The National Guardianship Network hosted the Third World Congress on Adult Guardianship on May 28–30, 2014 in Washington, D.C. Each World Congress on Adult Guardianship facilitates learning and collaboration with participants from around the world who are involved in adult guardianship, aging, disability, and elder law. The theme of the Third World Congress was "Promising Practices to Ensure Excellence in Guardianship Around the World" with focus on the individual, guardians, the courts, and decision-making.

The convention included 120 presenters representing 21 countries over six continents. Most of the following articles are materials adapted from speeches of the Third World Congress on Adult Guardianship presenters. Therefore, the submissions included in this volume do not reflect a standard article publication.

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ISSN: 1947-7392

PERSON-CENTERED GUARDIANSHIP AND SUPPORTED DECISION MAKING: AN ASSESSMENT OF PROGRESS MADE IN THREE COUNTRIES

A. Frank Johns, Editor*

I. INTRODUCTION

The World Congress on Adult Guardianship is an unparalleled international gathering of guardianship advocates to examine problems from new perspectives and offer solutions from multiple viewpoints and cultures. The World Congress has convened every two years since the first Congress in Yokohama, Japan in 2010[1] and the second Congress in Melbourne, Australia in 2012.[2] Each World Congress has offered opportunities to learn and collaborate by bringing together those involved in adult guardianship, as well as those involved with aging, disability, and elder rights from around the globe. All participants bring a commitment to examine the best ways to shape guardianship systems so that they consistently treat vulnerable populations with dignity and respect.

The Third World Congress on Adult Guardianship convened in May 2014 near Washington D.C., United States. The session of the Third World Congress from which this article has been generated was chosen to be a ninety-minute plenary, general session

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[1] INT'L GUARDIANSHIP NETWORK, YOKOHAMA DECLARATION (Oct. 4, 2010), http://www.international-guardianship.com/pdf/IGN-Yokohama_Declaration_2010.pdf.

[2] Austl. Guardianship & Admin. Council, *2012 (Oct) 2nd World Congress: Melbourne*, AGAC.ORG, http://agac.org.au/conference-papers/72-2012-oct-2nd-world-congress-melbourne (last visited Oct. 3, 2016).

of panelists providing assessments and commentary from six countries,[3] including a moderator and facilitator, examining person-centered guardianship within the judicial process and supported decision making outside the judicial process. Panelists were instructed to focus on several areas targeted for the Third World Congress, including: (1) the individual—autonomy versus protection, self-determination, and right to legal capacity (supported decision making; implementing United Nations Convention on Rights of Persons with Disabilities);[4] (2) decision-making options and standards—person-centered planning; and 3) judicial funding—addressing limited court resources with increased demand. In addition, each panelist contributed questions and answers for a transponder exercise during the session in which participants were given the questions and used remote devices to give their answers. (The participants' answers can be found in graphs that are attached as Appendix A to this article).

Panelists that were proponents of person-centered guardianship within the judicial process began with the proposition and perspective from the United States. First, the United States does not require the fifty sovereign states to change their current judicial processes, with one exception. Second, person-centered guardianship was the focus of the Third National Summit on Guardianship in the United States (hereinafter, "the Summit"),[5] and was identified as a core value that should promote changes in the uniform model law, the Uniform Guardianship Protective

[3] The participants included A. Frank Johns, originator; Professor Rebecca C. Morgan, moderator; Professor Roberta Flowers, facilitator; Professor Doctor Makoto Arai, presenter from Japan; Professor Kees Blankman, from the Netherlands; Doctor Christer Fjordevik, from Sweden; Sue Field, from Australia; Professor Robert Gordon, from Canada; and Professor A. Frank Johns and Professor Tanya Richmond, presenters from the United States.

[4] Convention on the Rights of Persons with Disabilities (New York, 13 Dec. 2006) 2515 U.N.T.S. 3, *entered into force* 3 May 2008, *available at* https://treaties.un.org/doc/Publication/UNTS/Volume%202515/v2515.pdf.

