012. p. 19–34.
- [31] Carney T, Tait D. *The adult guardianship experiment: tribunals and popular justice*. Sydney: Federation Press; 1997. p. i–vii [1–229 p].
- [32] Johns AF. Person-centered planning in guardianship: a little hope for the future. *Utah LR* 2012;2012(3):1541–73.
- [33] Boundy M, Fleischner B. Supported decision making instead of guardianship: an international overview Washington: TASC [Training & Advocacy Support Center]. National Disability Rights Network; 2013.
- [34] Cripps DA. The social gradient of adult guardianship in South Australia. *Psychiatr Psychol Law* 2015, <http://dx.doi.org/10.1080/13218719.2014.960030> [forthcoming].
- [35] Sabatino C, Wood E. The conceptualization of capacity of older persons in Western law. In: Doron I, Soden A, editors. *Beyond elder law*. Dordrecht: Springer; 2012. p. 35–55.
- [36] Devereux J, Parker M. Competence issue for young persons and older persons. In: Freckelton I, Peterson K, editors. *Disputes and dilemmas in health law*. Sydney: Federation Press; 2006. p. 55–76.
- [37] Weisstub D. *Enquiry on mental competency: final report*. Toronto: Publications Ontario; 1990.
- [38] Flynn E, Arstein-Kerslake A. The support model of legal capacity: fact, fiction, or fantasy? *Berkeley J Int Law* 2014;32(1):134–281.

- [39] Pathare S, Shields L. Supported decision-making for persons with mental illness: a review. *Public Health Rev* 2012;34(2):1–40.
- [40] Gooding P. Supported decision-making: a rights-based disability concept and its implications for mental health law. *Psychiatr Psychol Law* 2012;20(3):431–51.
- [41] Devi N. Supported decision-making and personal autonomy for persons with intellectual disabilities: Article 12 of the UN Convention on the Rights of Persons with Disabilities. *J Law Med Ethics* 2013;41(4):792–806.
- [42] Weller P. Supported decision-making and the achievement of non-discrimination: the promise and paradox of the disabilities convention. *Law Context* 2008;26(2):85–110.
- [43] Gooding P. Supported decision-making: a disability and human rights-based concept for mental health law. Melbourne: Monash University; 2014 [PhD D thesis].
- [44] Gordon R. The emergence of assisted (supported) decision-making in the Canadian Law of adult guardianship and substitute decision-making. *Int J Law Psychiat* 2000;23:61–77.
- [45] Kohn NA, Blumenthal JA. A critical assessment of supported decision-making for persons aging with intellectual disabilities. *Disabil Health J* 2014;7(1):S40–3.
- [46] Kohn NA, Blumenthal JA, Campbell AT. Supported decision-making: a viable alternative to guardianship? *Penn LR* 2013;117(4):1111–57.
- [47] Power A, Lord J, deFranco A. Active citizenship and disability: implementing the personalisation of support. Cambridge: Cambridge University Press; 2013.
- [48] Hall M. Mental capacity in the (civil) law: capacity, autonomy and vulnerability. *McGill LJ* 2012;58(1):61–94.
- [49] Bach M, Kerzner L. A new paradigm for protecting autonomy and the right to legal capacity. Toronto: Law Commission of Ontario; 2010.
- [50] Harmon L. Falling off the vine: legal fictions and the doctrine of substituted judgment. *Yale LJ* 1990;100(1):1–71.
- [51] Carney T. Guardianship, citizenship, & theorizing substitute-decisionmaking law. In: Doron I, Soden A, editors. *Beyond elder law: new directions in law and ageing*. Berl: Springer; 2012. p. 1–17.
- [52] Carney T. Participation & service access rights for people with intellectual disability: a role for law? *J Intellect Dev Disabil* 2013;38(1):59–69.
- [53] Carney T, Beupert F. Public and private bricolage-challenges balancing law, services & civil society in advancing CRPD supported decision making. *UNSWLJ* 2013;36(1):175–201.
- [54] Carney T. Supporting people with cognitive disability with decision making: any Australian law reform contributions? *Res Pract Intellect Dev Disabil* 2015;2(2), <http://dx.doi.org/10.1080/23297018.2015.1020852> [pre-print].
- [55] Advance directives: disputes and dilemmas. Stewart C, Freckelton I, Peterson K, editors. *Disputes and dilemmas in health law*. Sydney: Federation Press; 2006. p. 38–53.
- [56] Ambrosini DL, Latimer E. Preferences for instructional or proxy advance directives in mental health: an exploratory mixed methods study. *J Ethics Ment Health* 2012;5(1):1–19.
- [57] Atkinson J, Garner H, Gilmour H. Models of advance directives in mental health care: stakeholder views. *Soc Psychiatry Psychiatr Epidemiol* 2004;39(8):673–80.
- [58] Matsumura K. Binding future selves. *LA Law Rev* 2014;75(1):71–125 [Available at SSRN: <http://ssrn.com/abstract=2510220>].
- [59] White B, Willmott L, Then S-N. Adults who lack capacity: substitute decision-making. In: White B, McDonald F, Willmott L, editors. *Health Law in Australia*. Sydney: Thompson Reuters Lawbook Co; 2014. p. 193–253.
- [60] Kohn NA. Elder empowerment as a strategy for curbing the hidden abuses of durable powers of attorney. *Rutgers Law Rev* 2006;59(1):1–53.
- [61] Arstein-Kerslake A. An empowering dependency: exploring support for the exercise of legal capacity. *Scand J Disabil Res* 2014:1–16 [ahead-of-print].
- [62] Burns F. The changing patterns of total intestacy distribution between spouses and children in Australia and England. *UNSWLJ* 2013;36(2):470–513.
- [63] Carney T, Tait D. Adult guardianship: narrative readings in the “shadow” of the law? *Int J Law Psychiatry* 1998;21:147–62.

Supported Decision-Making: A Viable Alternative to Guardianship?†

Nina A. Kohn,* Jeremy A. Blumenthal** & Amy T. Campbell***

Abstract

The law has traditionally responded to cognitive disability by authorizing surrogate decision-makers to make decisions on behalf of disabled individuals. However, supported decision-making, an alternative paradigm for addressing cognitive disability, is rapidly gaining political support. According to its proponents, supported decision-making empowers individuals with cognitive challenges by ensuring that they are the ultimate decision-maker but are provided support from one or more others, giving them the assistance they need to make decisions for themselves. This article describes supported

† This article was supported by a grant from the Administration on Aging and the National Institute on Disability & Rehabilitation Research. An earlier version of this article was presented at a conference entitled *Aging with a Disability: Demographic, Social, and Policy Considerations* organized by the Center for Aging and Policy Studies at Syracuse University and the Michigan Center on the Demography of Aging at the University of Michigan and held at the U.S. Department of Health & Human Services in May 2012. Another version was circulated for discussion at an October 2012 roundtable entitled *Beyond Guardianship: Supported Decision-Making by Individuals with Intellectual Disabilities*, hosted at the New York City Surrogates Court by the American Bar Association (ABA) Commission on Disability Rights and the ABA Commission on Law and Aging, in cooperation with the Administration on Intellectual and Developmental Disabilities in the Administration for Community Living, U.S. Department of Health and Human Services. The authors extend thanks to those participating in the above conference and roundtable for their insights, and to Lisa Iezzoni and Arlene Kanter for their helpful comments on earlier drafts.

* Professor and Judith Greenberg Seinfeld Distinguished Faculty Fellow, Syracuse University College of Law. J.D., Harvard Law School; A.B., Princeton University.

** Professor, Syracuse University College of Law. J.D., University of Pennsylvania Law School; A.B., A.M., Ph.D., Harvard University.

*** Associate Professor, Center for Bioethics and Humanities and Department of Psychiatry, Upstate Medical University. M. Bioethics, University of Pennsylvania; J.D., Yale Law School; B.A., University of Notre Dame.

decision-making and its normative appeal. It then provides a descriptive account of how supported decision-making works based on the empirical literature on supported decision-making as well as that on shared decision-making, a related model used in medical contexts. The article shows how employing supported decision-making in lieu of guardianship, or integrating it into the guardianship system, has the potential to promote the self-determination of persons with intellectual and cognitive disabilities consistent with international and national legal norms. However, we find that, despite much rhetoric touting its advantages, little is known about how supported decision-making processes operate or about the outcomes of those processes. Further research is necessary to design and develop effective supported decision-making systems. We therefore propose a series of research questions to help inform policy choices surrounding supported decision-making.

Table of Contents

I.	INTRODUCTION	1113
II.	THE CALL FOR SUPPORTED DECISION-MAKING.....	1114
	A. The Current Approach: Surrogate Decision-Making	1115
	B. The Paradigm Shift: Supported Decision-Making	1120
	1. Models of Supported Decision-Making	1121
	2. Proposals for Integrating Supported Decision-Making into U.S. Legal Systems	1124
	3. The Appeal of Supported Decision-Making	1126
III.	THE EVIDENCE BASE FOR SUPPORTED DECISION-MAKING.....	1128
	A. Research on Supported Decision-Making Utilization.....	1130
	1. Frequency of Utilization	1130
	2. Demographics of Principals	1132
	3. Demographics of Supporters.....	1134
	4. Impact of Race and Ethnicity.....	1135
	B. Research on Supported Decision-Making Outcomes.....	1135
	1. Process Outcomes	1136
	2. Substantive Outcomes.....	1138
	a. Psychological Impacts on Principals	1138
	b. Congruency Between Wishes and Decisions.....	1140
	c. Quality of Decisions Made	1141
	d. Psychological Impact on, and of, Supporters.....	1143
	3. Effect of Individual Differences and Context on Outcomes	1144
	a. Individual Factors	1144
	b. Contextual Factors	1146
IV.	IMPLICATIONS OF RESEARCH ON SHARED DECISION-MAKING	1146
V.	NEXT STEPS	1154
VI.	CONCLUSION	1157

I. INTRODUCTION

While all people can struggle to reach satisfying decisions, persons with intellectual and cognitive disabilities face additional and often profound challenges when doing so. The U.S. legal system has historically responded to these challenges by creating mechanisms that authorize others to make decisions for persons with intellectual and cognitive disabilities. The most powerful and important of these surrogate decision-making mechanisms is a guardianship proceeding, in which a court appoints a third party to make decisions for a person with a disability.

The use of surrogate decision-making and guardianship, however, is coming under increasing criticism from disability rights advocates and scholars who urge replacing it—or at least supplementing it—with a process called “supported decision-making.” Proponents of supported decision-making tout it as a means to empower persons with disabilities by providing them with help in making their own decisions, rather than simply providing someone to make decisions for them. Their impassioned call to replace surrogate decision-making (sometimes referred to as “substitute decision-making”) with supported decision-making is rapidly gaining political momentum. This momentum is attributable in part to the adoption of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which includes language that embraces supported decision-making and which is seen by some as requiring nations to adopt supported decision-making mechanisms.

Despite the growing interest in supported decision-making, this article represents the first systematic attempt to evaluate the claims and arguments made by its promoters. Whereas previous writing on the topic has focused almost exclusively on the normative arguments in favor of supported decision-making, we seek to inform the supported decision-making debate by determining how its processes actually operate in practice. To do so, we not only analyze the limited empirical literature on supported decision-making but also draw insight from the literature on “shared decision-making,” a related approach that has been promoted in medical settings. Our review of this literature allows us to identify what policymakers need to know about supported decision-making in order to determine whether it should be incorporated into surrogate decision-making processes, used in lieu of surrogate decision-making processes, or rejected altogether.

We conclude that, although supported decision-making presents an appealing alternative to guardianship and therefore policymakers in the United States should give serious consideration as to how it might be incorporated into public policy, there is currently insufficient empirical

evidence to know the extent to which (or the conditions under which) it can remedy the problems posed by surrogate decision-making processes. Specifically, we find that, despite years of use, there is almost no evidence as to how decisions are actually made in supported decision-making relationships; the effect of such relationships on persons in need of decision-making assistance; or the quality of the decisions that result. Without more information, it is impossible to know whether supported decision-making actually empowers persons with cognitive and intellectual disabilities. Furthermore, there is reason to be concerned that supported decision-making might actually have the opposite effect, disempowering such individuals or making them more vulnerable to manipulation, coercion, or abuse. Therefore, in addition to making policy recommendations, we suggest a series of research questions designed to increase the likelihood that policymakers will have the information they need to evaluate supported decision-making and the claims of its proponents.

This article proceeds in four major Parts. Part II explores criticisms of the U.S. legal system's current approach to addressing decision-making challenges faced by persons with cognitive and intellectual disabilities, the ways in which implementation of supported decision-making could fundamentally alter that approach, and the normative arguments in favor of such a shift. Part III explores the empirical literature on supported decision-making and not only discusses what that literature shows but also identifies the important questions this literature fails to answer.¹ Part IV then suggests how research on shared decision-making (a related decision-making paradigm) might inform policy and research on supported decision-making. Finally, Part V makes a series of recommendations for policy and future research.

II. THE CALL FOR SUPPORTED DECISION-MAKING

Individuals with intellectual disabilities (ID) or other forms of cognitive disability can face significant decision-making challenges. Some of these challenges are the result of their underlying disabilities, which make analytical and other cognitive tasks more difficult for them. Other challenges are the result of their social environment. For example, stereotypical thinking about persons with ID may result in their being

1. A condensed review of the findings from the empirical literature on supported decision-making can be found in Nina A. Kohn & Jeremy A. Blumenthal, *A Critical Assessment of Supported Decision-Making for Persons with Intellectual Disabilities*, *DISABILITY & HEALTH J.* (forthcoming 2013), published in conjunction with the May 2012 conference noted above.

denied the opportunity to develop and practice decision-making skills.² These decision-making challenges typically increase and evolve as such individuals grow older. For example, the primary source of decision-making assistance for persons with ID is typically their parents.³ Existing decision-making systems can become destabilized and may even disappear as these parents themselves age and increasingly predecease their children. As a result, persons with ID may be confronted with the need to establish new systems for obtaining the help they need in making everyday decisions. In addition, such transitions may precipitate the need to make momentous life decisions,⁴ such as the decision of where to live after the death of a parent with whom the person with ID resided.⁵

In this Part, we describe the legal system's current approach to addressing the decision-making challenges faced by such individuals and the growing critique of that approach. We then explore how such challenges might be addressed under an alternative, supported decision-making paradigm in which a person with the disability is the ultimate decision-maker but receives support from other people as well. Specifically, we provide an overview of supported decision-making, the arguments in favor of its use, and the potential advantages it might afford persons with cognitive and intellectual disabilities.

A. *The Current Approach: Surrogate Decision-Making*

The U.S. legal system's primary response to the decision-making challenges faced by persons with cognitive and intellectual disabilities is to provide for the appointment of surrogate (or "substitute") decision-

2. See Barbara L. Ludlow, *Life After Loss: Legal Ethical and Practical Issues*, in AGING, RIGHTS AND QUALITY OF LIFE: PROSPECTS FOR OLDER PEOPLE WITH DEVELOPMENTAL DISABILITIES 189, 197 (Stanley S. Herr & Germain Weber eds., 1999) (suggesting that decision-making is a skill that can be learned); ROBERT M. LEVY & LEONARD S. RUBENSTEIN, THE RIGHTS OF PEOPLE WITH MENTAL DISABILITIES 106 (1996) (noting that many persons with ID "are frequently not allowed to participate in decision making to the extent of their abilities").

3. See CHRISTINE BIGBY, AGEING WITH A LIFELONG DISABILITY 193 (2004).

4. Both types of challenges are exacerbated by the fact that many families do not adequately plan for these transitions. See Tamar Heller & John Kramer, *Involvement of Adult Siblings of Persons with Developmental Disabilities in Future Planning*, 47 INTELL. & DEVELOPMENTAL DISABILITIES 208, 208 (2009) (citing research indicating that only between 25% and 50% of families of adults with developmental disabilities have made plans for future living arrangements); BIGBY, *supra* note 3, at 204 ("Most studies show that only between one-third and one-half of parents make concrete plans for the future of an adult with intellectual disability who is living at home.").

5. Cf. BIGBY, *supra* note 3, at 161 (stating that most adults with intellectual disabilities live with their parents "well into middle age" and showing how parental aging and death precipitate difficult decisions about housing).

makers for them. Typically, the appointment is made through a guardianship proceeding, a court proceeding in which a judge appoints a third party (called a “guardian”) to make some or all decisions on behalf of an incapacitated individual (called a “ward”).⁶ Indeed, many states effectively encourage guardianship over persons with ID by creating special, streamlined processes for obtaining guardianship over persons with ID or developmental disabilities that are not available for persons with other disabilities.⁷ These specialized processes can reduce the barriers to obtaining guardianship and can also encourage the use of plenary guardianships—those that cover all types of decisions, as opposed to decisions about select issues, such as finances.⁸

Although guardianship is the most comprehensive method for legally empowering surrogate decision-makers, other surrogate decision-making mechanisms also exist. Some states have created processes by which third parties can make surrogate decisions for persons with ID without specific court authorization. For example, New York State empowers panels of four volunteers (which by law must include both a health care professional and an attorney) to make major medical treatment decisions in state-operated or state-licensed facilities.⁹ The Social Security Administration can appoint a third party (called a “representative payee”) to manage an individual’s public benefits

6. As state law governs the guardianship process, its procedural requirements vary somewhat from state to state. Key differences include how states define “incapacity” for the purposes of imposing a guardianship, how states select a guardian for a ward, the extent and nature of state supervision over the guardian once appointed, and the extent and nature of due process protections provided to would-be wards. Guardianship proceedings are initiated by an interested party who files a petition with the appropriate court, alleging that an individual cannot make all or some decisions on his own behalf and that, therefore, the state should appoint a guardian to make decisions for him. This triggers a court fact-finding process to determine whether a guardianship should be imposed and, if so, who should serve as guardian. As the result of such a proceeding, a court can deny the petition, grant a plenary guardianship, or grant a limited guardianship. In a plenary guardianship, the ward is completely stripped of his or her legal decision-making capacity; in a limited guardianship, by contrast, the ward retains certain forms of decision-making power. Some states also differentiate between guardianship over the person (in which the guardian is granted the right to make personal and health care decisions for the ward) and conservatorship (in which the guardian is granted the right to make financial decisions for a ward). Increasingly, however, the term “guardianship” is used to refer to both situations. See NINA A. KOHN, *ELDER LAW: CASES, PROBLEMS, EXERCISES* (forthcoming 2013).

7. See, e.g., ALA. CODE § 12-13-21 (2012); N.Y. Surr. Ct. Proc. Act § 1750 (2012).

8. For one court’s thoughtful and disconcerting explanation of the issue, see *In re Chaim A.K.*, 885 N.Y.S.2d 582 (N.Y. Surr. Ct. 2009) (discussing the difference between the Article 17-A guardianship and Article 81 guardianship in New York).

