

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.

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