[5] *See generally Third National Guardianship Summit Standards and Recommendations*, 2012 UTAH L. REV. (Symposium on the Third National Guardianship Summit: Standards of Excellence) 1191. The Third National Summit on Guardianships was held at University of Utah College of Law, located in Salt Lake City, Utah. *Id.*

Proceedings Act ("UGPPA").[6] The panelists also discussed the Summit topic of funding through Centers for Medicare and Medicaid Services that would implement person-centered guardianships within current judicial constructs in the states. The panelist from Australia, as a proponent implementing person-centered guardianship outside the United States, discussed advocating a third proposition of implementation that would serve as a "road map" to implementation of person-centered guardianship that should be replicated in the United States. The Canadian and Swedish proponents advocated the more radical approach of "supported decision making" as a political force that would dismantle the judicial function of guardianship and embrace Article Twelve of the United Nations Convention.[7]

II. THE CHIEF GUARDIAN SYSTEM IN SWEDEN

Dr. Theol. Christer Fjordevik[8]
Värnamo, Sweden

The Chief Guardian system in Sweden is different from other countries in that the responsibility lies at the local level, the municipality.[9] Furthermore the Chief Guardian or Chief Guardian Board[10] are elected every fourth year by the Local Government Council; therefore, the Chief Guardians or the Board members are

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[6] Nat'l Conf. of Comm'r on Uniform State Laws, *The Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act: A Summary*, UNIFORM LAW COMMISSION, http://www.uniformlaws.org/Act.aspx?title=Adult%20Guardianship%20and%20Protective%20Proceedings%20Jurisdiction%20Act (last visited Oct. 3, 2016).

[7] Convention on the Rights of Persons with Disabilities, *supra* note 4, at art. 12.

[8] The author is the Chief Guardian and the Chairman in the Municipal Council in Värnamo Municipality, Sweden. He is a clergyman in the Church of Sweden and is a doctor of theology in the field of Diaconia.

[9] *See* European Union Agency for Fundamental Rights, *Legal Capacity of Persons with Intellectual Disabilities and Persons with Mental Health Problems* (Feb. 2013), *available at* http://fra.europa.eu/sites/default/files/legal-capacity-intellectual-disabilities-mental-health-problems.pdf; *see also* Swedish Ass'n of Local Authorities & Regions, *Municipalities, County Councils and Regions*, SVERIGES KOMMUNER OCH LANDSTING, http://skl.se/tjanster/englishpages/municipalitiescountycouncilsandregions.1088.html (last visited Oct. 3, 2016).

[10] It is possible, according to the law, for the municipality to choose either a Chief Guardian or a Board, often with three or five members.

politicians. This model has been used since 1957 and before 1957, the District Courts were responsible for the Guardianship.[11]

Sweden has 290 municipalities,[12] each with a Chief Guardian or a Chief Guardian Board as the local authority. Due to the complexity in many of the cases and the lack of lawyers in the municipalities, many of the municipalities are cooperating and have one office together with a legal support team.

Sweden has about 9.9 million inhabitants[13] and the demographic situation does not differ from the majority of the European Union members.[14] The population in Sweden is getting older and older and today, in Sweden, there are almost 500,000 people older than eighty years.[15] That figure will increase during the coming decades and more people will need to have a guardian in their last days in life because of disease and because they do not have any relatives who can help them by a power of attorney. In addition, many young people need help from a representative in some form due to the increasing number of people with mental disabilities.[16]

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[11] Maarit Jänterä-Jareborg et al., *National Report: Sweden* 3 (n.d.), *available at* http://ceflonline.net/wp-content/uploads/Sweden-Parental-Responsibilities.pdf. Today's Swedish legislation regarding parental responsibilities originated in the late 1910s and 1920s when a number of Acts, commonly referred to as "the Child Acts," were passed. *Id.* In 1949, these Acts were combined into a comprehensive code, called Swedish Children and Parents Code (Föräldrabalken), which entered into force on January 1, 1950. *Id.*

[12] Swedish Ass'n of Local Authorities & Regions, *supra* note 9.

[13] Statistics Sweden, *Population Statistics*, STATISTICS SWEDEN (May 31, 2016), http://www.scb.se/be0101-en.

[14] Sweden has been a member of the EU since 1995. European Union, *Sweden: Overview*, EUROPA.EU http://europa.eu/european-union/about-eu/countries/member-countries/sweden_en (last visited Oct. 1, 2016).

[15] Some statistics show that in 2014 more than 800,000 people in Sweden were over the age of seventy-five, including almost 20,000 over the age of ninety-five. Statistics Sweden, *supra* note 13 (select "Make your own tables in the Statistical Database," then select "Number of inhabitants," then select "Population by age and sex. Year 1860–2015," finally select "age" from the classification drop down menu and year to create a table with specified information).