9. See NY MENTAL HYG. L. art. 80 (McKinney’s 2013); see also LEVY & RUBENSTEIN, *supra* note 2, at 107.

without triggering a court process. In addition, despite misconceptions to the contrary, many persons with cognitive and intellectual disabilities can themselves appoint surrogate decision-makers by executing powers of attorney or advance directives for health care.¹⁰

Even so, in recent years, disability rights scholars and advocates, both in the United States and internationally, have challenged the appropriateness and acceptability of guardianship for persons with disabilities, especially those with ID. One concern is that guardianship law is frequently misapplied, with significant consequences for individuals' basic civil rights and civil liberties.¹¹ The guardianship system is designed as a last resort, applied only when an individual lacks capacity to make decisions. However, there is reason to believe that guardianships are imposed on many individuals without sufficient evidence of their decision-making incapacity¹² and that, in some cases, disability alone appears to be used as a sufficient justification for the imposition of guardianship.¹³ Thus, rather than being treated as the extraordinary proceedings that they are, guardianships are often treated

10. See GARY L. STEIN, U.S. DEP'T OF HEALTH & HUMAN SERVS., *ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING FOR PEOPLE WITH INTELLECTUAL AND PHYSICAL DISABILITIES* (2007), available at <http://aspe.hhs.gov/daltcp/reports/2007/adacp.htm> (discussing the ability of persons with ID to engage in advance care directives); Marshall Kapp, *Health Care DecisionMaking*, in *AGING, RIGHTS AND QUALITY OF LIFE*, *supra* note 2, at 45, 53 (stating that "many older adults with mental retardation are capable and, with adequate and timely counseling, desirous of executing a proxy directive when a close family member or friend is available to serve in the surrogate role," and noting that less capacity may be needed to appoint a surrogate decision-maker than to make the ultimate health care decision the surrogate is appointed to make).

11. See, e.g., *Guardianship*, THE ARC (Oct. 29, 2009), <http://www.thearc.org/page.aspx?pid=2351> ("Guardianship has been over-used by those who were unaware of less intrusive alternatives or who simply wanted to have their views prevail over the wishes of the individual. Frequently, lesser forms of legal intervention, such as limited guardianship and use of powers of attorney or advance directives, have been either overlooked, intentionally avoided, or unavailable.").

12. See PAMELA B. TEASTER ET AL., *WARDS OF THE STATE: A NATIONAL STUDY OF PUBLIC GUARDIANSHIP 15-16* (2005) (discussing research and evidence on the misuse of guardianship, including a 1994 national study by the Center for Social Gerontology finding that the majority of guardianship hearings last less than 15 minutes); Lawrence A. Frolik, *Guardianship Reform: When the Best is the Enemy of the Good*, 9 STAN. L. & POL'Y REV. 347, 354 (1998) (noting that, "as long as the law permits plenary guardianship, courts will prefer to use it[.]" even though plenary guardianship is only appropriate in a sub-set of cases, and urging those promoting guardianship reform to prioritize educating judges about limited guardianship).

13. See Dorothy Squatrito Millar, *Age of Majority, Transfer of Rights and Guardianship: Consideration for Families and Educators*, 38 EDUC. & TRAINING IN DEVELOPMENTAL DISABILITIES 378, 390 (2003) (noting that "disability alone does not equate with incapacity resulting in a need for guardianship," despite a tendency to treat it as such).

as a routine part of permanency planning for persons with ID.¹⁴ Significant reforms have been implemented to reduce the overbreadth of guardianship orders by encouraging the use of limited guardianships in lieu of plenary ones; nevertheless, these reforms have had remarkably little effect on judicial behavior.¹⁵ The result is that guardianships—including plenary guardianships—appear to be routinely granted over persons with ID.

The excessive use of guardianship and, in particular, the use of excessively broad guardianship orders is a problem that is not limited to wards with ID.¹⁶ However, the over-imposition of guardianship may be an especially acute problem for persons with ID because guardianship proceedings are frequently treated as a central part of permanency planning for adults with ID.¹⁷ Moreover, caregivers of persons with ID may be pushed to apply for guardianship in order to access or manage benefits. For example, provisions in the Individuals with Disabilities Education Act (IDEA) encourage parents to obtain guardianship over their children with ID in order to continue to manage their children's public education benefits after they reach the age of majority.¹⁸

Another criticism is that the guardianship system in its current form is unlawful even if properly applied. Specifically, some critics have assailed the concept of guardianship as inconsistent with Article 12 of the CRPD.¹⁹ Article 12 states that “persons with disabilities enjoy legal

14. See Ludlow, *supra* note 2, at 198 (“Assignment of a guardianship to parents is all too often a rite of passage for people with developmental disabilities as they enter adulthood.”); BIGBY, *supra* note 3, at 203-04 (2004) (describing guardianship as part of the standard practice of planning for the future of persons with ID).

15. See Frolik, *supra* note 12, at 349, 354 (explaining that limited guardianships are rarely ordered, even when legally appropriate); Pamela B. Teaster et al., *Wards of the State: A National Study of Public Guardianship*, 37 STETSON L. REV. 193, 233 (2007) (reporting, based on a national study, that “[c]ourts rarely appoint the public guardian as a limited guardian”).

16. Jennifer Moye et al., *Clinical Evidence in Guardianship of Older Adults Is Inadequate: Findings from a Tri-State Study*, 47 GERONTOLOGIST 604 (2007) (in a study of guardianships of people age 55 and older, discussing the larger problem of inadequate clinical bases for guardianship).

17. See sources cited *supra* note 14 and accompanying text.

18. Millar, *supra* note 13, at 390 (noting that the IDEA states that students are to be decision-makers once they reach the age of majority unless they are considered to be incompetent).

19. See Michael L. Perlin, “*Striking for the Guardians and Protectors of the Mind*”: *The Convention on the Rights of Persons with Mental Disabilities and the Future of Guardianship Law*, 117 PENN STATE L. REV. 1159, 1177 (2013) (“The Convention forces us to abandon substituted decisionmaking paradigms and to replace them with supported decisionmaking ones.”); TINA MINKOWITZ, SUBMISSION TO THE COMMITTEE ON THE RIGHTS OF PERSONS WITH DISABILITIES, DAY OF GENERAL DISCUSSION ON CRPD ARTICLE 12 (2010) (declaring guardianship and all other forms of substituted decision-making to be contrary to the CRPD); cf. Robert D. Dinerstein, *Implementing Legal Capacity Under*

capacity on an equal basis with others in all aspects of life.”²⁰ Some have interpreted this Article as inconsistent with state removal of legal capacity through the guardianship system,²¹ or at least with plenary guardianship.²² Arguably, overuse of guardianships also constitutes disability discrimination in violation of the Americans with Disabilities Act (ADA) insofar as individuals are not provided with reasonable, less restrictive alternatives to guardianship.²³

A third concern is that guardianship is anti-therapeutic.²⁴ Guardianship need not mean that wards are not involved in making decisions about their lives.²⁵ Current systems, however, do not promote such involvement²⁶ and may leave wards feeling isolated and lonely.²⁷

Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making, 19 HUM. RTS. BRIEF 8 (2012) (discussing different countries’ responses to Article 12 in relation to guardianship).

20. Convention on the Rights of Persons with Disabilities (CRPD) art. 12, G.A. Res. 61/106, U.N. Doc. A/RES/61/106 (Dec. 13, 2006). Notably, this is a departure from the approach of the 1971 Declaration of the Rights of Mentally Handicapped, which stated that “the mentally retarded person has a right to a qualified guardian when this is required to protect his personal well-being and interests.” ANDREAS DIMOPOULOS, ISSUES IN HUMAN RIGHTS PROTECTION OF INTELLECTUALLY DISABLED PERSONS 69 (2010).

21. See Amita Dhanda, *Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?*, 34 SYRACUSE J. INT’L L. & COM. 429, 460-62 (2007) (arguing that, while the language of Article 12 does not prohibit substituted decision-making, reading Article 12 in light of the process that led to its creation supports interpreting it as doing so).

22. See Barbara Carter, *Adult Guardianship: Human Rights or Social Justice?*, 18 J.L. & MED. 143 (2010), available at http://www.publicadvocate.vic.gov.au/file/file/Research/Adult_Guardianship.pdf (describing the active debate over whether Article 12 permits guardianship). But see Dhanda, *supra* note 21, at 460-61 (arguing that the CRPD should be read as promoting the recognition that persons with disabilities have full legal capacity but acknowledging that “[t]he text of Article 12 does not prohibit substituted decision-making and there is language which could even be used to justify substitution”).

23. See Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. COLO. L. REV. 157 (2010) [hereinafter Salzman, *Rethinking Guardianship*] (arguing that the United States’ current approach to guardianship violates the ADA’s mandate that services be provided in the most integrated and least restrictive manner).

24. See, e.g., Jennifer Wright, *Guardianship for Your Own Good: Improving the Well-Being of Respondents and Wards in the USA*, 33 INT’L J.L. & PSYCHIATRY 350 (2010) (discussing a variety of ways in which guardianship can be anti-therapeutic).

25. Pamela Teaster, *The Wards of Public Guardians: Voices of the Unbefriended*, 51 FAM. RELATIONS 344, 348 (2002) (in a qualitative study interviewing 13 wards of public guardians, finding that four contributed to decisions about daily activities).

26. *Id.* (in a qualitative study interviewing 13 wards of public guardians, finding that there was an absence of documentation in wards’ case files about wards’ “needs and wishes, such as a values history”).

27. *Id.* (in a qualitative study interviewing 13 wards of public guardians, finding such sentiments common); Salzman, *Rethinking Guardianship*, *supra* note 23, at 163 (describing guardianship as creating “constructive isolation”).

Guardianship may also undermine wards' physical and psychological well-being by reducing their sense of control over their own lives.²⁸ Ironically, such anti-therapeutic effects may be the cost of obtaining needed, or at least beneficial, services and support. For example, The Arc, a leading advocacy and service organization for persons with intellectual and development disabilities, explains that caregivers may feel forced into obtaining guardianship over a person with ID in order to help the individual access medical care and other supports.²⁹

Finally, there is a moral critique of surrogate decision-making, and especially guardianship, as an affront to the humanity of those subject to it. For example, Canadian disability rights advocate Michael Bach has declared guardianship to be "[s]tate-sanctioned removal of personhood from an individual with respect to one or more or all areas of personal decision-making."³⁰ Others have characterized imposition of guardianship as a form of "civil death."³¹

B. *The Paradigm Shift: Supported Decision-Making*

In light of these serious concerns, critics of guardianship and surrogate decision-making have suggested replacing that approach with "supported decision-making." As a general matter, supported decision-making occurs when an individual with cognitive challenges is the ultimate decision-maker but is provided support from one or more persons who explain issues to the individual and, where necessary, interpret the individual's words and behavior to determine his or her preferences.³² However, some advocates do not use the term "supported decision-making" this broadly. Instead, they reserve the term for situations in which the person being supported has voluntarily entered into the arrangement, and these advocates use terms like facilitated decision-making and co-decision-making to describe other versions of

28. See Wright, *supra* note 24, at 355-56 (arguing that guardianship may harm individuals by reducing their sense of control).

29. See THE ARC, *supra* note 11.

30. Michael Bach, PowerPoint, *Legal Capacity, Personhood and Supported Decision Making*, Can. Ass'n for Cmty Living (U.N. Enable Working Group, Jan. 2006), available at <http://www.un.org/esa/socdev/enable/rights/ahc7docs/ahc7ii3.ppt>.

31. See, e.g., Perlin, *supra* note 19, at 1162 (endorsing this view, at least with regard to the use of guardianship in certain jurisdictions).

32. See UNITED NATIONS ENABLE, HANDBOOK FOR PARLIAMENTARIANS ON THE CONVENTION OF RIGHTS OF PERSONS WITH DISABILITIES ch. 6 (2007), available at <http://www.un.org/disabilities/default.asp?id=212> (providing a parallel but longer definition); MICHAEL BACH & LANA KERZNER, A NEW PARADIGM FOR PROTECTING AUTONOMY AND THE RIGHT TO LEGAL CAPACITY (2010), available at <http://www.lco-cdo.org/disabilities/bach-kerzner.pdf>.

supported decision-making.³³ Further confusing the definition of supported decision-making is the fact that many of the statutory schemes widely described as enabling supported decision-making have features that are inconsistent with how its promoters typically define supported decision-making. For example, as noted below, there is a tendency to describe supported decision-making as providing the principal with full control over what decisions are made, even when the underlying law provides exceptions to this approach.³⁴

1. Models of Supported Decision-Making

There is no single model of supported decision-making.³⁵ Supported decision-making can be purely informal—something done without legal sanction or legal enforceability. Alternatively, it can be formalized through a private but legally enforceable or legally significant agreement between the person with a disability and a trusted third party. Such formalized supported decision-making relationships, in turn, may be pre-existing relationships to which the state gives legal recognition,³⁶ or they may be new relationships created for the purpose of providing state-sanctioned support.

Perhaps the most frequently cited model of supported decision-making is British Columbia's Representation Agreement. British Columbia is one of several Canadian provinces that have statutorily enabled private contracts as alternatives to guardianship.³⁷ In British Columbia, an adult may enter into a Representation Agreement that

33. For a discussion of these different definitions, see LANA KERZNER, *PAVING THE WAY TO FULL REALIZATION OF THE CRPD'S RIGHTS TO LEGAL CAPACITY AND SUPPORTED DECISION-MAKING: A CANADIAN PERSPECTIVE* (2011), available at http://www.anth.ubc.ca/fileadmin/user_upload/CIC/documents/In_From_The_Margins_Paper-Lana_Kerzner-FINAL-April_22_2011_2_.pdf; BACH & KERZNER, *supra* note 32.

34. See, e.g., BACH & KERZNER, *supra* note 32, at 90 (recognizing the reasonableness limitation in the British Columbia model but then stating that the supporter in that system is always bound by the wishes and instructions of the principal). In addition, while most definitions of supported decision-making do not include (and indeed, often explicitly exclude) the use of advance planning tools by which a person appoints a surrogate decision-maker (e.g., health care proxies and durable powers of attorney), even this is not uniformly the case. See Soumitra Pathare & Laura S. Shields, *Supported Decision-Making for Persons with Mental Illness: A Review*, 34 PUB. HEALTH REVS. 1, 4 (2012) (describing such advance planning tools as a form of supported decision-making).

35. See Leslie Salzman, *Guardianship for Persons with Mental Illness—A Legal & Appropriate Alternative?*, 4 ST. LOUIS U. J. HEALTH L. & POL'Y 279, 306 (2011) [hereinafter Salzman, *Guardianship for Persons*].

36. See Terry Carney, *Participation and Services Access Rights for People with Intellectual Disability: A Role for Law?*, 38 J. INTELL. & DEVELOPMENTAL DISABILITY 59, 60 (2013) (noting that supported decision-making is frequently described as simply recognizing existing social structures).

37. See BACH & KERZNER, *supra* note 32, at 53.

authorizes a third party to act on his or her behalf for a broad range of personal decisions as well as many, but not all, financial decisions. The person creating the Agreement retains his or her full legal capacity, can revoke the Agreement at any time, and must be consulted by the representative.³⁸ There is only a minimal capacity requirement³⁹ to enter into a standard Representation Agreement (*i.e.*, one that does not delegate certain powers, such as the ability to make decisions about placement in a nursing home or refusal of life-sustaining treatment),⁴⁰ and there is a presumption that all people are capable of entering into one absent a showing to the contrary.⁴¹ Consequently, a person who would not have sufficient capacity to execute an enduring power of attorney or other form of contract may enter into a standard Agreement.⁴²

Ordinarily, under the British Columbia approach, a representative acting according to a Representation Agreement must, consistent with common conceptions of supported decision-making, consult with the principal and comply with his or her wishes.⁴³ Even so, the model actually empowers a representative to act in a way inconsistent with full self-determination for the principal: statutorily, the representative need only consult with the principal “to the extent reasonable”⁴⁴ and need only comply with the principal’s wishes “if reasonable to do so.”⁴⁵ This is one example of ways in which the description of these models by those calling for supported decision-making is somewhat inconsistent with the underlying statutes governing these models.⁴⁶

38. In British Columbia, the charity Nidus Personal Planning Resource Centre helps individuals form Representation Agreements, and its website is a valuable explanatory resource. See *Representation Agreement*, NIDUS, http://www.nidus.ca/?page_id=50/ (last visited Mar. 22, 2013).

39. See Representation Agreement Act, R.S.B.C. 1996, ch. 405, pt. 2.8 (Can.) (providing that an adult may enter into a standard Representation Agreement despite being “incapable of (a) making a contract, (b) managing his or her health care, personal care or legal matters, or (c) the routine management of his or her financial affairs”).

40. See *id.* pt. 2.4 (simply stating that “[a]n adult may make a representation agreement unless he or she is incapable of doing so” but not defining what it means to be incapable of doing so).

41. See *id.* pt. 1.3 (“Until the contrary is demonstrated, every adult is presumed to be capable of (a) making, changing or revoking a representation agreement, and (b) making decisions about personal care, health care and legal matters and about the routine management of the adult’s financial affairs.”).

42. See *id.* pt. 2.8 (setting forth the test of incapability for standard agreements).

43. See *id.* pt. 3.16 (setting forth the duties of the representative).

44. Representation Agreement Act, R.S.B.C. 1996, ch. 405, pt. 3.16 (Can.).

45. *Id.*

46. See, e.g., BACH & KERZNER, *supra* note 32, at 90 (recognizing the reasonableness limitation in the British Columbia model but then stating that the supporter in that system is always bound by the wishes and instructions of the principal).

Although supported decision-making is typically presented as involving a single decision-making supporter, private supported decision-making relationships may also occur in the context of a “circle of support” or a “microboard.” A circle of support is a group of people, typically family members and friends, who meet regularly with a person with a disability to help that person formulate and realize his or her hopes or desires. Circles of support are seen as a way of creating or re-invigorating a support network for a person with a disability,⁴⁷ which may be especially important for persons with ID experiencing generational transitions in their support network. A microboard is similar to a circle of support in that it is also comprised of a group of people who aim to help an individual meet his or her needs in a manner consistent with his or her hopes and desires. However, the term “microboard” is typically used to refer to organizations that are more formal: non-profit organizations formed to support and, in some cases, to act as the service provider for an individual with a disability.⁴⁸ To the extent that a circle of support helps a person understand various life choices and choose among them, or that a microboard is structured to allow the person with a disability to direct its actions (*e.g.*, such as by having that individual serve as the President of the Board),⁴⁹ both approaches can be mechanisms for implementing supported decision-making. By contrast, if the members of a micro-board or circle of support ultimately make decisions on behalf of the person with a disability—even if they consult with that person and consider the person’s wishes—then such arrangements should not be classified as supported decision-making.

Alternatively, supported decision-making can be accomplished through public appointment.⁵⁰ For example, Sweden provides for the

47. See, *e.g.*, Allison Rowlands, *Ability or Disability?: Strengths-based Practice in the Area of Traumatic Brain Injury*, 82 *FAMILIES IN SOC.* 273, 274 (2001) (describing circles of support as “a contrived, purpose-built friendship network, established and facilitated by a worker or trained volunteer, to replace or re-invigorate the natural network of a person whose disability may have led to former friends dropping away . . .”).

48. For a discussion of the work and impact of three successful microboards, see Paul H. Malette, *Lifestyle Quality and Person-Centered Support: Jeff, Janet, Stephanie, and the Microboard Project*, in *PERSON-CENTERED PLANNING* 151 (Steve Holburn & Peter M. Vietze eds., Paul Brooks Publishing 2002).

49. For descriptions of microboards and their structures, see JACKIE L. GOLDEN, INCLUSION RESEARCH INST., *SELF-DIRECTED SUPPORT CORPORATIONS* (n.d.), available at <http://www.reinventingquality.org/docs/golden.pdf>; Kristi Dezonis, *Microboards: An Option in Life Span Supports*, 39 *THE EXCEPTIONAL PARENT* 56 (2009).