[16] Shruti Singh, *Sweden: Tackling Mental Health Problems Is Critical to Boosting Job Prospects of Young Swedes*, Org. for Economic Co-operation and Dev. (Mar. 5, 2013), http://www.oecd.org/newsroom/swedentacklingmentalhealthproblemsiscriticaltoboostingjobprospectsofyoungswedes.htm ("Disability benefit claims among youth for mental ill-health have almost

A. How Person-Centered Guardianship Has Been Used in Sweden

Currently, the Swedish guardianship system consists of three forms of representation for minors and adults. First, a guardian may be appointed for the protection of a minor child.[17] Today there are a lot of unaccompanied minors in almost every municipality in Sweden; consequently, there is a strong need for guardians for these minors. During 2015, the Swedish Migration Board assigned over 33,000[18] unaccompanied minors to municipalities in Sweden, most of them from Afghanistan. The guardians in these cases were appointed by the local Chief Guardian.[19]

The second form of representation is a custodian or "god man," and they may be appointed to act on behalf of an incapacitated adult.[20] Sometimes the individual has applied for the custodianship,

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quadrupled since the early 2000s, by far the largest increase across OECD countries for which data is available.").

[17] Jänterä-Jareborg et al., *supra* note 11, at 10–12 (Guardianship refers to both the administration of the minor's property and legal representation of the minor's finances.). Normally a child's parents are both custodians and guardians of the child, but if custody is transferred from the parent(s) to specially appointed custodian(s), the custodian(s) will become both custodian and guardian of the child. *Id.* However, if either parent retains custody, then no other person will be appointed as the child's custodian). *Id.*

[18] Swedish Migration Agency, *Applications for Asylum Received, 2015*, MIGRATIONSVERKET (Jan. 1, 2016), *available at* http://www.migrationsverket.se/download/18.7c00d8e6143101d166d1aab/1451894593595/Inkomna+ans%C3%B6kningar+om+asyl+2015+-+Applications+for+asylum+received+2015.pdf (The agency received over 160,000 applications for asylum in 2015, and more than 35,00 of those applications were for unaccompanied minors.). The Migration Agency is commissioned by the Swedish Parliament and government and has the authority to consider applications from people who want to visit, live in, or seek asylum in Sweden, or who want to become Swedish citizens. Swedish Migration Agency, *The Mission of the Migration Agency*, MIGRATIONSVERKET, http://www.migrationsverket.se/English/About-the-Migration-Agency/Our-mission.html (last updated Apr. 12, 2016).

[19] Alzheimer Eur., *Sweden: 2010: Legal Capacity and Proxy Decision Making*, ALZHEIMER EUR. (Mar. 28, 2012), http://www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons/Legal-capacity-and-proxy-decision-making/Sweden ("In 1989, the system of legal incompetence was replaced by the system of administrators. Trusteeship replaced the system of declaring people incompetent."). In Sweden, we have had no declaration of incapacity since 1989 after a child has reached eighteen years old. *Id.*

[20] FÖRÄLDRABALK [FB] [PARENTAL CODE] 11:4 (Swed.) ("If someone because of illness, mental disorder, poor health or similar relationship needs help to defend their rights, manage their property

but often it is Social Services who has sent a report of the need for a custodianship for a client to the Chief Guardian. Before the Chief Guardian will apply to the District Court, the Municipal Council will be in contact with nearby relatives and ask them if they agree. The Municipal Council will also request a Medical Certificate.[21] Custodianship allows an individual to maintain all legal capacities. The custodian provides assistance for an adult who needs his or her rights protected, administers property, and provides for the ward's needs. Appointment of a custodian requires consent from both the individual and the custodian, unless the individual's condition makes it impossible for the court to get his or her opinion.[22] Most often, the custodian will be appointed by a court after proposal from the Chief Guardian, who also has researched the proposed custodian and his or her suitability. The proposed custodian will be checked by the criminal register and by the Enforcement Office. In Sweden, a custodian, or "god man," is the preferred and predominant method of support.

In some cases, the custodians are appointed by the Chief Guardian,[23] instead of the District Court. For example, the custodian will be appointed if a custodian and a ward both have the same interests in an estate division and especially when it comes to the distribution of the estate. The Chief Guardian must also appoint a custodian for an individual who has an estate to administer and has a municipality as his or her place of registration, but lives in an unknown place. Even if an individual is dead but has not been found; the custodian must stay until the individual has been declared dead by the District Court. Finally, the Chief Guardian must also appoint a custodian in estate distribution cases when some of the heirs who

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or to arrange for their person, the Court shall, if necessary, decide to hold trusteeship for him or her.").