50. See Salzman, *Guardianship for Persons*, *supra* note 35, at 307-09 (dividing supported decision-making approaches into two major groups: private agreement approaches and court-appointed approaches).

appointment of a *god man*, which translates roughly as “good man” or “mentor,” who can provide many of the services that a guardian would provide in the United States. Appointment of a *god man* does not affect the legal capacity of the recipient. The *god man* concept contains a central paradox: the *god man* is said to act with the consent of the person with cognitive challenges and to be limited in his or her ability to act without that consent; however, the *god man* can be appointed without consent and for an individual who lacks capacity to provide consent.⁵¹ The Canadian province of Saskatchewan takes an approach similar to that of Sweden, but one that works through the court system instead of through municipal government.⁵² Specifically, Saskatchewan authorizes its courts to appoint a co-decision-maker for personal and/or property decisions for people whose cognitive capacity is impaired to the extent that they require assistance.⁵³ Unlike a guardian, the co-decision-maker must “acquiesce in any decision made by the adult provided that a reasonable person could have made that decision and the decision is not likely to result in a loss to the adult’s estate.”⁵⁴ Co-decision-makers are also explicitly required to maximize the participation of the person they assist in decisions with which they are assisting.⁵⁵

2. Proposals for Integrating Supported Decision-Making into U.S. Legal Systems

Just as there are a variety of supported decision-making models, the call to formalize supported decision-making takes several forms. First, there have been proposals to integrate supported decision-making into existing guardianship structures. The 2011 National Guardianship Network convened the Third National Guardianship Summit, an interdisciplinary consensus conference that brought together experts from across the United States. The Summit released a series of recommendations for guardianship reform that implicitly called for the incorporation of supported decision-making components into the existing

51. Stanley S. Herr, *Self-Determination, Autonomy, and Alternatives for Guardianship*, in THE HUMAN RIGHTS OF PERSONS WITH INTELLECTUAL DISABILITIES: DIFFERENT BUT EQUAL 429, 433 (Stanley S. Herr et al. eds., 2003).

52. See Doug Surtees, *The Evolution of Co-Decision-Making in Saskatchewan*, 73 SASK. L. REV. 75 (2010) (describing Saskatchewan’s system).

53. See BACH & KERZNER, *supra* note 32, at 55 (distinguishing co-decision making from supported decision making on the grounds that the subject does not voluntarily enter into the arrangement); Surtees, *supra* note 52 (describing when appointment of a co-decision maker is authorized under Saskatchewan law).

54. Surtees, *supra* note 52, at 85.

55. See *id.*

guardianship system.⁵⁶ Many of the recommendations took the form of recommended “standards,” calling for the ward to be involved in decision-making about his or her life. The recommendations included an overall call for guardians to engage in “person-centered planning,” defined by the Summit as an approach that seeks to “discover, understand, and clearly describe the unique characteristics of an individual,” with the aim of ensuring that an individual is supported in a “web of relationships,” is valued for his or her contributions to the community, and has control over his or her own life.⁵⁷ Supportive elements were also incorporated into a number of more specific standards. For example, in the context of residential decisions, the Summit recommended that guardians “do everything possible to help the person express his or her goals, needs or preferences” if he or she has difficulty doing so.⁵⁸ In the context of financial decision-making, the Summit recommended that wards be “encourage[d] . . . to act on [their] own behalf and to participate in decisions,”⁵⁹ and be assisted in developing or regaining capacity to make decisions.⁶⁰ Second, some have called for establishing supported decision-making structures as an alternative to guardianship, thereby diverting some or most would-be wards into an alternative model.⁶¹ This approach is consistent with the concept of guardianship as a last resort. As Salzman has observed,

56. Cf. Kristin Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship & Beyond*, 44 COLUM. HUM. RTS. L. REV. 93 (2012) (describing how supported decision-making principles came to be incorporated into the Summit’s recommendations).

57. Symposium, *Third National Guardianship Summit Standards and Recommendations*, 2012 UTAH L. REV. 1191, 1192 (2012).

58. *Id.* at 1197.

The guardian shall identify and advocate for the person’s goals, needs, and preference. Goals are what are important to the person about where he or she lives, whereas preferences are specific expressions of choice. First, the guardian shall ask the person what he or she wants. Second, if the person has difficulty expressing what he or she wants, the guardian shall do everything possible to help the person express his or her goals, needs, and preferences. Third, only when the person, even with assistance, cannot express his or her goals and preferences, the guardian shall seek input from others familiar with the person to determine what the individual would have wanted. Finally, only when the person’s goals and preferences cannot be ascertained, the guardian shall make a decision in the person’s best interest. *Id.*

59. *Id.* at 1194.

60. *Id.*

61. See, e.g., Salzman, *Guardianship for Persons*, *supra* note 35 (arguing that states should embrace supported decision-making as an alternative to guardianship and that doing so may be required by the Americans with Disabilities Act); Glen, *supra* note 56 (arguing that guardianship should be reserved for only the most extreme cases of incapacity, and showing why fewer cases may satisfy this criterion than commonly thought).

guardianship cannot truly be a last resort unless there are meaningful alternatives to it.⁶² Notably, there is overlap between these two approaches in that a jurisdiction could both create supported decision-making alternatives to guardianship and incorporate supported decision-making elements into guardianship proceedings.⁶³

Finally, some advocates and scholars have recommended that the court-based guardianship system be abolished in favor of supported decision-making mechanisms, while others have called for abolishing plenary guardianship in favor of supported decision-making but would accept retaining limited guardianship.⁶⁴ Either approach would be a departure from the current practice in countries seen as models for supported decision-making, as all retain guardianship as a safety net.⁶⁵

3. The Appeal of Supported Decision-Making

Despite this variation in types of calls for supported decision-making, they all share a common recognition that persons with cognitive and intellectual disabilities typically require more support to make decisions than persons without such disabilities, and embrace a role for

62. Salzman, *Guardianship for Persons*, *supra* note 35, at 312.

63. See OFFICE OF THE PUB. ADVOCATE, SUPPORTED DECISION-MAKING: BACKGROUND AND DISCUSSION PAPER 17 (2009) (stating that “[m]any of the principles of supported decision-making can be incorporated into guardianship legislation[.]” but also suggesting the adoption of supported decision-making alternatives to guardianship).

64. See, e.g., EUR. COMM’R H.R., ISSUE PAPER, WHO GETS TO DECIDE? RIGHT TO LEGAL CAPACITY FOR PERSONS WITH INTELLECTUAL AND PSYCHOSOCIAL DISABILITIES (2012), available at <https://wcd.coe.int/ViewDoc.jsp?id=1908555> (advocating for abolishment of plenary guardianship); Nandini Devi et al., *Moving Towards Substituted or Supported Decision-Making? Article 12 of the Convention on the Rights of Persons with Disabilities*, 5 EUR. J. DISABILITY RES. 249 (2011); DIMOPOULOS, *supra* note 20, at 46-47 (calling the “basic form of guardianship” unsatisfactory and stating that it must be “replaced by a legal framework of both protection and support, which will be offered non-coercively and tailored to meet the needs of each person with intellectual disability”); MENTAL DISABILITY ADVOCACY CTR. & ASS’N OF SOC. AFFIRMATION OF PEOPLE WITH MENTAL DISABILITIES, OUT OF SIGHT: HUMAN RIGHTS IN PSYCHIATRIC HOSPITALS AND SOCIAL CARE INSTITUTIONS IN CROATIA 12, 14, 57 (2011), available at http://www.mdac.info/sites/mdac.info/files/croatiareport2011_en.pdf (recommending that guardianship be abolished in Croatia, but then apparently limiting this recommendation to the abolishment of plenary guardianship); Dhanda, *supra* note 21, at 460-62 (arguing that guardianship is a result of prejudice and is inconsistent with Article 12 of the CRPD); Bach, *supra* note 30.

65. Salzman, *Guardianship for Persons*, *supra* note 35, at 311. For example, while Sweden does not have a system called “guardianship,” its “administrator” system is effectively a guardianship system. Indeed, Herr describes the administrator system as essentially identical to guardianship except that the subject retains capacity to vote. See Herr, *supra* note 51. Yet, in a number of U.S. states, wards retain their right to vote. See Sally Balch Hurme & Paul S. Appelbaum, *Defining and Assessing Capacity to Vote: The Effect of Mental Impairment on the Rights of Voters*, 38 MCGEORGE L. REV. 931, 950-57 (2007).

the state in providing or facilitating that support. This recognition is consistent with current understandings of the challenges faced by persons with such disabilities. While individuals with cognitive and intellectual disabilities tend to have preferences as to their daily living arrangements, they may need extensive support to understand the options they have relative to those preferences and to understand how to effectuate their wishes.⁶⁶ For example, a study of adults with learning disabilities being cared for by elderly caregivers found that it was difficult for some participants to consider and talk about housing arrangements if their parents died or became too ill.⁶⁷ In part, the need for additional support reflects such individuals' underlying disability. It also, however, may reflect the fact that individuals with ID often have little experience making important life decisions for themselves because they have been given few opportunities to do so.⁶⁸

The concept of supported decision-making is therefore appealing from multiple perspectives. From a civil rights perspective, it recognizes the personhood of persons with cognitive and intellectual disabilities and avoids stripping them of their fundamental freedoms. It is also consistent with the CRPD's call for states to provide access to the support that persons with disabilities "may require in exercising their legal capacity."⁶⁹ From a disability rights perspective, the supported decision-making model is consistent with the social model of disability that sees disability as socially constructed and seeks to avoid the use of disabling labels such as "incompetent." Adoption of supported decision-making has been described as presenting "an opportunity to re-imagine the disabled legal subject"⁷⁰ and may thus have political and symbolic value in and of itself. From a public health perspective, supported decision-making has the potential to improve the overall physical and psychological well-being of persons with cognitive and intellectual disabilities by creating a sense of empowerment, which in turn has been linked to positive health outcomes. In short, a move toward supported

66. Laura Bowey & Alex McGlaughlin, *Adults with a Learning Disability Living with Elderly Carers Talk about Planning for the Future: Aspirations & Concerns*, 35 BRIT. J. SOC. WORK 1377, 1386 (discussing the "need for adults with learning disabilities to be given extensive support and accessible information in exploring options in order that they can make informed choices about their future plans").

67. *Id.*

68. LEVY & RUBENSTEIN, *supra* note 2, at 106 (noting that many persons with ID "are frequently not allowed to participate in decision making to the extent of their abilities"); Ludlow, *supra* note 2, at 197 (discussing the experience of loss for persons with developmental disabilities and suggesting that decision-making is a skill that can be learned).

69. See CRPD, *supra* note 20.

70. See Carney, *supra* note 36, at 62.

decision-making may have both symbolic and instrumental value from a variety of perspectives.⁷¹

Despite its appeal, however, the call for supported decision-making raises significant policy questions, as well as descriptive empirical ones. First and foremost, it raises concerns about whether supported decision-making mechanisms can in fact achieve the lofty goals set out for them and, if so, how. For example, how can supporters effectively empower individuals with cognitive and intellectual disabilities to make decisions on their own behalf? How can supported decision-making systems ensure that they are truly voluntary and minimize the risk that they will subject persons with disabilities to new forms of coercion? In advocating for a move toward supported decision-making as an alternative to guardianship, Salzman has described supported decision-making models as having four primary characteristics: (1) the individual retains legal decision-making authority; (2) the relationship is freely entered into and can be terminated at will; (3) the individual actively participates in decision-making; and (4) decisions made with support are generally legally enforceable.⁷² This is, however, a normative description, and the question is whether it is empirically supported. Accordingly, Part III explores the evidence base for supported decision-making.

III. THE EVIDENCE BASE FOR SUPPORTED DECISION-MAKING

Perhaps surprisingly for a model in its second decade of development, there is little empirical evidence directly evaluating supported decision-making. Indeed, a number of recent discussions of supported decision-making note the lack of, and need for, empirical evidence that evaluates the different models of supported decision-making.⁷³ Even articles that provide extensive discussions of the benefits

71. *Cf. id.* (suggesting that the move toward supported decision-making should be “highly . . . commended on the basis of its *symbolic* significance” despite concerns that it may be in reality “de facto” guardianship) (emphasis in original).

72. Salzman, *Guardianship for Persons*, *supra* note 35, at 306-07.

73. *See, e.g.*, NIDUS, A STUDY OF PERSONAL PLANNING IN BRITISH COLUMBIA: REPRESENTATION AGREEMENTS WITH STANDARD POWERS 4 (2010), *available at* www.nidus.ca/PDFs/Nidus_Research_RA7_InAction.pdf (“There is a need for qualitative research to gain insight into the motivations and experiences of adults and their personal supporters with respect to the making and using of Representation Agreements with standard powers.”); OFFICE OF THE PUB. ADVOCATE, *supra* note 63, at 8 (“Supported decision-making is presently quite loosely defined and articulated and there is very little material in literature or policy to draw on.”); Wendy Harrison, Representation Agreements in British Columbia: Who is Using Them and Why? 2 (unpublished M.A. thesis, Simon Fraser University) (2008) (“To date, there has been no research undertaken in British Columbia examining the use of representation agreements.”); *Improving Supported Decision Making*, VICTORIAN L. REFORM COMM’N

and potential drawbacks of supported or co-decision-making provide little or no empirical support for their claims.⁷⁴ This dearth of empirical literature is not unique to supported decision-making; there is also surprisingly little evaluative empirical literature on guardianship.⁷⁵ Nevertheless, this lack of evidence is unfortunate not only because it means that we do not know whether supported decision-making is achieving its goals but also because it makes it difficult to develop and support effective evidence-based supported decision-making practices. In this Part, we therefore identify some of the potential contexts in which supported decision-making could and should be evaluated moving forward, noting the existing research and incorporating additional findings. The overarching questions are whether supported decision-making achieves its goals and whether it achieves such goals better than existing practices such as guardianship models.

In discussing the existing and needed research on supported decision-making, we find it helpful to distinguish between two key types of research questions. First, there are questions related to the utilization of supported decision-making (*e.g.*, what are the demographic characteristics of those involved, and how common are such arrangements?). Second, there are questions about the outcomes of the supported decision-making process. Outcomes, in turn, can be divided into process-oriented outcomes on the one hand and substantive outcomes on the other, a distinction that serves as a useful tool in identifying existing research and in prompting further research.⁷⁶

(June 1, 2011), <http://www.lawreform.vic.gov.au/journal-articles/improving-supported-decision-making> (calling for submissions providing opinions and evidence as to benefits of supported or co-decision making); Pathare & Shields, *supra* note 34, at 27, 30 (exploring research on supported decision-making—very broadly defined—for persons with mental illness and concluding that the research on supported decision-making is limited and that more research is “urgently needed”).

74. See *e.g.*, Devi et al., *supra* note 64; Sarah Burningham, *Developments in Canadian Adult Guardianship and Co-Decision-Making Law*, 18 DALHOUSIE J. LEGAL STUD. 119 (2009).

75. See Linda S. Whitton & Lawrence A. Frolik, *Surrogate Decision-Making Standards for Guardians: Theory and Reality*, 2012 UTAH L. REV. 1491 (2012) (describing the lack of empirical literature on how guardians make decisions on behalf of wards); TEASTER ET AL., *supra* note 12, at 15 (noting that there is little empirical literature on guardianship provisions); see also CTR. FOR ELDERLY & THE COURTS, NAT'L CTR. FOR STATE COURTS, ADULT GUARDIANSHIP COURT DATA AND ISSUES: RESULTS FROM AN ONLINE SURVEY 8 (2010), available at http://www.guardianship.org/reports/Guardianship_Survey_Report.pdf (“Recent attempts at collecting state data on guardianships have demonstrated the absence of meaningful data.”).

76. See Nina A. Kohn & Jeremy A. Blumenthal, *Designating Health Care Decisionmakers for Patients Without Advance Directives: A Psychological Critique*, 42 GA. L. REV. 979, 1008-10 (2008) (making the distinction and discussing tradeoffs

A. *Research on Supported Decision-Making Utilization*

Understanding how supported decision-making systems are being utilized has the potential to help identify those populations that might benefit from or desire decision-making support, and thus those populations to whom resources and services related to supported decision-making might be most profitably directed. Understanding the gaps in knowledge about supported decision-making utilization can also serve to target much-needed further empirical research. Accordingly, in this Section we identify research, and, more importantly, gaps in research, on the rate at which existing supported decision-making systems are utilized, and the demographic composition of both the individuals receiving decision-making support (*i.e.*, “principals”) and those appointed to provide that support (*i.e.*, “supporters”).

1. Frequency of Utilization

One fundamental question about supported decision-making is how often individuals make use of supported decision-making arrangements where they are currently available. Whether because of differences in actual utilization, reporting, or the populations making use of such arrangements, estimates of such rates vary substantially. For instance, Surtees identified a small number of cases filed under Saskatchewan’s Adult Guardianship and Co-decision-making Act (2001), about 500 in approximately a seven-year period.⁷⁷ He found that more than 90 percent of applications seeking some sort of support under the Act asked for a guardian to be appointed to help with decisions regarding person or property; only about seven percent (30/446) applied to have a co-decision-maker appointed.⁷⁸ By contrast, a review of Representation Agreements in British Columbia conducted by Nidus Personal Planning Resource Centre and Registry⁷⁹ identified far more Agreements over a three-and-a-half-year period: almost 1,000 Agreements requesting a representative to help with standard decisions.⁸⁰

between process outcomes and substantive outcomes in the context of default surrogate statutes).

77. Surtees, *supra* note 52, at 92. Surtees noted that the cases he reviewed did not include 83 closed cases placed in storage that he was unable to access. *Id.*

78. *Id.* Surtees did not report further individuating information about the cases. *Id.*

79. Nidus is a nonprofit organization that provides training and assistance to those interested in forming such agreements. *See supra* note 38.

80. *Id.* (identifying 989 Representation Agreements with standard powers). Under the relevant Act, “standard powers” can include personal care, routine management of financial affairs, or certain health care decisions. Non-standard (or Section 9) Agreements grant broader authority to the representative, especially in the health-care context, and include the authority to override some decisions by the principal.

Neither study, however, allows for a good estimate of the rate of uptake among those subsets of the population for which they are touted as advantageous. This is because neither study identified the population out of which these counts were made, *i.e.*, whether 500 or 1,000 represented a large proportion of those who might be eligible for assistance under the relevant legislation. The Nidus study also did not compare the rate of those choosing standard Agreements with the rate of those selecting non-standard ones, perhaps because this number is not clear either. One unpublished study (a master's thesis by Harrison) identified approximately 600 individuals in British Columbia who had entered in Section 9 (non-standard) Agreements as of mid-2007, with a final sample of 93 individuals.⁸¹

Thus, it is difficult to determine to what extent persons with cognitive and intellectual disabilities would utilize supported decision-making if made available in the United States. Moreover, even if we were able to predict what proportion of those who would otherwise be subject to guardianship would likely be diverted to a supported decision-making alternative, we would have difficulty predicting the number of persons likely affected. One reason that it is hard to predict is that it is unknown how many people in the United States are subject to guardianship. Researchers have estimated that approximately 1.5 million people in the United States are subject to guardianship at any given time.⁸² However, the actual numbers are unknown, in part because the guardianship process is state-specific and many states fail to provide the types of records that would enable a national assessment.⁸³

81. Harrison, *supra* note 73, at 22-25.

82. See BRENDA K. UEKERT & RICHARD VAN DUIZEND, NAT'L CTR. FOR STATE COURTS, ADULT GUARDIANSHIPS: A "BEST GUESS" NATIONAL ESTIMATE AND THE MOMENTUM FOR REFORM 107, 108-09 (2011), available at http://www.guardianship.org/reports/Uekert_Van_Duizend_Adult_Guardianships.pdf (estimating that there are 1.5 million guardianships in the United States but suggesting that the actual number could range from 1 to 3 million); Dorothy Squatrito Millar & Adelle Renzaglia, *Factors Affecting Guardianship Practices for Young Adults with Disabilities*, 68 EXCEPTIONAL CHILDREN 465 (2002) (estimating 1.25 million adults under guardianship in the United States); TEASTER ET AL., *supra* note 12 (discussing different estimates and the overall lack of evidence on the frequency of guardianship); ERICA F. WOOD, AM. BAR ASS'N COMM'N ON LAW & AGING FOR THE NAT'L CTR. ON ELDER ABUSE, STATE-LEVEL ADULT GUARDIANSHIP DATA: AN EXPLORATORY STUDY 11 (2006) (discussing different estimates and the overall lack of good numbers on the frequency of guardianship). That number may have increased over the past 25 years. See TEASTER ET AL., *supra* note 12, at 4 (noting a 1988 Associated Press estimate putting the number at 400,000).