[21] Alzheimer Eur., *supra* note 19. A custodian (god man) may be requested by the person concerned, his/her immediate family, and the Chief Guardian or Public Trustees' Committee. *Id.* An application must be sent to the Public Trustees' Committee, along with the reasons for the application outlined in the social welfare report. *Id.* If possible, the application should be approved by the concerned person, but when that is not possible, a medical certificate confirming the person's inability to consent must accompany the application. *Id.*

[22] *Id.*

[23] FÖRÄLDRABALK [FB] [PARENTAL CODE] 11:1–3 (Swed.).

cannot be contacted before or after the estate division because the individual's residence is unknown.

The third form of assistance or representation is a "*Förvaltare*," which is a trustee for an incapacitated adult, appointed by the District Court.[24] The procedure to apply for a trustee is similar to the process for a custodian, however, the medical report is more decisive in the process for a trustee. The appointment of a trustee results in a loss of many of the individual's legal capacities, except for the rights to vote and marry.[25] Thus, trusteeship should only be used if absolutely necessary, to protect the individual, and if a custodianship is not sufficient. Unlike custodians, who are required to consult with the individual needing protection before acting on his or her behalf, trustees may make substitute decisions. Every year the Chief Guardian must consider if the trusteeship shall remain.

There are two main reasons to appoint a trustee: (1) to protect the individual from harming themselves or their estate; or (2) to protect the individual from the undue influence of "friends," who want to "help" him or her. For example, a trustee is needed when an individual's friends want to help the individual invest money, lend money, or give gifts to someone, and the individual is not strong enough to say no.[26] Generally, volunteers are used as trustees, however, in some complicated cases, a social company, specialized to take care of wards with this complex situation, is engaged.[27]

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[24] FÖRÄLDRABALK [FB] [PARENTAL CODE] 11:7 (Swed.).

[25] Alzheimer Eur., *supra* note 19; *see also* European Union Agency for Fundamental Rights, *supra* note 9.

[26] The Trustee's duties vary according to the specific needs of the Ward; the Trustee may solely manage the Ward's property or capital. Alzheimer Eur., *supra* note 19. In such cases, the Ward loses the right to decide matters relating to property or capital, but retains legal competence in all other matters. *Id.* The legal effects of guardianship will last until they are no longer necessary, and "[d]ecisions regarding the discontinuation of guardianship measures are made by court or the chief guardian." *Id.*

[27] There are some municipalities that for ideological reasons try to use just volunteers. However, if the custodian or Trustee is to be paid, they receive fees for their services and sometimes also for costs. *Id.* These are paid "from the ward's funds if his/her income totals more than twice the base amount or if his/her assets exceed three times the base amount. If this is not the case, the set fees are paid by the municipal authority. This is determined by the public trustees." *Id.*

B. How Supported Decision Making, Separate from Guardianship, Is Being Used in Sweden

The Chief Guardian must support the representatives when: (1) a custodian needs to move money on behalf of his or her ward, from an account which is locked by the Chief Guardian, to the custodian's account, in order to pay extra expenses on behalf of the ward, in order to protect the custodian;[28] (2) the approval of a contract for sale of property is needed[29] (i.e. house or apartment); (3) distributing an estate;[30] and (4) the Chief Guardian makes the decision when exchanging custodians or trustees.

C. Three Promising Practices in Värnamo, Sweden Implementing One or the Other Philosophy

Education of representatives will be a legal obligation for the municipalities according to a proposal for a reformed Parental Code from the January 2015. Our local experiences are that education of representatives is the best way to get high quality annual reports from custodians and trustees. So far, we have invested in education of the representatives in our region in order to increase the status for the voluntary custodians and trustees. The purpose is to determine whether all custodians and trustees should have some form of certification.

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[28] *Id.* "Certain bank accounts must be blocked to prevent unauthorized withdrawals. If it is necessary to access these funds, the approval of the public trustee must be obtained. Funds needed to cover daily expenses can be placed in an unblocked account. All accounts remain in the name of the ward." *Id.*

[29] *See generally* OM VERKAN AV AVTAL, SOM SLUTITS UNDER PÅVERKAN AV EN PSYKISK STÖRNING (Svensk författningssamling [SFS] 1924:323) (Swed.). The statute states that a contract is invalid if entered into by a person suffering from a mental disorder at the time. *Id.* Consequently, the contracting parties must return goods that were exchanged or provide adequate compensation if return or exchange is impossible. *Id.* In 1991, the law was amended to ensure that when "a contract is concluded in good faith, to such an extent as is found reasonable, [the party has] a right to receive compensation for the loss occasioned by the contract." Alzheimer Eur., *supra* note 19.

[30] ÄRVDABALK [ÄB] [INHERITANCE CODE] 13:2 (Swed.) (Swedish law states that "[a] will that has been written under the influence of a mental disorder is not valid.").

We try to encourage all representatives to keep in mind that their main goal is to make themselves unnecessary. Although that is usually impossible, having that in mind creates a respectful relationship with the ward.

Representatives are volunteers and they will earn a small remuneration once a year for their work. In some cases, often trusteeships, the recruiting of volunteers is almost impossible because of complications with the ward, such as violence and threats from young persons. In these cases, it is necessary to engage social companies who enter into a general agreement with the municipality and then an individual commissioned agreement for the ward.

D. Some Additional Personal Remarks

I have been working as a Chief Guardian since 2002, and my experience is that this is a very important work. If the Chief Guardian's office functions well, you not only help disabled individuals, you also save money for the municipality. In Sweden, the municipalities are responsible for all their inhabitants, and citizens who are in need and cannot manage their economic situations, have to be helped by the social welfare.

Second, my experience is that the Chief Guardian's work is invisible to the municipality, and most of the politician colleagues are not well informed about the work, especially not about its complexity. Without legal support, it is very difficult for a layman, an elected politician, to manage the work.

Third, my experience is that the Swedish word for the Chief Guardian is not up-to-date. The Swedish *Överförmyndare* associates to a former society, a time when there was a greater divide between the rich and poor, the powerful and powerlessness. I think we need to find another word for the function. It is the same problem with "god man," "a good man," because this is a word that can be

wrongly associated and can be used cynically to express an opposite meaning, "a bad man."

One of the backgrounds to our system with a politically elected Chief Guardian or Board is that the society wants to have democratic control over the work, which is a good intention, but can be questioned for two reasons. First, the Chief Guardian needs economic resources in order to build up an office with a competent staff. Second, the Chief Guardian needs to have the legal support of a lawyer, who is well informed and can interpret the Parental Code, which is the main law ruling the Chief Guardian's work. Not all of our municipalities in Sweden have such possibilities, which can risk the rule of law for our citizens. The Chief Guardian is the regulatory authority over the Guardians, the Custodians, and Trustees, and they often control very large sums of money, and therefore, economic and competent advisory resources are very important.

III. SUPPORTED DECISION MAKING IN CANADA
Professor Robert Gordon[31]

The practice of supported (also known as assisted or interdependent) decision making is relatively well established in many Canadian jurisdictions[32] due, primarily, to the efforts of the Canadian Association for Community Living and related organizations.[33] Supported decision making is especially popular

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[32] Canada has a federal system of government with thirteen provinces and territories each legislating separately in the areas of adult guardianship, substitute decision making, and incapacity planning. The provinces and territories are common law jurisdictions with the exception of the Province of Quebec, which is a Civil Code jurisdiction. The Canadian Charter of Rights and Freedoms is the overarching superior legislation governing human and civil rights issues but the provinces and territories have also legislated in the same general area (e.g., Human Rights Codes).

[33] The Ontario Association for Community Living and Inclusion B.C. (formerly, the British Columbia Association for Community Living) is a long-standing and extremely effective non-government organization with branches in each jurisdiction. The organization is a family-based non-profit that develops and advocates for progressive policies and policy reforms which benefit people with developmental disabilities and their families and friends. The organization also contract with governments to provide a range of related services. For a review of adult guardianship legislation in Canada see COMPARATIVE PERSPECTIVES ON ADULT GUARDIANSHIP 109, 109–20 (A. Kimberley Dayton ed., 2014).

west of the Great Lakes, but it is also the subject of extensive discussions, and some debate, in jurisdictions that have yet to legislate in favor of the practice.[34]