83. WOOD, *supra* note 82, at 33-34 (finding that nearly two-thirds of state court administrative offices that responded to a national survey on guardianship did not keep separate data on guardianship cases, and even those that did tended to limit the separate data to that on frequency of filings and dispositions).

Another reason that it is hard to predict the number of persons who could be diverted from guardianship into supported decision-making is that it is also unknown what portion of persons subject to guardianship are persons with ID—the population most frequently discussed as having the potential to benefit from supported decision-making.⁸⁴ However, the United States likely has a sizeable population of persons with ID subject to guardianship. A 2005 survey of public guardianship programs found that those programs providing researchers with adequate information about their wards reported that more than half of such wards had a primary diagnosis of either developmental disability or mental retardation.⁸⁵ The study reported that this finding represented a shift in the guardianship system away from an older adult population to a younger adult population.⁸⁶ However, the study did not examine the diagnoses of wards with private guardians, and it is certainly possible that there are significant differences in the diagnoses of those in private guardianship relationships.⁸⁷

2. Demographics of Principals

Another fundamental question about supported decision-making is what groups of people tend to utilize such arrangements. Unfortunately, there are also few data on the demographic composition of those who enter into supported decision-making relationships as principals. Data from British Columbia⁸⁸ suggest that women are more likely to be principals than are men. Nidus's figures indicate that, when it comes to Representation Agreements involving "standard" provisions, there was a 55 percent to 45 percent disparity between women and men.⁸⁹ Harrison's smaller study suggests, however, that the disparity is even greater when non-standard provisions are involved; the breakdown was

84. *See id.* at 34 (stating that it is unknown what percentage of wards have "mental retardation" or "developmental disabilities").

85. *See TEASTER ET AL.*, *supra* note 12, at 66. Among them, the responding groups had served over 24,000 wards. This figure is based on adding up the figures provided in the "extent of guardianship tables" from Section IV of the report. *See id.* § IV.

86. *See id.* at 95.

87. It is also unknown what percentage of guardians are public guardians, as opposed to family members, friends, or other third parties. *See WOOD*, *supra* note 82, at 34 (lamenting this lack of information). It can be reasonably assumed, however, that most guardians are not public guardians. *Cf. id.* at 12 (referring to a study of guardianships in the San Francisco Probate Court that found 29% of guardians appointed were public guardians).

88. Much of the data discussed herein comes from British Columbia-based studies. This is simply due to a lack of empirical studies from other jurisdictions.

89. NIDUS, *supra* note 73, at 2.

approximately 2:1.⁹⁰ In terms of age, some evidence suggests a bimodal distribution of those who engage representatives, at least ones for Agreements with “standard” provisions. In particular, adults in their 20s were the largest age category of those making such selections (23 percent), with those in their 80s at just under 20 percent.⁹¹ Together, adults over 70 made up about 40 percent of those selecting representatives, while those over 60 made up about 50 percent.⁹² Harrison’s study suggests, however, that those selecting Agreements involving non-standard provisions tend to be older than those selecting Agreements with standard provisions.⁹³ The Harrison study also found that principals involved with non-standard Agreements tended to be married, relatively well-off financially, and relatively educated.⁹⁴

Nevertheless, because supported decision-making is often seen as particularly likely to benefit those with ID, a fundamental concern with these demographic data is that it is unclear how representative they are of individuals with ID. As noted, for instance, Surtees did not distinguish among the cases he reviewed, and it is not evident whether Harrison’s sample included persons with ID,⁹⁵ nor is it clear from the Nidus study that a significant portion (or even any) of the 989 individuals had some form of ID. Thus, if these samples are not representative, then it is harder to draw inferences from the research. That is, on the one hand, finding that individuals without ID make use of supported decision-making would only reinforce the idea that this approach could promote inclusion of persons with ID by offering them the same supports that are used by a broader population. On the other hand, that same finding would give little insight into the important question of the extent to which persons with ID make use of supported decision-making or how supported decision-making can help persons with ID. Thus, further research addressing these basic questions of who uses supported decision-making, and when, is of substantial importance.

90. Harrison, *supra* note 73, at 30 (noting a 62.5% to 37.5% women-to-men split).

91. NIDUS, *supra* note 73, at 2.

92. *Id.* This may be consistent with findings that elderly persons seem to prefer group decision-making by multiple family members. See Suzanne B. Yellen et al., *Communication About Advance Directives: Are Patients Sharing Information With Physicians?*, 1 CAMBRIDGE Q. HEALTHCARE ETHICS 377 (1992).

93. Harrison, *supra* note 73, at 30.

94. *Id.* at 30-32.

95. *Id.* at 36 tbl.1 (setting forth diagnoses of principals and not listing either ID or developmental disability; however, persons with ID may have been included in other categories—*e.g.*, the category of “Alzheimer’s or other dementia”).

3. Demographics of Supporters

Just as it is important to understand who elects to receive support, in order to understand how supported decision-making actually works, it is critical to understand who tends to provide that support. Unfortunately, there are also little data available as to those selected to be supporters. We know that, in the context of surrogate decision-making for health care, patients who execute advance directives (documents that allow someone else to make health care decisions on their behalf in the event that they lose capacity to make those decisions for themselves) overwhelmingly select relatives as proxies or surrogates.⁹⁶ Some evidence suggests a similar trend for the selection of supporters in supported decision-making arrangements. Specifically, close to 90 percent of Agreements in British Columbia appointed a parent, child, sibling, spouse, or other family member as a representative.⁹⁷ Similar to surrogate selection, immediate family took precedence: less than ten percent of representatives were “other family members”—the same percentage as “friends.”⁹⁸ Similar results came from the small sample of non-standard (Section 9) Agreements in British Columbia: over 80 percent of individuals selected a spouse (29 percent) or other family member (54 percent) as the representative, with 17 percent appointing a friend.⁹⁹

Non-relatives, however, appear to be frequently selected as alternative representatives in the British Columbia system, at least for standard Representation Agreements. In this context, the proportion of non-immediate family members (others and friends) rises to about 40 percent. Interestingly, however, when monitors are selected—*i.e.*, someone to oversee the representative—these proportions reverse. Approximately 30 percent of monitors are “other family members” and an equal percentage of monitors are “friends,” perhaps suggesting the desire to have a more objective level of “checks and balances.”¹⁰⁰

The existing information suggests that supported decision-making is likely to occur primarily within families and thus be subject to the attendant family dynamics—dynamics which may or may not be

96. See Kohn & Blumenthal, *supra* note 76, at 990 & n.55.

97. NIDUS, *supra* note 73, at 3. Thus, the representative is probably likely to be the same person who would be selected as a guardian if a guardianship had been pursued instead. Where a guardianship is pursued over a person with ID, the petitioner is typically the allegedly incapacitated person’s parent and, in particular, his or her mother. See Millar, *supra* note 13, at 379 (finding that petitions for guardianship over persons with ID are typically filed by family members, usually mothers).

98. NIDUS, *supra* note 73, at 3.

99. Harrison, *supra* note 73, at 69.

100. NIDUS, *supra* note 73, at 3.

empowering. However, more information on the identities of supporters and their relationships to principals is critical if we are to understand how supporters are selected and the relational context in which supported decision-making is likely to occur.

4. Impact of Race and Ethnicity

None of the empirical studies we identified as discussing supported decision-making addressed any racial demographics. However, such information would be valuable to those evaluating supported decision-making practices because race and ethnicity may affect whether people engage in supported decision-making and who is selected as a supporter. Specifically, racial and ethnic differences exist in patients' approaches to medical decision-making, with members of some groups preferring a more distributed, non-patient-centered approach.¹⁰¹ Members of such groups may be more willing than average to engage in supported decision-making in situations in which the principal would otherwise be expected to make decisions independently, but perhaps less likely than average to see supported decision-making as a desirable alternative to guardianship. Racial and socio-economic status differences also appear in the likelihood of possessing advance directives generally, with white, higher socio-economic status, and more educated individuals more likely to execute advance directives.¹⁰² Thus, some persons belonging to certain racial groups and those with higher socio-economic status may similarly be more likely to enter into supported decision-making arrangements. However, from existing studies, we cannot ascertain whether such differences exist.

B. Research on Supported Decision-Making Outcomes

The most important questions related to supported decision-making are those related to the ability of supported decision-making systems to achieve their goals. In this Section, we therefore analyze the meager existing research on the effect and impact of supported decision-making systems and identify key gaps in that research. To do so, we divide the research into two broad categories: (1) research that provides insight into the process of supported decision-making (*e.g.*, the types of

101. See, *e.g.*, Leslie J. Blackhall et al., *Ethnicity and Attitudes Toward Patient Autonomy*, 274 JAMA 820, 824 (1995).

102. See Rebecca S. Allen & John L. Shuster, Jr., *The Role of Proxies in Treatment Decisions: Evaluating Functional Capacity to Consent to End-of-Life Treatments Within a Family Context*, 20 BEHAV. SCI. & L. 235, 239 (2002); Sarah Forbes et al., *End-of-Life Decision-Making for Nursing Home Residents with Dementia*, 32 J. NURSING SCHOLARSHIP 251, 252 (2000).

discussions that occur in supported decision-making relationships); and (2) research that provides insight into the substantive outcomes of those processes (*e.g.*, the decisions that are reached).

1. Process Outcomes

There is a growing literature addressing how supported decision-making *should* work;¹⁰³ there is far less literature on how it in fact *does* work.¹⁰⁴ Harrison's unpublished thesis examining Representation Agreement arrangements in British Columbia¹⁰⁵ is one of the more thorough descriptive accounts. Harrison found that over 80 percent of individuals she studied spoke with their representative at least several times a week and that nearly half spoke daily.¹⁰⁶ Harrison also inquired into some of the substance of these discussions, focusing on the health care aspects of the discussions. Among other findings, Harrison discovered that about half of the individuals studied had only general discussions with their representatives, but others had discussed specific issues such as life support, organ donation, pain control, or do-not-resuscitate orders.¹⁰⁷ Harrison also found that most of her subjects had discussed "their feelings and values about the types of situations that could arise and what impact that should have on how their representative made treatment decisions."¹⁰⁸ When principals and supporters do discuss values, there may be an increased likelihood that supporters will come to understand, agree with, and share the principal's values, and thus be more likely to effectuate the principal's preferences.¹⁰⁹ Accordingly, Harrison's findings—especially if corroborated by further supported

103. See generally, *e.g.*, Salzman, *Guardianship for Persons*, *supra* note 35; Robert M. Gordon, *The Emergence of Assisted (Supported) Decision-Making in the Canadian Law of Adult Guardianship and Substitute Decision-Making*, 23 INT'L J. L. & PSYCHIATRY 61 (2000).

104. Some research presents case studies of individuals selecting supported decision-making, *e.g.*, Gordon, *supra* note 103, at 64-65; however, the actual decision-making process is not described in any detail.

105. See Harrison, *supra* note 73.

106. *Id.* at 71 tbl.25.

107. *Id.* at 77 tbl.28.

108. *Id.* at 78.

109. Elsewhere, two of us have suggested that surrogate health care decision-makers be selected based on degree of shared values in order to maximize the likelihood of proxies making the treatment decision that matches what a patient would choose. See Kohn & Blumenthal, *supra* note 76, at 1011-12 (suggesting this as an alternative to selection based on familial proximity). But see Carol Matheis-Kraft & Karen A. Roberto, *Influences of a Values Discussion on Congruence Between Elderly Women and Their Families on Critical Health Care Decisions*, 9(4) J. WOMEN & AGING 5, 15 (1997) (noting that prior discussion by competent patients and their proxies rarely led to improved proxy accuracy, but noting methodological limitations in their study).

decision-making research confirming that such discussion occurs regularly—provide reason to be optimistic that supported decision-making will protect individuals' preferences.

Although there is a literature base, albeit limited, on the types of discussions that occur in supported decision-making, we were unable to identify any research on the internal dynamics of those discussions. Even the Harrison study did not discuss the dynamics of particular decisions. This absence presents a significant problem for evaluating the impact and efficacy of supported decision-making.

One of the primary worries, even for those advocating supported decision-making, is the potential for coercion or other inappropriate influence by a representative or supporter.¹¹⁰ Exploitation and abuse certainly occur in guardianship context (although it is unclear how frequently),¹¹¹ and supported decision-making arrangements create new opportunities for abuse. Indeed, when we turn to more informal arrangements such as supported decision-making, which may occur in private and with less accountability, the potential for financial or other abuse likely increases. However, data do not seem available on the incidence of such abuse in the supported decision-making context.

Undue influence can occur even if the supporter or representative may not deliberately set out to take advantage of or influence the principal decision-maker, leading him or her to a desired outcome. Through particular issue-framing, inaccurate assessment of the principal's preferences, or simple conversational style, a discussion may easily be led one way or another to an outcome that does not accurately reflect the principal's preferences. Both kinds of undue influence, moreover, might be facilitated by third parties mistakenly assuming that supporters have decisional power and thus erroneously elevating supporters' opinions or wishes above those of principal.¹¹²

In addition to undue influence resulting from deliberate coercion or unconscious influence by the supporter, undue influence may also

110. See OFFICE OF THE PUB. ADVOCATE, *supra* note 63, at 25 (“Supported decision-making does open up the possibility of conflict, undue influence, abuse and exploitation.”); Salzman, *Guardianship for Persons*, *supra* note 35, at 309 (noting the difficulty of assisting someone in making a decision “without inappropriately influencing her final decision” and noting importance of protecting decision-maker from being “harmful or exploited within, or as a result of, the support arrangement”); Gordon, *supra* note 103, at 75 (noting potential for abuse or undue influence).

111. U.S. GOV'T ACCOUNTABILITY OFFICE, GAO-10-1046, CASES OF FINANCIAL EXPLOITATION, NEGLECT, AND ABUSE OF SENIORS 5 (2010) (identifying “hundreds of allegations” of abuse of seniors under guardianship as well as confirming cases); Naomi Karp & Erica F. Wood, *Guardianship Monitoring: A National Survey of Court Practices*, 37 STETSON L. REV. 143, 150 (2007).

112. Cf. Carney, *supra* note 36 (discussing this possibility).

originate in deliberate deference by the principal decision-maker. That is, some research on surrogate health care decision-making suggests that older adults tend to prefer trusting a surrogate decision-maker rather than expressing a treatment preference themselves.¹¹³ To the extent this deference occurs in the supported decision-making context, a substantial part of the model's goals would be subverted. Unfortunately, however, the little evidence regarding the dynamics of the supported decision-making process does not allow investigation of whether and how this might occur. Evidence is also needed regarding the incidence of undue influence, coercion, or abuse in these arrangements, as well as regarding what risk factors exist that might encourage such influence and what structures might help to discourage it.

2. Substantive Outcomes

In assessing supported decision-making, perhaps the most important questions, and the most difficult, are: (1) how to ensure that a decision arrived at through supported decision-making truly expresses and effectuates the wishes or preferences of the person with intellectual or cognitive disability; and (2) whether such decisions are more beneficial to the person with a disability compared to decisions made using other approaches (*e.g.*, decisions made without support, by a guardian, or by another form of surrogate decision-maker).

a. Psychological Impacts on Principals

There is reason to suspect that the interactive, dynamic results of the supported decision-making process may have beneficial psychological consequences for the participants, especially persons with ID. For instance, there is some evidence that the guardianship model can lead to feelings of disempowerment and loss of control on the principal's part because he or she is not involved in the relevant decision-making.¹¹⁴ A more shared process where the supporters or representatives are generally, if not explicitly, seen as assisting¹¹⁵ may ameliorate this perception.¹¹⁶ Similarly, under the guardianship model, relegating an

113. Steven H. Miles et al., *Advance End of Life Treatment Planning: A Research Review*, 156 ARCH. INTERNAL MED. 1062, 1063 (1996).

114. See Teaster, *supra* note 25, at 348 (in a qualitative study interviewing 13 wards of public guardians, finding such sentiments common); Salzman, *Rethinking Guardianship*, *supra* note 23, at 163 (describing guardianship as creating "constructive isolation").

115. *E.g.*, Gordon, *supra* note 103, at 62-63.

116. See Nina A. Kohn, *Elder Empowerment as a Strategy for Curbing the Hidden Abuses of Durable Powers of Attorney*, 59 RUTGERS L. REV. 1, 44 (2006) (identifying

individual to “ward” status, making clear that another party has been appointed explicitly to make that individual’s decisions, may stigmatize the individual not only in his or her own eyes but also in the eyes of others. The supported decision-making model might counter such perceptions by highlighting that, even with some reduced capacity, an individual with cognitive or intellectual disabilities is nevertheless capable of engaging in, managing, or directing self-relevant decisions in a number of contexts.

As with some of the previous discussion, however, this is primarily speculation. We have insufficient data in the specific supported decision-making context to know whether such benefits are actually realized in supported decision-making. Given the often negative and harmful stereotypes about persons with cognitive and intellectual disabilities, however, and that the desire to address such stereotypes is one reason for the push toward supported decision-making, this too seems a valuable avenue of research.

There is also reason to suspect that supported decision-making may have a positive impact on the cognitive and emotional health of persons with cognitive and intellectual disabilities. Again, Harrison found that principals tended to speak with their representatives at least several times per week (though the substance of those discussions is not evident). The more that such discussions in fact reflected decision-making processes, especially active decision-making by the principal, then the more cognitively active the principal may have been and, as a result, the more cognitively healthy.¹¹⁷ Moreover, to the extent that the supported decision-making relationship enhances the person’s sense of connectedness with others, this too may have psychological benefits.¹¹⁸

Unfortunately, it is also possible that supported decision-making could have a negative impact on principals’ psychological well-being. To the extent that such relations do facilitate undue influence or

psychological studies suggesting circumstances that can lead to a benefit in the principal’s sense of control when assisted in making decisions).

117. Cf. Michael Valenzuela & Perminder Sachdev, *Can Cognitive Exercise Prevent the Onset of Dementia? Systematic Review of Randomized Clinical Trials with Longitudinal Follow-Up*, 17 AM. J. GERIATRIC PSYCHIATRY 179, 185-86 (2009) (noting that “cognitive exercise may be an effective strategy for delaying the onset of cognitive impairment in older adults”).

118. See Sarah H. Ailey et al., *Evaluating an Interpersonal Model of Depression Among Adults with Down Syndrome*, 20 RES. & THEORY FOR NURSING PRACTICE: AN INT’L J. 229, 241-42 (2006) (reporting that loneliness and social isolation are common among persons with Down syndrome and/or developmental disabilities and that these may increase such individuals’ risk for depression); BIGBY, *supra* note 3, at 116-19 (discussing the importance of social networks for the psychological well-being of persons with ID).

exploitation, as some fear, they may undermine individuals' senses of control and well-being. Similar results might occur if entering into a supported decision-making relationship is not voluntary but rather something foisted on the person with a disability, as some have warned may occur.¹¹⁹

b. Congruency Between Wishes and Decisions

As the Office of the Public Advocate in Victoria, Australia, aptly explained in its 2009 Discussion Paper on supported decision-making, “[L]iterature on supported decision-making speaks of discerning the will and preferences of the person and of assisting the person to make and communicate preferences and choices. There is often the implication that the if [sic] the person’s will, preferences and wishes are expressed, they are actually making the decision.”¹²⁰ Yet, as the report went on to explain:

A key issue in supported decision-making is how and whether a person can be supported to make their own decisions by assisting them with those elements of decision-making where they have difficulty. How does the group decide whether the decision is a valid decision? Can a person be assisted through information, emotional support or in some other way to make their own decisions if they do not have, for example, an appreciation of the significance of the decision they are making or a reasonably consistent set of values?¹²¹

In other words, there is a potentially unavoidable paradox in acknowledging that a person has diminished decision-making capacity but maintaining that he or she is nevertheless capable of meaningfully contributing to decision-making discussions and that the decisions that result from such discussions reflect his or her wishes. Similarly, how does one avoid a similar paradox in maintaining that a person can make that decision with assistance unless one is confident that person has a “consistent set of values” to ground such a decision?