Supported decision making was *not* introduced as a result of the U.N. Convention on the Rights of People with Disabilities;[35] indeed, existing Canadian legislative and policy initiatives in the area may have contributed to the development of some of the Articles in the Convention. Although the history is murky, supported decision making *as a practice* seems to have arrived in Canada in the 1970s with the appointment of the late Wolf Wolfensberger to the Toronto-based National Institute on Mental Retardation, and the subsequent promotion of the concepts of "normalization,"[36] "citizen advocacy,"[37] and the "dignity of risk."[38]

Supported decision making and its close cousins (e.g., assisted decision making and co-decision making) have been legislated in different ways in Canada and are viewed as some of several important alternatives to the use of court-ordered guardianship for particular constituencies of adults.[39] The tendency, across the country, is to discourage the use of court-ordered guardianship in favor of less restrictive, less intrusive, and less stigmatizing options that meet a disabled adult's needs and benefit

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[34] *See* Law Comm'n of Ont., *Legal Capacity, Decision-Making and Guardianship*, LAW COMM'N OF ONT., http://www.lco-cdo.org/en/capacity-guardianship (last visited Oct. 3, 2016).

[35] Convention on the Rights of Persons with Disabilities, *supra* note 4. Canada ratified the Convention in 2010 with some reservations and did not ratify the Optional Protocol dealing with complaints.

[36] *See generally* WOLF WOLFENSBERGER, & HELEN ZAUHA, CITIZEN ADVOCACY AND PROTECTIVE SERVICES FOR THE IMPAIRED AND HANDICAPPED (1972) (defining "citizen advocacy" as the provision of aid in the meeting of instrumental and expressive needs of a handicapped individual by a competent citizen volunteer).

[37] *Id.*

[38] *See generally* Robert Perske, *The Dignity of Risk and the Mentally Retarded*, 10 MENTAL RETARDATION, Feb. 1972, *available at* http://mn.gov/mnddc/ada-legacy/pdf/The_Dignity_of_Risk.pdf.

[39] Notably, adults with developmental disabilities and adults with brain injuries. *See, e.g.*, ROBERT M. GORDON, THE B.C. INCAPACITY PLANNING LEGISLATION, ADULT GUARDIANSHIP ACT, AND RELATED STATUTES, ch. 1 (2015); ROBERT M. GORDON & SIMON N. VERDUN-JONES, ADULT GUARDIANSHIP LAW IN CANADA, ch. 6 (1992).

the adult (as opposed to others), while preserving the person's fundamental rights and freedoms. In some jurisdictions, a specific provision is made for supported decision making as an option to be considered before and instead of court-ordered guardianship; in others, it can be a disposition of a court or administrative tribunal. It can also take the form of a specific legal relationship, similar to agency, created through written agreements between adults and their families and support networks,[40] but subject to monitoring and other forms of oversight, especially with respect to assisted financial management.[41] These provisions are often buttressed with legislated principles affirming every adult's right to autonomy and self-determination and to the least restrictive and intrusive, but most effective, form of support and assistance when incapable and in need. Court proceedings should only be used as a last resort and legislation often codifies the long standing, rebuttable, common law presumption of capacity of *all* adults (e.g., a person over the age of eighteen or nineteen, depending upon the jurisdiction).[42] Additionally, legislation in some jurisdictions makes it clear that an adult's manner of communication (i.e., the use of Bliss symbols or computer devices) cannot, alone, be used as grounds for deciding that the adult is incapable.[43]

Unfortunately, there is very little formal research on supported decision making in practice despite the long experience. In British Columbia, for example, legislation embracing the option was passed in 1993, and came into force in 2000.[44] However,

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[40] *See, e.g.*, 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, 69 (2000); Michael Bach & Lana Kerzner, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity*, LAW COMM'N OF ONT., Oct. 2010, at 1, 53–54, *available at* http://www.lco-cdo.org/disabilities/bach-kerzner.pdf.

[41] *See* Bach & Kerzner, *supra* note 40 at 118; Krista James & Laura Watts, *Understanding the Lived Experiences of Supported Decision-Making in Canada: Legal Capacity, Decision-Making and Guardianship*, LAW COMM'N ONT., Mar. 2014, at 1, 24, *available at* http://www.lco-cdo.org/capacity-guardianship-commissioned-paper-ccel.pdf.

[42] *See e.g.*, CIVIL CODE OF QUEBEC, S.Q. 2016, c. 64, art. 154 (Can.).