Determining whether supported decision-making helps persons achieve their wishes is further complicated by the fact that there are multiple ways of defining those wishes, and it may not be clear—even to the person with the cognitive or intellectual disability—what those wishes are. For example, people in general have significant difficulty with “affective forecasting,” that is, with predicting both their own and

119. See Carney, *supra* note 36, at 62.

120. OFFICE OF THE PUB. ADVOCATE, *supra* note 63, at 23.

121. *Id.*

others' future emotional states, reactions, and preferences.¹²² Moreover, a person may have preferences for certain procedures either in addition to, or even in lieu of, preferences for certain outcomes of those procedures. That is, individuals sometimes prefer that decisions be made via some particular process; if decisions are in fact made via that process, then the individuals are less concerned about the actual outcome.¹²³ In such cases, there is the possibility that a supported decision-making system will yield a process that is consistent with principals' wishes without yielding a substantive outcome that is consistent with their wishes. The crucial question then becomes whether the system should be considered to be effectuating their wishes. Some might argue that establishing that supported decision-making provides a satisfactory process for these persons might be as, if not more, important than addressing the success of the decisions that emerge. However, allowing process to be the sole criterion for evaluating the success of such decision-making could result in treating the process as a success even when it results in decisions that the principal perceives to be (or that objectively are) substantively harmful.

c. Quality of Decisions Made

We found no research evaluating the quality of decisions reached using supported decision-making. This lack of research may reflect the fact that it is very difficult to evaluate decision quality. Evaluating a particular decision (whether made through supported decision-making or

122. Jeremy A. Blumenthal, *Law and the Emotions: The Problems of Affective Forecasting*, 80 IND. L.J. 155, 217-22 (2005) (noting implications of affective forecasting research for euthanasia and advance directives). For instance, people do not consider the possibility of inaccurate assessment of their own preferences or the likelihood that their preferences may change based on future circumstances. As two of us have noted elsewhere, such difficulties can call into question the accuracy or value of decisions that are made by simply imagining what a future situation will be like. See Kohn & Blumenthal, *supra* note 76, at 995. Studies that ask prospective decision-makers to speculate about future preferences may mis-state their findings to the extent that those difficulties are not considered. More important, actual decisions (supported or not) that do not consider these possibilities may inaccurately predict preferences at some later time.

123. This point again draws on research in advance directive and surrogate decision-making contexts. See Kohn & Blumenthal, *supra* note 76, at 1007-10; Dallas M. High, *Standards for Surrogate Decision-Making: What the Elderly Want*, 17 J. LONG TERM CARE ADMIN. 8, 11 (1989) (elders seemed more interested in whom to select as a surrogate than in which standard the surrogate would use for making decisions about them); Angela Fagerlin et al., *The Use of Advance Directives in End-of-Life Decision-Making: Problems and Possibilities*, 46 AM. BEHAV. SCIENTIST 268, 278 (2002) (some decision-makers seem "less concerned with the specific treatment decisions that are made than about having the decisions made by someone they trust").

otherwise) involves establishing a criterion against which the decision can be measured. Thus, both policy- and data-driven research will be necessary in developing appropriate criteria by which to evaluate decisions obtained through supported decision-making processes. The most obvious standards include whether a decision increases an individual's welfare in some way. For example, evaluators might ask whether the decision maintains the individual's autonomy or capacity for self-determination, allows him or her to pursue work, leads to profitable management of his or her finances, or avoids detrimental health outcomes.

In evaluating decision-making quality, it is important to recognize that the goal of reaching decisions that are in the best interest of the person with a disability may come into tension with other values that supported decision-making processes seek to promote, such as autonomy, self-determination, and dignity.¹²⁴ For example, allowing or even encouraging a person with cognitive or intellectual disability to "learn from mistakes" may undermine efforts to protect that person from harmful outcomes. Ultimately, the decision as to how to balance such tensions is one for legislative bodies or, if they decline to do so, supporters. For example, legislation might permit a supporter not to acquiesce in a decision that might negatively affect a principal's estate (as in Saskatchewan)¹²⁵ or that is not "reasonable" (as in British Columbia).¹²⁶

In order to determine how best to address such tensions when they arise, it would be helpful to have empirical evidence on issues such as the extent to which such individuals truly might learn from their mistakes,¹²⁷ the value they (or their supporters) may in fact attach to such personhood factors, and the likelihood that supporters will feel comfortable either allowing a decision that may be harmful, or "interfering" to redirect such a decision.¹²⁸

Assessing the relative quality of decisions made using supported decision-making, moreover, will require more than simply determining whether it yields a beneficial or effective outcome. It will also require

124. "It is easy to say that a person has the right to make unwise decisions and that there is dignity in risk. . . . It is less easy to determine whether the person understands the risks or can foresee the consequences of their decision," and thus who should make the decision. OFFICE OF THE PUB. ADVOCATE, *supra* note 63, at 23.

125. See *supra* note 54 and accompanying text.

126. Representation Agreement Act, R.S.B.C., c. 405, pt. 3.16 (1996) (Can.) (setting forth the duties of the representative).

127. Cf. Jeremy A. Blumenthal, *Emotional Paternalism*, 35 FLA. ST. U. L. REV. 1, 70-72 (2007) (suggesting the difficulty of learning from mistakes even for persons without cognitive or intellectual disabilities).

128. See OFFICE OF THE PUB. ADVOCATE, *supra* note 63, at 23.

comparing the quality of decisions made using supported decision-making to those made by guardians. There are a number of ways such comparisons could be investigated. For instance, researchers could identify some decisions involved in actual supported decision-making interactions and then present the facts involved—facts regarding both the decision to be made and the individual and her circumstances—to a mock or actual guardian. That guardian would render a decision that could then be compared to the outcome of the actual supported decision-making decision. Other paradigms might be developed, of course, but the important point is that empirical research comparing supported decision-making and guardian decision-making will be useful in evaluating supported decision-making (as well as guardianship).

d. Psychological Impact on, and of, Supporters

Research on how supported decision-making affects those charged with providing support is also needed. Such research might follow a number of related avenues. First, we might investigate the effect of participation on these supporters. Providing care for others often takes a substantial physical and psychological toll on the caregivers. One plausible hypothesis is that any psychological benefits accruing from the supported decision-making model might benefit the supporter as well as the principal, perhaps because the actual participation might be less onerous than “traditional” methods of support or perhaps because of the actual dynamics of the supported decision-making interaction. Another hypothesis, however, might be that continually participating in another person’s decision-making, without the “luxury” of one party or the other simply making the decision, creates more stress on the supporter than might otherwise occur or otherwise be expected. Similarly, we might study the effect of the supported decision-making process on supporters’ psychological characteristics such as locus of control, perceived empowerment, *etc.*

A second line of research might explore who is the most helpful at assisting a person with a cognitive or intellectual disability to reach a beneficial decision¹²⁹—*e.g.*, family members (of varying degrees of proximity), friends, health-care providers, or others. Such research would build upon evidence that in the surrogate decision-making context, different proxies are differentially accurate at discerning and effectuating a patient’s preferences.¹³⁰

129. Again, of course, whether the decision is in fact “beneficial” will depend on which criterion is used.

130. For instance, family members’ decisions are somewhat more accurate than physicians’ decisions, but there is little evidence of differences among family members.

Third, advocates of supported decision-making often note the importance of training and of the development of safeguards, formal and informal, in curbing deliberate or unintentional influence or abuse.¹³¹ It would therefore be helpful to determine whether some supporters are more “trainable” than others and, if so, which ones. It would also be valuable to examine what types of safeguards, and what training in those safeguards, might be most effective in reducing inappropriate influence. Ultimately, the goal of such research would be to develop “adequate and appropriate safeguards” that neither become too burdensome¹³² nor fail to balance an individual’s “freedom of action” with protection against “undue influence, abuse and exploitation.”¹³³ As part of this research into safeguards, we might also recognize that, since third-party monitors may be an important type of safeguard,¹³⁴ such research would ideally inquire into the conditions, if any, under which such monitors are effective and who is best suited to serve as a monitor.

3. Effect of Individual Differences and Context on Outcomes

In addition to the need for broad research on these supported decision-making topics, more focused study would be valuable. The impact and effectiveness of supported decision-making may vary by population and context, and such variations could potentially yield different specific policy recommendations.

a. Individual Factors

One useful approach might examine whether and to what extent supported decision-making outcomes vary by age and disability. As an initial matter, which, if any, of the findings sketched above (or that might result from further research) vary depending on the age of the person with a disability or the type of disability? For example, when might older persons with a certain disability act, feel, or decide differently from younger persons with that disability? Do such decisions, feelings, or actions differ by type of disability? Under what circumstances are older

See Kohn & Blumenthal, *supra* note 76, at 999. Commentators have called for additional research in this context to determine whether non-family members are any better. *Id.* at 999-1000.

131. *See, e.g.*, Salzman, *Guardianship for Persons*, *supra* note 35, at 310 (discussing the need for “adequate training of support personnel, monitors, and those acting as surrogate decision-makers”).

132. *Id.*

133. OFFICE OF THE PUB. ADVOCATE, *supra* note 63, at 25.

134. *See* BACH & KERZNER, *supra* note 32, at 168 (recommending that monitors be included in supported decision-making processes).

individuals, or those with different kinds of disabilities, perceived or treated differently, either by their supporters or representatives, by the public, or by the mental health or judicial systems? If supported decision-making leads to coercive discussion processes (whether intentional or not), or even abuse, does the incidence of such occurrences vary with the principal's age group or type of disability? Do any psychological benefits that accrue from the supported decision-making model accrue differently for older persons, or ones with different types disabilities, and, if so, why?

Other personal characteristics should also be investigated. Socio-economic status, race, and education level often factor into health-related decision-making, especially in the proxy or surrogate contexts;¹³⁵ such characteristics thus warrant consideration as part of future research on supported decision-making. Gender is also an important factor in a number of health-care decision-making contexts, and preliminary evidence suggests some small gender differences in supported decision-making-related areas as well. For instance, Harrison found slight differences in the reasons that men and women enter into Representation Agreements¹³⁶ and found that men and women may have different understandings or expectations of what their representatives will do to effectuate their preferences.¹³⁷ The Nidus study indicated that women undertook a majority of the Agreements described (55 percent to men's 45 percent).¹³⁸

A plethora of psychological personality traits might also be associated with differences in supported decision-making outcomes. One of the most relevant traits might be differences in perceptions of, or locus of, control. Studies seem to show that a more internal sense of control is associated with taking steps toward having an advance directive or other similar initiatives,¹³⁹ which generates at least two research hypotheses: first, that those with an internal sense of control might be more likely to undertake a Representation Agreement or pursue another form of supported decision-making (and, similar to the point above, that those who choose not to engage in supported decision-

135. See *supra* notes 101-02 and accompanying text.

136. Harrison, *supra* note 73, at 64-65.

137. See *id.* at 95.

138. NIDUS, *supra* note 73, at 2.

139. See generally Harrison, *supra* note 73, at 11-12; J. LaPuma et al., *Advance Directives on Admission: Clinical Implications and Analysis of the Patient Self-Determination Act of 1990*, 266 JAMA 402 (1991); K.L. Rodriguez & A.J. Young, *Elderly Veterans' Beliefs Concerning Life-Sustaining Treatment and the Control of their End-of-Life Health and Health Care*, 18 J. AGING & HEALTH 686 (2006); C.B. Rosnick & S.L. Reynolds, *Thinking Ahead: Factors Associated with Executing Advance Directives*, 15 J. AGING & HEALTH 409 (2003).

making would have a lower sense of control); and second, that the shared decision-making of the supported decision-making process might increase a principal's sense of control. Indeed, Harrison found that those who undertook Representation Agreements reported feeling a better sense of control over their futures.¹⁴⁰ Both would seem positive outcomes, especially in light of findings that a higher sense of control can be physically and psychologically beneficial.¹⁴¹

b. Contextual Factors

Finally, just as capacity is generally recognized as varying by context and decision,¹⁴² the circumstances under which supported decision-making will be beneficial and effective likely also vary by context and decision-type. It would be impractical to suggest research into supported decision-making's effectiveness with regard to every different decision in which a person with intellectual or cognitive disability might be involved. As an initial matter, we might therefore focus on those contexts in which those persons might most commonly find themselves. Health-care and financial arrangements seem the most obvious and are, unsurprisingly, the primary focus of legislative responses to the decision-making challenges of persons with intellectual and cognitive disabilities. Nevertheless, as noted at the beginning of this article (and as recognized in some legislation), there is a wide variety of everyday decision-making for which persons with cognitive and intellectual disabilities might invite assistance, and supplemental research on these would be valuable too.

IV. IMPLICATIONS OF RESEARCH ON SHARED DECISION-MAKING

The preceding Part suggested a discouraging dearth of empirical information as to how supported decision-making functions in practice and as to its outcomes. Fortunately, studies of related practices have the potential to provide some insight. In particular, research on shared decision-making in the health-care context is useful—with some

140. Harrison, *supra* note 73, at 40.

141. See Kohn, *supra* note 116, at 44-45 (discussing such findings); Kohn & Blumenthal, *supra* note 76, at 1010 (“Executing an advance directive and expressing one’s desires as part of that process may also help instantiate a sense of control over one’s life and treatment, which can be beneficial for an individual’s mental and physical health.”). *But see* Kohn, *supra* note 116, at 44-45 (acknowledging studies showing circumstances in which sense of control might not be beneficial).

142. See OFFICE OF THE PUB. ADVOCATE, *supra* note 63, at 19; *see also* Lawrence A. Frolik & Mary F. Radford, “Sufficient” Capacity: *The Contrasting Capacity Requirements for Different Documents*, 2 NAELA J. 303 (2006) (discussing the level of capacity required to execute different types of legal documents).

important caveats—because this model shares some key attributes with supported decision-making.

Shared decision-making has been described as an interactive “process in which both the physician and patients participate in the treatment decision-making process,”¹⁴³ involving deliberation to achieve agreement on a treatment choice.¹⁴⁴ Although there has been little consensus on an overarching definition of shared decision-making,¹⁴⁵ there appears to be fairly widespread agreement as to its central features. Shared decision-making involves both clinicians and patients sharing information and—to some extent—values, in the hope of assisting patients to make better decisions.¹⁴⁶ Thus, shared decision-making is seen as a way to promote patient self-determination, the primary value that guides health care decision-making in the United States,¹⁴⁷ while

143. Cathy A. Charles et al., *Shared Treatment Decision Making: What Does It Mean To Physicians?*, 21 J. CLINICAL ONCOLOGY 932, 932 (2003) [hereinafter Charles et al., *Shared Treatment*]; Isabelle Scholl et al., *Measurement of Shared Decision Making—A Review of Instruments*, 105 Z. EVID. FORTBILD. QUAL. GESUNDHEITWESEN (ZEFQ) 313 (2011).

144. Cathy Charles et al., *Decision-Making in the Physician-Patient Encounter: Revisiting the Shared Treatment Decision-Making Model*, 49 SOC. SCI. & MED. 651, 656 (1999) [hereinafter Charles et al., *Physician-Patient Encounter*]; see also Charles et al., *Shared Treatment*, *supra* note 143, at 932 (discussing essential characteristics of shared decision-making, including need to share not only information but also the process of decision-making with patient). We recognize that, at times, the dyad may involve a health care professional other than a physician. However, the physician is typically the focus of this empirical literature and is typically the other authority regarding treatment decisions.

145. N. Mounjid et al., *Shared Decision Making in the Medical Encounter: Are We All Talking About the Same Thing?*, 27 MED. DECISION MAKING 539, 539 (2007) (noting lack of common definitions of shared decision-making and inconsistent definitions within articles). Charles et al. attribute the divergence in definitions or lack of conceptual clarity to differences in patient and physician roles, how and when each should be involved, and what should be shared. See Charles et al., *Shared Treatment*, *supra* note 143, at 932. Noting the “murkiness” in such definitions, Makoul and Clayman developed an integrative model building on existing conceptions of shared decision-making. See G. Makoul & M.L. Clayman, *An Integrative Model of Shared Decision Making in Medical Encounters*, 60 PATIENT EDUC. & COUNSELING 301 (2006). Their model identified essential elements (*e.g.*, eliciting patient preferences and values, sharing physician knowledge and recommendations, making a decision) and ideal elements (*e.g.*, presenting evidence, reaching mutual agreement) of shared decision-making, and noted general qualities (*e.g.*, partnership, deliberation/negotiation). See *id.* at 305 tbl.3.

146. See Charles et al., *Shared Treatment*, *supra* note 143 (specifically defining shared decision-making by its four critical characteristics: involving at least two parties (physician and patient); both parties sharing information; both parties taking steps to reach consensus around the preferred option; and reaching mutual agreement); Makoul & Clayman, *supra* note 145.

147. See, *e.g.*, Cathy Charles et al., *Shared Decision-Making in the Medical Encounter: What Does it Mean? (Or It Takes at Least Two to Tango)*, 44 SOC. SCI. & MED. 681, 682 (1997). Consistent with this approach, decisions are seen as best made—ultimately—by patients, with shared decision-making adding the concepts of partnership

simultaneously promoting important clinical objectives, such as patient-centered care and evidence-based patient choice.¹⁴⁸

Thus, shared decision-making is roughly analogous to supported decision-making in the sense that the former is a form of dyadic supported decision-making in which the physician (clinician) is the “supporter” of a patient making a health care related decision or decisions. However, shared decision-making is distinct from more general conceptions of the supported decision-making model in four key ways.

First, in shared decision-making, the “supporter” is the clinician. Accordingly, empirical research into shared decision-making focuses on this dyadic (clinician-patient) relationship, for the most part excluding contexts where more parties are involved.¹⁴⁹ In supported decision-making, by contrast, the supporter is typically a family member or friend (or multiple such supporters).¹⁵⁰ Second, shared decision-making does not involve a formally—or legally—appointed party to assist with decision-making, while supported decision-making does involve such a party. Third, shared decision-making focuses on *medical* or *health-care* decisions, and, thus, empirical research on it emphasizes those types of decisions. Supported decision-making, as discussed earlier, can be much broader than “only” medical decisions. It can, and is generally intended to, include financial, legal, daily, and other decisions. Fourth, much of the existing shared decision-making research has been with populations that are dissimilar to the populations that are typically described as having particular potential to benefit from supported decision-making (*i.e.*, persons with cognitive and intellectual disabilities). Although research on shared decision-making has been conducted with a variety of

and deliberation to achieve, arguably, greater connection to the goal of informed consent. *See, e.g.*, Simon N. Whitney et al., *A Typology of Shared Decision Making, Informed Consent, and Simple Consent*, 140 ANNALS INTERNAL MED. 54 (2003).

148. Whitney et al., *supra* note 147, at 54; Eleanor Herriman & Jessica Cerretani, *Shared Decision Making—Benefits and Technologies*, 2 MEDICAL INFORMATICS REV. 1 (2007).

149. *See* Charles et al., *Physician-Patient Encounter*, *supra* note 144, at 657, 685. Some shared decision-making researchers have built on this point to emphasize concerns—which are also present in supported decision-making—regarding the possibility of undue influence and the importance of “checks and balances” to avoid “coalitions” forming that might influence a principal’s decision-making. *See* J. Gabe et al., *It Takes Three to Tango: A Framework for Understanding Patient Partnership in Pediatric Clinics*, 59 SOC. SCI. & MED. 1071 (2004).

150. Indeed, even in the shared decision-making context, such relationships may be more complex than a simple physician-patient dyad for many patients, especially those who are members of more vulnerable populations who may rely on family and natural supports or those with complex cases where multiple clinicians are involved. *See* R.K. Sharma et al., *Family Understanding of Seriously-Ill Patient Preferences for Family Involvement in Decision Making*, 26 J. GEN. INTERNAL MED. 881 (2011).

populations (children, racial and ethnic minorities, as well as mental health patients)¹⁵¹ and in a variety of medical contexts (palliative care, breast cancer, and other clinical settings),¹⁵² it has not emphasized populations with cognitive or intellectual disabilities. Thus, research in each of these areas may have implications for supported decision-making models, but, at this point, perhaps only at a broad level. Although research on shared decision-making can be analogized to supported decision-making contexts, the analogy will be limited until further research is done.

Despite these differences, research on shared decision-making provides some helpful insight into supported decision-making practice and policy. One important contribution is that it suggests conditions under which supported decision-making might be considered appealing to principals. Specifically, research on shared decision-making suggests that the extent to which principals feel that support is valuable may vary based on the principal's age and on the type of decision being made. For instance, a recent study from the Netherlands examined the use of shared decision-making in medical (*e.g.*, surgery or vaccination) and non-medical (*e.g.*, occupational healthcare, lifestyle decisions, diet, work-related decisions, *etc.*) contexts, as well as patient preferences about shared decision-making in those contexts.¹⁵³ Older patients (often

151. See, *e.g.*, Alexander G. Fiks et al., *Shared Decision-Making in Pediatrics: A National Perspective*, 126 PEDIATRICS 306 (2010) (providing a descriptive account of how often shared decision-making is used in pediatric contexts); Lainie Friedman Ross, *Health Care Decisionmaking by Children—Is it in Their Best Interest?*, 27 HASTINGS CTR. REP. 41 (1997) (cautioning against too much authority in patient (child) versus parent in pediatric setting); Monica E. Peek et al., *Are There Racial Differences in Patients' Shared Decision-Making Preferences and Behaviors Among Patients with Diabetes?*, 31 MED. DECISION MAKING 422 (2011) (examining racial differences in preferences and behaviors regarding shared decision-making); Lilisbeth Perestelo-Perez et al., *Patient Involvement and Shared Decision-Making in Mental Health Care*, 6 CURRENT CLINICAL PHARMACOLOGY 83 (2011). A prominent U.S. mental health advocacy organization, Mental Health America, has even created a website specifically to promote shared decision-making. See *You're on the Team: How Shared Decision-making Works*, MENTAL HEALTH AM., <http://www.nmha.org/go/youreontheteam/howitworks> (last visited Mar. 20, 2013).

152. See, *e.g.*, Lisa J.M. Caldon et al., *Clinicians' Concerns about Decision Support Interventions for Patients Facing Breast Cancer Surgery Options: Understanding the Challenge of Implementing Shared Decision-Making*, 14 HEALTH EXPECTATIONS 133 (2010) (discussing shared decision-making in the context of breast cancer treatment decisions); Emmanuelle Bélanger et al., *Shared Decision-Making in Palliative Care: A Systematic Mixed Studies Review Using Narrative Synthesis*, 25 PALLIATIVE MED. 242 (2011) (providing a narrative synthesis of literature on shared decision-making in the palliative care context).

153. Atie van den Brink-Muinen et al., *Preferences and Experiences of Chronically Ill and Disabled Patients Regarding Shared Decision-Making: Does the Type of Care to be Decided Upon Matter?*, 84 PATIENT EDUC. & COUNSELING 111 (2011).

thought to favor more paternalistic decision-making) found shared decision-making important and also were more likely to experience more involvement in decision-making in practice than were younger patients.¹⁵⁴ Further, researchers reported that patients' preferences varied by context, with patients attaching greater importance to shared decision-making in occupational health-care contexts, less in medical care contexts, and the least in lifestyle choices.¹⁵⁵ The authors suggested that

whether a patient wants to be involved in decision-making has been treated in most other research as some kind of trait characteristic of patients or at least determined by rather stable patient characteristics such as education, locus of control or self-efficacy. Few authors have suggested that patients' preferences and experiences may develop over time as people are more exposed or familiar with involvement in decision-making or vary from one situation or context to another for an individual patient.¹⁵⁶

If a similar phenomenon occurs in supported decision-making models—which, given the parallels between shared and supported decision-making, seems plausible—preferences about supported decision-making processes may also vary by the sort of decision to be made. Alternatively, of course, the findings may simply reflect that the decisions involved are somewhat different: medical decisions such as treatment or medication choices, versus occupational health-care decisions such as when and whether to return to work.¹⁵⁷ Such different decisions may be made with different supporters, and, thus, the relevant decision-making dynamics might be different.

Research on shared decision-making also suggests reason to question the extent to which individuals being supported actually want to be involved in decision-making. A systematic review of 69 “preference-matched” studies (*i.e.*, studies that examined whether patient preferences matched what actually occurred) made two important findings as to shared decision-making. First, a “sizeable” minority of patients preferred a passive role (*i.e.*, delegating decision-making to the physician) in decision-making, rather than a sharing or active role in decision-making.¹⁵⁸ Indeed, in a number of the studies reviewed, a

154. *Id.* at 115. The former finding about importance placed on shared decision-making was consistent with previous shared decision-making research, but the latter finding was not. *Id.*

155. *Id.*

156. *Id.* at 116 (footnotes omitted).

157. *Id.* at 112 (Box 1).

158. Donald J. Kiesler & Steven M. Auerbach, *Optimal Matches of Patient Preferences for Information, Decision-Making and Interpersonal Behavior: Evidence, Models and Interventions*, 61 *PATIENT EDUC. & COUNSELING* 319, 330 (2006).

majority of patients preferred a passive role.¹⁵⁹ These findings highlight how critical it is to explore what proportion of those who participate in supported decision-making in fact want to be involved in the decision-making process (and to what extent). Second, although a number of studies in the review showed that matching preferences to actual experience led to positive outcomes (*e.g.*, measured by patient satisfaction, adjustment, or symptom reduction), due to methodological limitations and “inconsistent” results, the authors were not comfortable concluding that this was so in all cases.¹⁶⁰ A robust research program exploring the outcomes of successful preference-matching in the supported decision-making context will be of significant value.

A second key insight offered by the shared decision-making research is that training matters, but not just for those providing decision-making assistance. The literature emphasizes that effective shared decision-making may require education and training for both clinicians and patients. Clinicians might be taught, for instance, how to recognize when and how to use shared decision-making, how to collaborate effectively with patients, and how to discuss lifestyle or other “preference sensitive” decisions.¹⁶¹ Patients, too, might benefit from training, for instance in how to determine and communicate their preferences.¹⁶² As noted earlier,¹⁶³ training and education of potential supporters is of paramount concern in the supported decision-making context, both to improve outcomes and to avoid manipulation or undue influence. The shared decision-making literature shows that education of the person being supported may be useful as well.

Finally, the shared decision-making literature suggests caution about claims that supported decision-making will lead to improved outcomes, whether psychological or otherwise. The literature has investigated whether engaging in shared decision-making in fact leads to better patient outcomes, such as increased satisfaction, treatment

159. *See id.* at 324 tbl.3.

160. *See id.* at 330.

161. *See, e.g.*, K.E. Hauer et al., *Assessment of Medical Students' Shared Decision-Making in Standardized Patient Encounters*, 26 J. GEN. INTERNAL MED. 367 (2010) (calling for more education for clinicians regarding lifestyle discussions and collaboration with patients); van den Brink-Muinen et al., *supra* note 153, at 116 (arguing that, rather than searching for perfect “tool” for physicians to use to implement shared decision-making, greater physician awareness of its value is more critical).

162. *See* Angela Towle & William Godolphin, *Framework for Teaching and Learning Informed Decision Making*, 319 BRITISH MED. J. 766 (1999); Kiesler & Auerbach, *supra* note 158, at 335 (suggesting that focus on the patient would bear more fruit than seeking to alter clinician behaviors, and arguing for improving physician skills in tailoring shared decision-making approaches based on patient preferences).

163. *See supra* Part III.B.2.d.

adherence, and actual health. Joosten et al.'s recent systematic review of the approach's effectiveness (vis-à-vis these outcomes) found some positive results where shared decision-making involved long-term decisions and/or chronic diseases in treatment programs involving more than one visit.¹⁶⁴ Results, however, were mixed. Of eleven randomized control trials that fit the authors' inclusion criteria, nine focused on physical health and two focused on mental health conditions. Five of those eleven found no difference between the shared decision-making intervention and control group on outcome measures (all of which were in physical health and involved a single decision or one consultation); one of the eleven showed only long-term effects; and five of the eleven (including the two in mental health) showed improved outcomes.¹⁶⁵ The most frequently studied outcome measure was patient satisfaction, yet only one study found improvement in patient satisfaction, and it involved shared decision-making in a mental health treatment program.¹⁶⁶ Of the three studies that included an additional outcome of patient knowledge, two found an increase.¹⁶⁷

Of course, as highlighted above, supported decision-making involves a broader range of decision-making contexts than mental health and medical decision-making, and this review found no benefits for physical health-care decisions.¹⁶⁸ Moreover, one significant drawback of Joosten et al.'s review—as with a number of the other overviews of the shared decision-making literature—is that the authors failed to include discussion of the *strength* of the effects they discussed. For instance, the review only reported that the studies reviewed “reported positive effects,” or “found no difference between intervention and control” groups; nowhere did the review report or calculate effect sizes of those studies' data, as would be useful (if not essential) to evaluate the state of the literature in question.¹⁶⁹ Furthermore, other reviews of shared decision-making are simply narrative, thus, again, missing the opportunity to meaningfully quantify the overall effect or usefulness of shared decision-making.¹⁷⁰ Therefore, for shared decision-making literature reviews to be truly helpful for supported decision-making

164. E.A.G. Joosten et al., *Systematic Review of the Effects of Shared Decision-Making on Patient Satisfaction, Treatment Adherence and Health Status*, 77 *PSYCHOTHERAPY & PSYCHOSOMATICS* 219 (2008).

165. *Id.* at 222-23.

166. *Id.* at 223.

167. *Id.*

168. *Id.*

169. See generally Jeremy A. Blumenthal, *Meta-Analysis: A Primer for Legal Scholars*, 80 *TEMP. L. REV.* 201 (2007).

170. E.g., Bélanger et al., *supra* note 152.

research (or, to be candid, for shared decision-making research itself), more detailed syntheses and meta-analyses, including summaries and comparisons of effect sizes, will need to be conducted.¹⁷¹

In sum, the shared decision-making literature provides some useful insights for supported decision-making researchers, although the analogy between the two approaches is a broad one. First, the literature reinforces the perspective that the context in which individuals face decisions is important to consider, not just personal characteristics of the person with a disability or of his or her supporters. Second, it is consistent with literature on supported decision-making that discusses the importance of educating the stakeholders involved about the most effective means of reaching a beneficial outcome (and, most likely, developing appropriate criteria for evaluating whether the outcome is beneficial at all), as well as a means of avoiding undue influence. Notably, the shared decision-making literature highlights that the principal stakeholder, the person with ID or other cognitive disability, might benefit from education and training as well, though the supported decision-making conversation has not reached that point. Yet the literature on shared decision-making also suggests that education alone may not be sufficient to guide supporter behavior; it may also be important to craft incentive structures that encourage particular behavior.¹⁷² Finally, this literature suggests types of research questions that we might wish to apply in the supported decision-making context. For instance, those seeking to understand supported decision-making should consider undertaking research similar to that which has been done in the shared decision-making context: among other things, (1) evaluating the preferences of persons with cognitive and intellectual disabilities in various contexts; (2) examining whether such preferences are matched in the real experience of supported decision-making; and (3)

171. An additional advantage of conducting such meta-analyses is that doing so addresses concerns such as the “heterogeneity of the samples, settings, and measurements [that] might affect the generalization of the results.” Joosten et al., *supra* note 164, at 224. That is, Joosten and colleagues were concerned that differences among the studies being reviewed would vitiate the usefulness of a broad review. This is, however, precisely the purpose for which meta-analysis is useful, especially when moderator analyses are conducted—*i.e.*, analyses that use differences across studies as evaluative criteria in and of themselves. See Blumenthal, *supra* note 169.

172. See Angela Coulter et al., *Implementing Shared Decision Making in the UK*, 105 Z. EVID. FORTBILD. QUAL. GESUNDHEITWESEN (ZEFAQ) 300, 301 (2011) (“[T]argets and centralised guidelines, supported by financial incentives and managerial imperatives, have had much greater impact on the way clinicians work than exhortations about patient-centred care.”) Thus, for supported decision-making to be effective, it may require ensuring that decision-making supporters have not only the resources and skills they need to provide effective support but also the incentives to do so.

assessing whether such a match has any effect on the process or substance outcomes of decision-making.¹⁷³

V. NEXT STEPS

There is reason to be optimistic about the potential for supported decision-making processes to enhance the well-being of persons with cognitive and intellectual disabilities. Supported decision-making has the potential to provide individuals with cognitive and intellectual disabilities the help they may need to manage their affairs and make decisions about their own lives and, by so doing, to improve their well-being and promote their dignity.

Moreover, there are real problems with the current guardianship system, which making supported decision-making available might ameliorate. Most importantly, consistent with the notion that all people are entitled to live in the least restrictive manner practicable, guardianship should be imposed only when alternative mechanisms for meeting its objectives are not reasonably feasible. Thus, for example, guardianship should not be considered a routine part of permanency planning for persons with ID.

However, without viable alternative decision-making models such as supported decision-making, guardianship will likely continue to be treated as a routine response to the decision-making challenges facing persons with intellectual and cognitive disabilities instead of a true last resort. It is therefore important for policymakers to consider how supported decision-making systems might be institutionalized in the United States to better serve the needs of persons with cognitive and intellectual disabilities.¹⁷⁴

Accordingly, policymakers should explore how supported decision-making could reduce the use of guardianship as well as how supported decision-making approaches could be integrated into guardianship systems. As explained earlier in this article, policymakers can promote supported decision-making either by creating opportunities and mechanisms for formally recognizing an individual's decision-making supporter or by creating opportunities and mechanisms for providing individuals with such supporters.¹⁷⁵ Both approaches may be necessary

173. In another example of process versus substantive preferences, one study showed that simply engaging in shared decision-making leads to better outcomes on some measures than actually matching patient preference to experience. M. Gattellari et al., *Sharing Decisions in Cancer Care*, 52 SOC. SCI. & MED. 1865 (2001).

174. Cf. KERZNER, *supra* note 33, at 59 (noting that many of the supported decision-making processes available in Canada "are of no use to the many people who have no supports in their lives").

175. See *supra* Part II.B.1.

in order for supported decision-making to benefit both those with and without pre-existing support networks.

Unfortunately, as this article has shown, the existing evidence base on supported decision-making is simply insufficient to know whether any given supported decision-making process can achieve its promise. To be sure, the goals of those promoting supported decision-making are generally laudable, and many of the problems that those seeking to move to a supported decision-making approach have identified are significant. However, little is known about how supported decision-making actually works in the jurisdictions where it is implemented. While there are some cursory data on demographics of individuals entering into supported decision-making agreements, it is clearly insufficient to understand to what extent the model will be considered attractive or workable across divergent populations. More importantly, there are virtually no data on how support is provided in supported decision-making relationships, including whether principals perceive it to in fact be “supportive” or are actually empowered by it. Nor are there data about the quality of the decisions reached under supported decision-making frameworks.

Given this dearth of information, it is simply too early to conclude that supported decision-making is an effective decision-making model, much less that supported decision-models should be institutionalized by state actors. It may well be that supported decision-making provides a meaningful, empowering alternative to more restrictive decision-making models such as guardianship. It may also be that supported decision-making is little more than a farce—a facade of support that, in fact, fails to provide it.

It is similarly too early to know whether certain forms of supported decision-making are more likely to achieve positive outcomes—either in terms of substance or in terms of process—than other forms. Thus, policymakers seeking to implement supported decision-making regimes have little guidance when choosing among different supported decision-making models.

Accordingly, significant research is needed to guide policy in this area if policymakers are to actually design and implement practices which effectively empower persons with intellectual and cognitive disabilities to engage to the fullest extent possible in decisions about their own lives. Our review of the existing literature on supported decision-making, combined with insight drawn from the related literatures on surrogate decision-making and shared decision-making,

suggests five primary areas for future research on supported decision-making:¹⁷⁶

1. *How do persons with intellectual and cognitive disabilities and decision-making supporters interact with one another? What techniques do supporters use to attempt to support decision-making? How do persons with cognitive and intellectual disabilities react to these techniques? To what extent do techniques and reactions vary based on the form of supported decision-making, the context in which it takes place, or the age or disability of the principal?*
2. *Is supported decision-making coercive and, if so, under what circumstances? Specifically, to what extent do supporters engage in behaviors that are designed to be, or have the effect of being, controlling or otherwise coercive? To what extent do such behaviors depend on the form of the supported decision-making relationship or the personal or demographic characteristics of those involved in the relationship?*
3. *Do supported decision-making processes result in decisions that are substantively different than the decisions reached under surrogate decision-making models such as guardianship? If so, what are the differences, when do they occur, and why? To what extent do these differences advantage or disadvantage those involved in the supported decision-making relationship?*
4. *Do differences in supported decision-making techniques influence the decisions made and whether principals are satisfied or empowered by the process? If so, do such differences vary based on supporter and principal characteristics such as age or type of disability?*
5. *Can process or substantive outcomes of supported decision-making be improved by training to supporters, principals, or both? If so, what types of training are most effective and under what conditions?*

176. See also Kohn & Blumenthal, *supra* note 1 (providing a condensed overview of the state of the evidence on supported decision-making, and making parallel research recommendations).

While investigating other questions would also be worthwhile, a focus on these five questions will help ensure that research findings are most useful in informing policy choices surrounding supported decision-making.

The answers to these questions would help indicate whether or not supported decision-making can achieve some or all of the goals its supporters envision, including whether it can ameliorate many of the problems associated with surrogate decision-making processes such as guardianship. Research into these questions could also indicate which forms of supported decision-making are most likely to achieve a particular goal or ameliorate a particular problem.

VI. CONCLUSION

Supported decision-making holds promise as an alternative to surrogate decision-making. For example, it has the potential to be an empowering alternative to the much-maligned process of guardianship, as well as an empowering element of the guardian-ward relationship. The question, however, is whether supported decision-making can fulfill that promise. If it empowers persons with cognitive and intellectual disabilities to make decisions for themselves as its proponents claim, it would advance the interests and human rights of persons with disabilities. However, without more evidence as to how supported decision-making functions in practice, it is too early to rule out the possibility that it may frequently have the opposite effect. For example, there is reason to be concerned that supported decision-making may allow largely unaccountable third parties to improperly influence the decisions of persons with disabilities, thereby disempowering persons with disabilities and undermining their rights.

In light of the growing chorus of calls for expanding supported decision-making practices, including integration into the U.S. legal system, it is imperative that substantial further research be conducted to examine how supported decision-making actually operates. Specifically, research is needed to determine the extent to which supported decision-making approaches achieve their goals, and the conditions under which they are likely to do so. If supported decision-making policies are not guided and informed by such research, there is a risk that supported decision-making will not, in fact, be supportive of persons with cognitive and intellectual disabilities.