[43] *See, e.g.*, The Adult Guardianship Act, R.S.B.C. 1996, c. 6, § 3(2); The Representation Agreement Act, R.S.B.C. 1996, c. 405, § 3(2), as amended. For a detailed analysis see, GORDON & VERDUN-JONES, *supra* note 39, at ch. 1–5.

[44] *See id*. at ch. 1–2.

supported decision making had been used, apparently with good results, from at least the 1980s onward, by those involved with community living associations. Supported decision making subsequently appeared in the package of new provincial adult guardianship (and non-guardianship) legislation that sought to meet the needs of the *full* range of adults with disabilities, including those with degenerative diseases of aging and those with brain injuries. There had been effective lobbying for supported decision-making provisions by individuals and organizations within the community living movement; the latter had a seat at the policy table, and therefore, direct involvement in the process of developing British Columbia's legislation. Community living organizations have also been, and continue to be, extremely influential in other Canadian jurisdictions, such as Saskatchewan, Manitoba, and Ontario.

Although supported decision making in Canada is associated primarily with developmental disabled people (and their families), there is interest on the part of other constituencies. This is becoming increasingly apparent as work begins on exploring supported decision-making practices, including the research that has been conducted by the Canadian Centre for Elder Law on behalf of the Ontario Law Commission. This research is aimed at a better understanding of both the lived experiences of, and the perspectives of those analyzing, assisted and supported decision making practices across Canada.[45] Although researchers acknowledge that they were only able to undertake an "initial scoping of the issues" with a small number of people in five jurisdictions,[46] the results are extremely helpful. Some of the issues that surfaced included the following: the tension between the originally informal and a more recently formalized conception of supported decision making and the difficulties in understanding the new legislation, on the part of both those providing support and those providing services to adults, such

[45] James & Watts, *supra* note 41.

[46] *Id.* at 5. Five jurisdictions address supported-decision making in Canada including British Columbia, Yukon, Alberta, Saskatchewan, and to a limited extent, Manitoba. *Id.* at 24.

as financial institutions. It was also noted that supported decision making seems to work best for younger adults with mild to moderate disabilities who have strong, active, and committed circles of support.[47] For those using supported decision making agreements of the kind found in British Columbia, there were additional concerns including the excessive formalization of a pre-existing system of family-based informal supports and assistance; the costs and complexity of creating agreements; the possibility that adults are entering into agreements without understanding what they are doing; and the lack of knowledge of agreements on the part of health and social service providers. Concerns were also expressed about the "challenging, pressure-filled responsibility" of being a supportive decision maker, and the slippage that frequently occurs at the interface of supported and substitute decision making; it is easier to decide than to support someone to decide.[48]

Supported decision making is an extremely difficult area to conduct evaluative research. There is significant access, funding, and ethical barriers, such that the question of evaluation should be approached differently.[49] Arguably, and given its popularity and acceptance within the community living movement in particular, the question should not be "does supported decision making work;" instead, the question should be, "is there anything to suggest it does *not* work?" This question is easier to tackle, and probably more useful in terms of developing policy and practice, because such research may point to concrete practice issues that can and should be addressed. Reports of abuse or financial mismanagement, for example, can signal problems but be the basis for remedial interventions by a public guardian, trustee service, or similar adult protection body.[50] It is far easier to assume the benefits of supported

[47] *Id.* at 8.
[48] *Id.* at 11.
[49] For example, access can be challenging in British Columbia because many representation agreements are done informally within the family unit, and are not required to be registered. Further, researchers are not granted easy access to the agreements that are registered. *Id.* at 47.
[50] Every Canadian jurisdiction has the equivalent of a public guardian and trustee service funded by a combination of fees for services on the financial management (i.e., trusteeship) side and by government. *See, e.g.*, Adult Guardianship Act, R.S.B.C. 1996, c. 6. (2015) (Can.); Adult Guardianship Act, R.S.A., c. A-4.2 (2013) (Can.).

decision making based upon years of informal practice, and then focus on measurable issues as they surface. At this time, there is considerable anecdotal evidence that, in Canadian jurisdictions, supported decision making works for people and no harm comes from it. Indeed, it is clear that supported decision making is an extremely popular alternative to court-ordered guardianship in some quarters and is embraced as an article of faith by many.