2014

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

Elionóir Flynn

Anna Arstein-Kerslake

Recommended Citation

Elionóir Flynn and Anna Arstein-Kerslake, *The Support Model of Legal Capacity: Fact, Fiction, or Fantasy?*, 32 BERKELEY J. INT'L LAW. 124 (2014).

Available at: <http://scholarship.law.berkeley.edu/bjil/vol32/iss1/4>

This Article is brought to you for free and open access by the Law Journals and Related Materials at Berkeley Law Scholarship Repository. It has been accepted for inclusion in Berkeley Journal of International Law by an authorized administrator of Berkeley Law Scholarship Repository. For more information, please contact jcera@law.berkeley.edu.

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

Dr. Eilionóir Flynn* and Anna Arstein-Kerslake, JD**

INTRODUCTION

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

* BCL, PhD, Senior Research Fellow, Centre for Disability Law and Policy, National University of Ireland Galway, eilionoir.flynn@nuigalway.ie.

** JD, Marie Curie Research Fellow, Centre for Disability Law and Policy, National University of Ireland Galway, anna.arsteinkerslake@nuigalway.ie.

1. Many scholars have written on the subject. *See, e.g.*, Tina Minkowitz, *The United Nations Convention on the Rights of Persons with Disabilities and the Right to Be Free from Nonconsensual Psychiatric Interventions*, 34 SYRACUSE J. INT’L L. & COM. 405, 408 (2006-2007); Amita Dhanda, *Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?* 34 SYRACUSE J. INT’L L. & COM. 429 (2006-2007); Gerard Quinn & Anna Arstein-Kerslake, *Restoring the ‘Human’ in ‘Human Rights’: Personhood and Doctrinal Innovation in the UN Disability Convention*, in *THE CAMBRIDGE COMPANION TO HUMAN RIGHTS LAW* 36 at 42-44 (Conor Gearty & Costas Douzinas eds., 2012).

2. *See, e.g.*, Comm. on the Rights of Pers. with Disabilities, *Consideration of Reports Submitted by States Parties under Article 35 of the Convention, Concluding Observations*, Tunisia, Apr. 11-15, 2011, U.N. Doc. CRPD/C/TUN/CO/1, available at http://www2.ohchr.org/SPdocs/CRPD/5thsession/CRPD-C-TUN-CO-1_en.doc; Comm. on the Rights of Pers. with Disabilities, *Consideration of Reports Submitted by States Parties under Article 35 of the Convention, Concluding Observations*, Spain, Sept. 19-23, 2011, U.N. Doc. CRPD/C/ESP/CO/1, available at http://www.ohchr.org/Documents/HRBodies/CRPD/6thsession/CRPD.C.ESP.CO.1_en.doc.

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

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

The denial of legal capacity to certain groups of persons on the basis of perceived characteristics of inferiority is not a new phenomenon. Indeed, women, slaves, and racial and ethnic minorities, among other groups, have long been denied legal capacity. However, at present, it appears that a diagnosis of a disability, and in particular a cognitive disability,⁴ is the one remaining characteristic upon which contemporary society is willing to justify stripping legal capacity from a person. Take for instance the following example, adopted from the facts of a European Court of Human Rights case, as reported by the Mental Disability Advocacy Center:⁵

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

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

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

5. *Sýkora v. Czech Republic*, Appl. No. 23419/07, Nov. 22, 2012, <http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-114658>; see *Kafka Storyline at The European Court of Human Rights*, MENTAL DISABILITY ADVOC. CENTER, <http://www.mdac.info/en/22/11/12/kafka-story-line-european-court-human-rights> (last visited Dec. 28, 2013).

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

As the above example demonstrates, the removal of legal capacity can have significant consequences, even when it occurs in relation to a single decision or area of decision-making (e.g., consent to medical treatment or financial decision-making). Where legal capacity is removed, one’s ability to challenge the removal or appointment of a guardian is, at best, compromised and often non-existent.⁶ Similarly, a disabled person’s views with respect to treatment are often inappropriately ascribed to the illness or disability, equated with a lack of understanding of the situation, and therefore ignored.

In the case above, the circumstances in which the plaintiff found himself are certainly not unique to the Czech Republic, where the case occurred. Similar instances take place daily in other countries, including the United States, where a combination of adult guardianship provisions⁷ and mental health laws,⁸ allow for individuals to be detained and treated against their will. Once detained, individuals have little recourse to legal redress when a guardian has consented to detention and treatment. These grievous human rights violations cannot be addressed simply by introducing more due process protections or merely allowing more weight to be given to the individual’s wishes. These types of incremental changes, while important, will not address the totality of the discrimination experienced by persons with disabilities, and those with cognitive disabilities in particular. The denial of legal capacity is a serious interference with an individual’s civil rights. It is paramount to the denial of personhood because it leaves the individual stripped of the freedom to engage with society to

6. See, e.g., PETER BARTLETT, ET AL., MENTAL DISABILITY AND THE EUROPEAN CONVENTION ON HUMAN RIGHTS 153 (Vol. 10 2007); Equality and Human Rts. Community, *Promoting the Safety and Security of Disabled People* (2009), available at http://www.equalityhumanrights.com/uploaded_files/research/promoting_safety_and_security_of_disabled_people.pdf; Stephanie Ortoleva, *Inaccessible Justice: Human Rights, Persons with Disabilities and the Legal System*, 17 ILSA J. INT’L & COMP. L. 281 (2011).

7. See AMERICAN BAR ASSOCIATION COMMISSION ON LAW AND AGING, STATE ADULT GUARDIANSHIP LEGIS.: DIRECTIONS OF REFORM, 1-2 (2011), available at http://www.americanbar.org/content/dam/aba/uncategorized/2011/2011_aging_gship_reform_12.aut_hcheckdam.pdf.

8. See, e.g., N.Y. MENTAL HYG. LAW §§ 9.27-9.37 (McKinney 2007) (governing involuntary detention); N.Y. MENTAL HYG. LAW § 9.60 (McKinney 2013) (governing involuntary outpatient treatment). For more information on mental health law in the United States, see generally MICHAEL L. PERLIN, MENTAL DISABILITY LAW: CASES AND MATERIALS (2d. ed., 2005).

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

I.

THE CASE FOR A SUPPORT MODEL OF LEGAL CAPACITY

Legal capacity includes both the ability to hold rights and to be an actor under the law (e.g., to enter into contracts, vote, and marry).⁹ The law's recognition and validation of an individual's will and preference is the key to accessing meaningful participation in society. Mental capacity—the decision-making ability of an individual—is distinct from legal capacity: mental capacity naturally varies among individuals, and may differ depending on environmental factors.

In modern times, the use of the functional approach to legal capacity denial has conflated the concepts of mental and legal capacity.¹⁰ The functional approach came into widespread use only in the late twentieth century, and the CRPD is the first major international human rights instrument to bring attention to the violations that occur under such an approach. The functional approach purports to assess mental capacity and deny legal capacity accordingly.¹¹ An individual's decision-making skills are accepted as a legitimate basis for denying legal capacity, and lowering one's status as a person before the law.¹² Because functional tests of mental capacity require either a "mental disability" or a finding of an "impairment of the mind or brain,"¹³ it is almost exclusively people with cognitive disabilities who have their legal capacity restricted on the basis of perceived decision-making skills.¹⁴

9. Sixth Sess. of the Ad Hoc Comm. on a Comprehensive and Integral Int'l Convention on the Prot. and Promotion of the Rights and Dignity of Pers. with Disabilities, Aug. 1-12, *OHCHR Background Conference Document on Legal Capacity*, ¶ 24, U.N. Doc. A/AC.265/2005/CRP.5.

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

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

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

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

14. In 2012, 375 people in Ireland had their legal capacity removed and were placed under wardship. Only seven of those people were reported as being placed under wardship for reasons

The most obvious human rights violation perpetrated by the functional approach is its facially discriminatory nature. Article 12 of the CRPD requires respect for the legal capacity of people with disabilities on an equal basis with others.¹⁵ Discrimination is defined in Article 2 of the CRPD as “any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.”¹⁶ Functional approaches that permit legal capacity denial only to individuals with cognitive impairments¹⁷ are facially discriminatory and interfere with the right to equal recognition before the law, guaranteed in Article 12.

If a functional approach were made facially neutral by eliminating the requirement of “impairment,” it would allow for the denial of legal capacity to *any* individual perceived to not understand the nature and consequences of her actions.¹⁸ Non-disabled people may realize what a high standard this is only when faced with having to meet it themselves—yet, as a society, we have continued to apply this high standard to individuals with cognitive disabilities. Due to stigma related to disability, there would still be a high risk of this system being discriminatorily applied to individuals with disabilities. Furthermore, even a facially neutral functional test of capacity that adequately deals with the stigma of disability would not adhere to Article 12 in its entirety. Article 12 calls for not only the respect for legal capacity on an equal basis but also places an obligation on states to provide access to the support necessary for the exercise of legal capacity.¹⁹ This requires the replacement of substituted decision-making regimes with supported decision-making ones.

The monitoring body of the CRPD has deemed substituted decision-making regimes incompatible with Article 12 of the Convention.²⁰ Although the

other than cognitive disability (two had experienced residential abuse and five were minors). IRISH COURTS SERVICE, ANNUAL REPORT (2012), *available at* [http://www.courts.ie/Courts.ie/library3.nsf/\(WebFiles\)/87BE463114EF96FF80257BA20033953B/\\$FILE/Courts%20Service%20Annual%20Report%202012.pdf](http://www.courts.ie/Courts.ie/library3.nsf/(WebFiles)/87BE463114EF96FF80257BA20033953B/$FILE/Courts%20Service%20Annual%20Report%202012.pdf).

15. United Nations Convention on the Rights of Persons with Disabilities art. 12, *opened for signature* Mar. 30, 2007, 46 I.L.M. 443 [hereinafter Convention on the Rights of Persons with Disabilities].

16. Convention on the Rights of Persons with Disabilities art. 2, *opened for signature* Mar. 30, 2007, 46 I.L.M. 443.

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

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

19. Convention on the Rights of Persons with Disabilities, *supra* note 16, art. 12(3).

20. *See, e.g., Consideration of Reports Submitted by States Parties Under Article 35 of the Convention: Concluding Observations, Tunisia*, Committee on the Rights of Persons with

Committee on the Rights of Persons with Disabilities has not yet provided a conclusive definition of substituted decision-making regimes, a tentative proposal has been made in the Committee's Draft General Comment on Article 12. In this document, the Committee states that a substituted decision-making regime is a system where: (1) legal capacity is removed from the individual, even if just in respect to a single decision, (2) a substituted decision-maker can be appointed by someone other than the individual, and, (3) any decision made is bound by what is believed to be in the objective "best interests" of the individual as opposed to the individual's own will and preferences.²¹ The Committee's Draft General Comment also states that "functional tests of mental capacity . . . that lead to denials of legal capacity violate Article 12 if they are either discriminatory or disproportionately affect the right of persons with disabilities to equality before the law."²²

Instead of systems of substituted decision-making, the CRPD calls for support to exercise legal capacity.²³ In a legal system that follows the support paradigm, there would be no denials of legal capacity; instead, it would be accepted as a universal attribute.²⁴ Supports for exercising legal capacity would be offered to the individual, but not imposed.²⁵ These supports could include relatively minor accommodations, such as accessible information and additional time to make a decision, or more formal measures, such as supported decision-making agreements nominating one or more supporters to assist the individual in making certain decisions and communicating them to others.²⁶ "Facilitated" decision-making²⁷ would be available where someone could be appointed to make a decision on behalf of another individual as a last resort. Safeguards would be in place to ensure that the decision fully respects the individual's "rights, will and preferences,"²⁸ as far as they can be ascertained. Facilitated

Disabilities (CRPD), 5th Sess., UN Doc CRPD/C/TUN/CO/1 (Apr. 11-15, 2011) at 4 [hereinafter *Consideration of Reports, Tunisia*]; *Consideration of Reports Submitted by States Parties Under Article 35 of the Convention: Concluding Observations, Spain*, Committee on the Rights of Persons with Disabilities (CRPD), 6th Sess., UN Doc CRPD/C/ESP/CO/1 (Sept. 19-23, 2011) at 5 [hereinafter *Consideration of Reports, Spain*].

21. Draft General Comment on Article 12: Advance Unedited Version, Committee on the Rights of Persons with Disabilities (CRPD), 10th Sess., (Sept. 2-13, 2013), at ¶ 23, available at <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx>

22. *Id.* at ¶ 21.

23. See, e.g., *Consideration of Reports, Tunisia*, *supra* note 19 at 4; *Consideration of Reports, Spain*, *supra* note 19 at 5.

24. Draft General Comment on Article 12, *supra* note 20 ¶ 8.

25. *Id.* at ¶ 25(g).

26. For an example, see supported decision-making agreements under the British Columbia Representation Agreement Act. Representation Agreement Act, R.S.B.C. 1996, c. 405 (Can.).

27. The concept of facilitated decision-making was conceptualized by Michael Bach & Lana Kerzner, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity*, Law Comm'n of Ontario (Oct. 2010), available at <http://www.lco-cdo.org/disabilities/bach-kerzner.pdf>.

28. Convention on the Rights of Persons with Disabilities art. 2, opened for signature Mar. 30, 2007, 46 I.L.M. 443.

decision-making would be used only as a last resort when others cannot determine the will and preference of the individual after exhausting all efforts.²⁹

II.

THE SUPPORT MODEL IN PRACTICE: POSITIVE REFORM TRENDS

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

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

29. Amnesty Int'l Ireland & The Ctr. for Disability Law & Policy, NUI Galway, *Essential Principles: Irish Legal Capacity Law* (2012), available at http://www.nuigalway.ie/cdlp/documents/principles_web.pdf.

30. See Dhanda, *supra* note 1, at 436.

31. See Bruce Winick, *The Side Effects of Incompetency Labeling and the Implications for Mental Health Law*, 1 PSYCHOL., PUB. POL'Y, & L. 6, 41-42 (1995); Richard M. Ryan & Edward L. Deci, *Self-Determination Theory and the Facilitation of Intrinsic Motivation*, 55 AM. PSYCHOLOGIST 68, 70 (2000); Edward L. Deci & Richard M. Ryan, *The "What" and "Why" of Goal Pursuits: Human Needs and the Self-Determination of Behaviour*, 11 PSYCHOLOGICAL INQUIRY 227, 230-31 (2000).

32. Gerard Quinn, *Rethinking Personhood: New Directions in Legal Capacity & Policy* 5 (Apr. 29, 2011) (unpublished manuscript), available at <http://www.inclusionireland.ie/sites/default/files/attach/basic-page/846/rethinkingpersonhood-newdirectionsinlegalcapacitylawandpolicy-gerardquinn-april2011.docx>; Gerard Quinn & Anna Arstein-Kerslake, *Restoring the 'Human' in 'Human Rights': Personhood and Doctrinal Innovation in the UN Disability Convention*, in THE CAMBRIDGE COMPANION TO HUMAN RIGHTS (Conor Gearty & Costas Douzinas eds., 2012).

33. See, e.g., Bach & Kerzner, *supra* note 27.

34. See S. Herr, *Self Determination, Autonomy, and Alternatives for Guardianship*, in THE HUMAN RIGHTS OF PERSONS WITH INTELLECTUAL DISABILITIES 440 (Stanley S. Herr et. al., eds., 2003); Dhanda, *supra* note 1, at 433, 459-60.

35. Minkowitz, *supra* note 1 at 406.

decisions are recognized and another category of persons whose are not, is fraught with pitfalls,³⁶ and can be profoundly disempowering for the group of people labeled “incapacitated.”³⁷ The support paradigm requires that the system begins with the assumption that all individuals have a decision-making ability and then determines what support each individual needs in augmenting that ability and expressing her preferences.³⁸ In this system, no labels are needed; instead, the goal is merely to determine what type of support an individual might need.

When an individual is faced with challenges in exercising her legal capacity, according to the support paradigm, the solution is not forced intervention or substituted decision-making. Instead, in a supported decision-making system, outside assistance for decision-making should generally be minimal and based on the needs of the individual. The individual is the center of the decision-making process and the support person is not permitted to utilize her judgment in place of the individual’s judgment. Rather, the support person is merely an interpreter of the will and preferences of the individual.³⁹

There are some people who require almost complete outside support for decision-making, such as those with impairments that significantly affect communication. For people in this situation, the support person should, to the fullest extent possible, still enable the individual to exercise her legal capacity.⁴⁰ This may mean a variety of things, including spending time learning the individual’s communication methods (e.g., movements of the eyelids, hand squeezing, and smiling), researching past communications, and any other means to ascertain the individual’s desires and decisions. The support person should try to ascertain, by any means available, the wishes of the individual. If it is not possible to discover the wishes of the individual, the support person should make a decision *not* based on what she believes are the best interests of the individual but instead on what she believes to be the individual’s true wishes. Even where communication is minimal or difficult to interpret, the support

36. For discussions of the complexities of incapacity labeling and “best interest” decision-making see the work of the Essex Autonomy Project at the University of Essex. See, e.g., Gareth S. Owen et. al., *Mental Capacity and Decisional Autonomy: An Interdisciplinary Challenge*, 52 INQUIRY 79 (2009); Antal Szerletics, *Best Interests Decision-Making Under the Mental Capacity Act*, ESSEX AUTONOMY PROJECT RES. (Feb. 1, 2012), available at <http://autonomy.essex.ac.uk/best-interests-decision-making-under-the-mental-capacity-act>; Vivienne Ashley, *Mental Capacity Act 2005 and Mental Health Act 1983*, ESSEX AUTONOMY PROJECT, BRIEFINGS (Aug. 8, 2011), available at <http://autonomy.essex.ac.uk/mental-capacity-act-2005-and-mental-health-act-1983>.

37. Winick, *supra* note 31; Susan Stefan, *Silencing the Different Voice: Competence, Feminist Theory, and Law*, 47 U. MIAMI L. REV. 763 (1993).

38. Gerard Quinn, *Personhood & Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD*, HARV.: HARV. PROJECT ON DISABILITY, (Feb. 20, 2010).

39. U.N. Dep’t of Econ. & Soc. Affairs, the Office of the U.N. High Comm’r for Human Rights, and the Inter-Parliamentary Union, *From Exclusion to Equality: Realizing the Rights of Persons with Disabilities: Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol* (2007).

40. *Id.*

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

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

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

III.

LEGAL CAPACITY LAW REFORM PROCESSES

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

41. For a discussion of the support paradigm of Article 12 and supported decision-making mechanisms, *see generally* CTR. FOR DISABILITY LAW & POLICY, NUI GALWAY, SUBMISSION ON LEGAL CAPACITY: THE OIREACHTAS COMMITTEE ON JUSTICE, DEFENCE & EQUALITY 55 (2011).

42. Draft General Comment on Article 12: Advance Unedited Version, Committee on the Rights of Persons with Disabilities, 10th Sess., (Sept. 2-13, 2013), ¶ 24.

A. Ireland

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

In August 2011, the parliamentary Joint Committee on Justice, Defence and Equality (the Justice Committee) called for submissions from interested parties on the content of what was then referred to as the Mental Capacity Legislation.⁴⁶ In response, the Centre for Disability Law and Policy and Amnesty Ireland co-chaired a coalition of organizations and individuals in the fields of intellectual disability, mental health, and older people. This group came together to discuss whether a joint approach to legal capacity reform could be developed across their interest groups. The result was the publication of a set of Essential Principles for Legal Capacity Reform in April 2012, which set out ten key principles that legislation should adhere to in order to comply with Article 12 of the CRPD.⁴⁷ Many of the groups involved presented at oral hearings convened by the Justice Committee in February 2012.⁴⁸ The Justice Committee subsequently published a report based on the oral hearings, requiring a shift away from the “best interests” model of substitute decision-making and endorsing the support model of legal capacity toward an approach that respects the will and preferences of the individual.⁴⁹

43. Lunacy Regulation (Ireland) Act 1871, 34 Vict., c. 22.

44. *Written Answers: National Disability Strategy*, DAIL DEBATES (MAY 22, 2012), available at <http://debates.oireachtas.ie/dail/2012/05/22/00318.asp>.

45. DEPARTMENT OF THE TAOISEACH, PROGRAMME FOR GOVERNMENT (2011), available at http://www.taoiseach.gov.ie/eng/Publications/Publications_Archive/Publications_2011/Programme_for_Government_2011.pdf.

46. Oireachtas Joint Committee on Justice, Defence and Equality, *Mental Capacity Legislation – Invitation for Submissions* (Aug. 2011), available at <http://www.oireachtas.ie/parliament/mcl/>.

47. AMNESTY INT’L IRELAND & THE CTR. FOR DISABILITY LAW & POLICY, *supra* note 29.

48. Press Release, Houses of the Oireachtas, Committee on Justice, Defence and Equality Continues Hearings on Proposed Mental Capacity Legislation (Feb. 2012), available at <http://www.oireachtas.ie/parliament/mediazone/pressreleases/2012/name-6931-en.html>.

49. HOUSE OF THE OIREACHTAS, JOINT COMMITTEE ON JUSTICE, DEFENCE AND EQUALITY, REPORT ON HEARINGS IN RELATION TO THE SCHEME OF THE MENTAL CAPACITY BILL (2012) (Ir.), available at <http://www.oireachtas.ie/parliament/media/michelle/Mental-capacity-text-REPORT-300412.pdf>.

The Assisted Decision-Making (Capacity) Bill was published in July 2013. It presents an interesting mix of supports (including the option of entering binding assisted decision-making agreements⁵⁰ and co-decision-making agreements⁵¹) and substitute decision-making (such as decision-making representatives⁵² and informal decision-makers⁵³), but continues to be premised on the individual reaching a certain standard of mental capacity as a prerequisite for retaining legal capacity with respect to a given decision. The definition of capacity does not include a diagnostic step (i.e., impairment in the functioning of the mind or brain). On the one hand, this makes it less obviously discriminatory, but on the other hand, any of the forms of decision-making prescribed under the Bill may occur only where the individual considers that her capacity is either “in . . . question” or “shortly [may] be . . . in question,”⁵⁴ which seems to imply that the main group of individuals affected by the legislation will be those with impaired decision-making ability and especially persons with cognitive disabilities.

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

The definition of capacity set out in Section 3 of the Bill reveals that the underlying premise of the legislation is that a certain standard of mental capacity is a prerequisite for the recognition of an individual’s legal capacity⁵⁶—a premise which is not, in our view, compatible with the CRPD’s interpretation of Article 12. Nevertheless, legal recognition of the various supports necessary to exercise legal capacity (such as assisted decision-making and co-decision making) is provided in the Bill,⁵⁷ which is certainly a positive step forward.

B. Canada

In the Canadian Province of Newfoundland and Labrador, the Minister for Justice, Felix Collins, made a commitment to reform at a symposium in 2011.⁵⁸

50. Assisted Decision-Making (Capacity) Bill 2013 (Act. No. 83/ 2013) § 10 (Ir.), available at <http://www.oireachtas.ie/documents/bills28/bills/2013/8313/b8313d.pdf>.

51. *Id.* at § 18.

52. *Id.* at § 24.

53. *Id.* at § 53.

54. *Id.* at § 2 (see definition of “relevant person”).

55. *Id.* at § 8.

56. *Id.* at § 3.

57. *Id.*

58. See *Securing Citizenship and Legal Capacity for All*, CANADIAN ASS’N OF CMTY. LIVING

Collins committed to work collaboratively with community actors to develop model legislation for legal capacity reform in the province, which could be subsequently used as an example of good practice for other Canadian provinces and jurisdictions outside of Canada.⁵⁹ Subsequently, a working group, which included Article 12 scholars Michael Bach and Lana Kerzner, developed a policy document that was submitted to the provincial government in early 2013.⁶⁰

While the contents of the submission have not yet been made public, it is expected that it will build on the existing work of Bach and Kerzner, who in 2010 proposed to the Ontario Law Commission that legislation to support the exercise of legal capacity and comply with Article 12 of the CRPD could recognize three key ways to exercise legal capacity.⁶¹ The first is where an individual is legally independent and requires only minor accommodations, such as accessible information, in order to make and communicate a decision.⁶² The second is a formal supported decision-making arrangement, where the individual makes an agreement with one or more supporters about the areas of decision-making with which she would like assistance, while retaining full legal capacity.⁶³ The third is facilitated decision-making, which applies as a last resort when the person is not legally independent or in a support arrangement. In this case, a facilitator will attempt to interpret the will and preferences of the individual and make a decision that she believes in good faith represents the wishes of the person.⁶⁴

C. India

In India, the draft Rights of Persons with Disabilities Bill 2011⁶⁵ and the proposed amendments to the National Trust Act⁶⁶ (establishing a support organization for persons with disabilities with high support needs) envisage a shift to universal legal capacity and supports to exercise legal capacity to replace substituted decision-making. The 2011 Bill proposes the abolition of plenary

(Aug. 8, 2011), <http://www.cacl.ca/news-stories/blog/securing-citizenship-and-legal-capacity-all>.

59. *Id.*

60. See *Policy Document Submitted to Justice Aims to Aid People with Intellectual Disabilities*, NFLD. ASS'N OF CMTY. LIVING, <http://www.nlacl.ca/news/article/getting-power-make-decisions-policy-document-submi/>.

61. Bach & Kerzner, *supra* note 27.

62. *Id.* at 83.

63. *Id.* at 84-90.

64. *Id.* at 91-94.

65. Committee Appointed by the Ministry of Society Justice and Empowerment, Gov't of India, *The Rights of Persons with Disabilities Bill*, CENTRE FOR DISABILITY STUD., NALSAR U. OF LAW (2011), <http://socialjustice.nic.in/pdf/report-pwd.pdf>.

66. Draft National Trust Act Amendments 2011 (India), available at http://capacityrights.org/uploads/3/1/8/0/3180011/national_trust_amendment-2.pdf [hereinafter Draft National Trust Act Amendments 2011].

guardianship,⁶⁷ and the transition of all those currently under plenary guardianship to a newly established limited form of guardianship, based on “joint decision making which operates on mutual understanding and trust between the guardian and the person with disability.”⁶⁸ In this new system, guardians are under a legal obligation to closely consult with persons with a disability to determine their will and preference. While the principles in this system reflect a move towards the support model, we are concerned that it may function as a substituted decision-making regime in violation of Article 12.

Importantly, no new entrants to limited guardianship will be permitted as this system is purely transitional for those currently under plenary guardianship. Limited guardianship did not exist prior to the new Bill. Individuals under limited guardianship will be supported to develop skills to enable them to transition out of limited guardianship into more progressive supported decision-making arrangements.⁶⁹ The 2011 Bill envisages that all those currently not under plenary guardianship (i.e., new entrants to the system) will be provided with supported decision-making options instead of being placed into limited guardianship.⁷⁰ The Bill also provides for a review of limited guardianship⁷¹ by the appropriate authorities designated by the government to establish whether this new system is effective in assisting “such persons with disabilities in establishing suitable support arrangements to exercise their legal capacity” and thus enabling them to transition out of limited guardianship.⁷²

D. Summarizing the Legal Capacity Reform Processes

These law reform processes and others developing throughout the world, including pilots of supported decision-making models,⁷³ indicate positive steps

67. Committee appointed by the Ministry of Social Justice and Empowerment, Government of India, *The Rights of Persons with Disabilities Bill 2011*, § 19(1) (Centre for Disability Studies, NALSAR University of Law, Hyderabad) (June 30, 2011), <http://socialjustice.nic.in/pdf/report-pwd.pdf> [hereinafter *The Rights of Persons with Disabilities Bill*].

68. *Id.* at § 19(3).

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

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

71. *Id.* at § 20(1)(c).

72. *Id.* at § 9(2)(ii).

73. MARGARET WALLACE, OFFICE OF THE PUBLIC ADVOCATE (SOUTH AUSTRALIA),

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

IV.

LEGAL CAPACITY REFORM AND THE COURTS

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

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

EVALUATION OF THE SUPPORTED DECISION-MAKING PROJECT, (MUIRGEN NOMINEES PTY LTD., 2012), http://www.opa.sa.gov.au/resources/supported_decision_making (then follow “Final independent evaluation” hyperlink).

74. Draft General Comment on Article 12: Advance Unedited Version, Committee on the Rights of Persons with Disabilities, 10th Sess., (Sept. 2-13, 2013) at 12(4).

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

76. See, e.g., Winterwerp v. The Netherlands, 2 Eur. Ct. H.R. Rep. 387 (1979); Ashingdane v. United Kingdom, 7 Eur. Ct. H.R. Rep. 528 (1985) (dissent); Shtukaturov v. Russia, Appl. No. 44009/05, Mar. 27, 2008, <http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-85611>; Salontaji-Drobnjak v. Serbia, Appl. No. 36500/05, Oct. 13, 2009, <http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-94985>; Stanev v. Bulgaria, 2012-I Eur. Ct. H.R. 46; D.D. v. Lithuania, Appl. No. 13469/06, Feb. 14, 2012,

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

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

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

<http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-109091D>; *Kędzior v. Poland*, Appl. No. 45026/07, Oct. 16, 2012, <http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-113722>; *Sýkora v. Czech Republic*, Appl. No. 23419/07, Nov. 22, 2012, <http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-114658>; *Lashin v. Russia*, Appl. No. 33117/02, Jan. 22, 2013, <http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-116020>; *Mihailovs v. Latvia*, Appl. No. 35939/10, Jan. 22, 2013, <http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-116075>.

77. See, e.g., *Lashin*, *supra* note 76, at ¶ 77; *Matter v. Slovakia*, 1999 Eur. Ct. H.R. 38, ¶ 68, Jul. 5, 2009, <http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-58266>; *Shtukaturov*, *supra* note 76, at ¶ 83.

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

79. For example, *In re Guardianship of Dameris L.*, 38 Misc. 3d 570 (N.Y. Sur. Ct. 2012).

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

81. *In re Guardianship of Dameris L.*, 38 Misc. 3d 570 (N.Y. Sur. Ct. 2012).

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

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

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

85. *In re Guardianship of Mark C.H.*, 28 Misc. 3d 765 (N.Y. Sur. Ct. 2010); *In re Guardianship of John J.H.*, 27 Misc. 3d 705 (N.Y. Sur. Ct. 2010); *In re Guardianship of Chaim A.K.*, 28 Misc. 3d 837 (2009).

86. See N.Y. SURR. CT. PROC. ACT LAW § 1750 (McKinney through L.2013, chapt. 1-340).

87. See generally *id.*

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

In the case, *Dameris*, a twenty-nine-year-old woman, had previously consented to being placed under the co-guardianship of her mother and husband. *Dameris* could take care of many of her daily needs, but the court found that she needed assistance with financial and medical affairs. Through the help of social services, family, and neighbors, *Dameris* and her family created a stable home and supportive environment for *Dameris* and her decision-making. It is significant that the court was involved in this case for three years, from the time that *Dameris*' mother first petitioned the court for guardianship in 2009. Although the law did not require it, in accordance with the principles of Article 12, the court sought *Dameris*' consent for her placement under guardianship. The court also encouraged the development of a support network for *Dameris* and her family. Additionally, the court appointed several monitors for the progress of the family and provided the family with translation services for interactions with the court because the family is primarily Spanish speaking. The court ultimately found in *Dameris L.* that *Dameris* was no longer in need of the guardianship, which it terminated.⁸⁸

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

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

88. *Dameris*, 38 Misc. 3d at 570.

89. For a description of the US government's disinterest in international human rights law and its efforts to weaken the force of international human rights law in the United States, see Jamie Mayerfeld, *Playing by Our Own Rules: How U.S. Marginalization of International Human Rights Law Led to Torture*, 20 HARV. HUM. RTS. J. 89, 94-96 (2007).

90. Convention for the Protection of Human Rights and Fundamental Freedoms, as amended by Protocols 11 and 14, supplemented by Protocols 1, 4, 6, 7, 12 and 13, Nov. 4, 1950, Europ. T.S. No. 5, 213 U.N.T.S. 221 [hereinafter European Convention on Human Rights (ECHR)]; Convention for the Protection of Human Rights and Fundamental Freedoms Rome, 4.XI., § 2, art. 19-51 (1950).

91. European Convention on Human Rights, *supra* note 90; Convention for the Protection of Human Rights and Fundamental Freedoms Rome, 4.XI., (1950) (preamble).

CRPD.⁹² While the ECHR does include a non-discrimination clause, it has no specific right to equal recognition before the law.⁹³ However, the court has interpreted certain restrictions on legal capacity as interfering with rights to privacy and family life,⁹⁴ liberty,⁹⁵ and a fair trial.⁹⁶ Although the ECtHR cases to date have been tinkering only around the edges of violations related to the right to legal capacity, the court appears to be slowly heading in the direction of Article 12 of the CRPD. The ECtHR has found an interference with the right to a fair trial where an individual does not have standing to engage the judicial system except through her appointed guardian.⁹⁷ It has also found that a deprivation of legal capacity can amount to a violation of the right to private life.⁹⁸ Finally, the ECtHR has held that the right to liberty is violated when an individual is stripped of her legal capacity and a guardian consents to her placement in an institution against her will.⁹⁹

These findings all describe positive steps in the journey toward the protection of the right to legal capacity and equality before the law, set forth in Article 12 of the CRPD. Unfortunately, the ECtHR has not yet interpreted the ECHR to include the right to legal capacity on an equal basis with others. One way the court could accomplish this, if a future case were to allow it, is through a finding that the denial of legal capacity to persons with disabilities is a violation of the right to freedom from discrimination.¹⁰⁰ This could be a very powerful holding. In order to find a violation of the right to freedom from discrimination in the ECHR, the discrimination must occur in relation to the enjoyment of another ECHR right.¹⁰¹ The discrimination can be direct or indirect.¹⁰² In order for a state to justify the discrimination, it must show that

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

93. European Convention on Human Rights, *supra* note 90, art. 14.

94. *Id.* at art. 8.

95. *Id.* at art. 5.

96. *Id.* at art. 6.

97. *See, e.g.*, Winterwerp v. The Netherlands, 2 Eur. Ct. H.R. Rep. 387, ¶¶ 69-73 (1979); Shtukaturov v. Russia, Appl. No. 44009/05, ¶ 108 (Mar. 27, 2008); Salontaji-Drobnjak v. Serbia, Appl. No. 36500/05, ¶¶ 124-128, Oct. 13, 200; Stanev v. Bulgaria, 2012-I Eur. Ct. H.R. 46 ¶ 132; D.D. v. Lithuania, Appl. No. 13469/06, ¶¶ 101-27, Feb. 14, 2012; Kędzior v. Poland, Appl. No. 45026/07, ¶¶ 80-91, Oct. 16, 2012; Sýkora v. Czech Republic, Appl. No. 23419/07, Nov. 22, 2012; Lashin v. Russia, Appl. No. 33117/02, ¶¶ 98-122, Jan. 22, 2013; Mihailovs v. Latvia, Appl. No. 35939/10, ¶¶ 154-58, Jan. 22, 2013.

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

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

100. European Convention on Human Rights, *supra* note 90, art. 14.

101. *Id.*

102. *See, e.g.*, Thlimmenos v. Greece, 2000-IV Eur. Ct. H.R. 162, ¶ 44.

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

A violation of the right to freedom from discrimination would, therefore, require a preliminary finding that the denial of legal capacity is itself a violation of ECHR rights—for example, the rights to privacy¹⁰⁴ and liberty.¹⁰⁵ It would then require a finding that people with disabilities are actually being discriminatorily denied legal capacity, thereby being discriminatorily denied their ECHR rights to privacy and liberty. Statistics on deprivations of legal capacity can often provide evidence for this claim, as they can clearly show that people with cognitive disabilities are disproportionately denied legal capacity.¹⁰⁶ *Prima facie* evidence would consist of any laws that are facially discriminatory and require a finding of cognitive disability before depriving legal capacity.

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

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

103. See, e.g., *James v. United Kingdom*, 2 Eur. Ct. H.R. 98 (ser. A), ¶ 75 (1986).

104. European Convention on Human Rights, *supra* note 90, art. 8.

105. *Id.* at 5.

106. See *supra* note 14.

107. See Winick, *supra* note 31, at 6-42, 41-42. For information on guardianship abuse in the United States see U.S. GOV'T ACCOUNTABILITY OFFICE, GAO-10-1046, GUARDIANSHIPS: CASES OF FINANCIAL EXPLOITATION, NEGLECT, AND ABUSE OF SENIORS (2010).

108. See, e.g., *James*, ¶ 75.

109. See, e.g., *id.* ¶ 50.

110. The right to equal recognition before the law is enshrined in the International Covenant on Civil and Political Rights, Dec. 16, 1966, 999 U.N.T.S. 171, art. 16, S. Exec. Doc. E, 95-2 (1978), S. Treaty Doc. 95-20, 6 I.L.M. 368 (1967). See also Universal Declaration of Human Rights, G.A. Res. 217A (III), art. 16, U.N. Doc. A/810 at 71 (Dec. 10, 1948). The CRPD establishes the right to legal capacity on an equal basis with others as an element of the right to equal recognition before the law. Convention on the Rights of Persons with Disabilities, *supra* note 16, at art. 12(2). See Anna Arstein-Kerslake, *A Call to Action: The Realisation of Equal Recognition Under the Law for People*

utmost importance and denial should be strictly scrutinized. Evidence could also be provided showing that the provision of support is more effective in creating citizens who are active participants in society and are at a lower risk of being significantly dependent on others or on government benefits.¹¹¹

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

CONCLUSION

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

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

with Disabilities in the EU, in 5 EUROPEAN YEARBOOK OF DISABILITY LAW (Gerard Quinn et al. eds.) (forthcoming 2014).

111. Although very little research has been done in this area, the successful supported decision-making pilot program in South Australia is evidence of this. See WALLACE, *supra* note 73.

112. In *Hugh Jordan v. United Kingdom*, 2001 Eur. Ct. H.R. 327, the court found that “where a general policy or measure has disproportionately prejudicial effects on a particular group, it is not excluded that this may be considered as discriminatory, notwithstanding that it is not specifically aimed or directed at that group.”

113. See, e.g., *Campeanu v. Romania*, Appl. No. 47848/08, Eur. Ct. H.R. (pending judgment) (lodged 2008); *Radiukevičius v. Lithuania*, Appl. No. 44376/06 (pending judgment) (lodged 2006).

114. This is based on the authors’ experiences of engaging in legal capacity law reform around the globe.

which have existed in substitute decision-making regimes is that safeguards for support are based on the core principle of respect for the individual's will and preferences, no matter what level of decision-making ability she holds. For example, in a support model there must be an adjudication mechanism for challenging support people if they fail to respect the will and preference of the individual. In contrast, adjudication in most current substituted decision-making regimes focuses on "protecting" the individual and discovering what is in her "best interest," with little importance placed on her will and preference.¹¹⁵ As set out in Section II, the support model does not preclude emergency interventions in exceptional circumstances to preserve the life, immediate safety, or well-being of the individual. However, further research is needed to determine a coherent basis for such interventions with appropriate safeguards to protect against a return to substituted decision-making regimes based on an objective-best-interests approach.

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

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