The hope is that others will build upon the Ontario Law Commission research. This would go a long way toward improving our understanding of supported decision making in practice, as well as enhancing and improving key policies and practices. Views about supported decision making tend to divide those who actually know about the practice; there are romantics and there are skeptics, as there are in many other areas of public policy. Importantly, though, pragmatists have identified the importance of deep and rich seams of support based upon family ties, commitments, and routinized involvement in the lives of adults receiving assistance. These elements are the hallmark of those involved with community living associations but are not exclusively held by that group. Other communities of interest who are equally dedicated and committed feel the option could be beneficial and want to try supported decision making; these groups include individuals with brain injuries and their families, and those with degenerative diseases of aging, particularly Alzheimer's disease.

At the same time, however, it will be clear that there are limits to the use of supported decision making. Those with Alzheimer's disease, for example, may lack the necessary participatory abilities, especially in the case of a person experiencing the late stages of the disease. Similarly, while individuals with psychiatric disorders may want to try supported decision making, as opposed to substitute decision making, this may

not be a good fit because of the often episodic and volatile nature of their disorders. Often, mental health advance directives made during a period of stability and capacity might make more sense for the members of this constituency. Arguably, as usage spreads beyond the original, core, community (i.e., those with developmental disabilities), the risk of failure increases and the growing acceptability of supported decision making may be reversed with significant consequences for all constituencies. Overreach could result in an unexpected, high profile, and extremely damaging incident that frustrates the kind of sea-change that is currently under way and needs to continue.

In conclusion, Canadian practice suggests that supported decision making works, and works well, but only when some specific elements are in place. There has to be a supportive infrastructure, preferably in the hands of family-based, non-government organizations, such as the Canadian Association for Community Living; a plentiful supply of support persons who are well versed in the gentle art of providing ethical decision-making support (as opposed to *substitute* decision making). Supported decision making requires appropriate adult protection agencies that can provide an effective and responsive safety net (i.e., a public guardian and trustee service); and gatekeeping organizations (notably, in the health, social service, and financial sectors) that recognize and respect this key alternative to court-ordered guardianship.

IV. THE AUSTRALIAN PERSPECTIVE ON ADULT GUARDIANSHIP[51]

Sue Field[52]

A. Preamble

Australia, like the United States of America and Canada (and unlike countries such as England and New Zealand), has a federal system of government and comprises six states and two territories. As a nation, Australia ratified the Convention on Rights of Persons with Disabilities in July 2008 and the Optional Protocol in August 2009.[53] However, although there is both federal and state/territory legislation prohibiting discrimination[54] on the grounds of disability, it would appear that it is more honored in the breach than the observance, should discrimination occur. Furthermore, legal redress may be difficult due to limited access to justice for those who are disadvantaged through disability, finances, or age.

B. Adult Guardianship Legislation

Although there is no federal legislation relating to guardianship, all states and territories have legislation in respect of adult guardianship.[55] Underpinning this legislation is general

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[51] Since the writing of this Article there have been some positive moves towards supported decision making in some Australian jurisdictions. For example, see the Victorian *Powers of Attorney Act 2014* – Part 7 – Supportive Attorney Appointments; A further Supported Decision Making Project in New South Wales; and a three jurisdiction study on supported decision making currently in progress and conducted by the Cognitive Decline Partnership Centre.

[52] Sue Field is an Adjunct Fellow in Elder Law at Western Sydney University and she is well known for her publications, presentations, and research in this emerging specialty.

[53] Convention on the Rights of Persons with Disabilities, *supra* note 4.

[54] *See, e.g.*, *Anti-Discrimination Act 1977* (NSW) (Austl.); *Anti-Discrimination Act 1991* (QLD) (Austl.); *Discrimination Act 1991* (ACT) (Austl.); *Anti-Discrimination Act 1998* (TAS) (Austl.); *Anti-Discrimination Act* (NT) (Austl.); *Disability Discrimination Act 1992* (Cth) (Austl.); *Equal Opportunity Act 1984* (WA) (Austl.); *Equal Opportunity Act 2010* (VIC) (Austl.); *Equal Opportunity Act 1984* (SA) (Austl.).

[55] *See Guardianship and Administration Act 1990* (WA) (Austl.); *Guardianship Act 1987* (NSW) (Austl.); *Adult Guardianship Act* (NT) (Austl.); *Guardianship and Administration Act 1990* (WA) (Austl.); *Guardianship and Administration Act 1995* (TAS) (Austl.); *Guardianship and Administration Act 2000* (QLD) (Austl.); *Guardianship and Administration Board Act 1985* (VIC)

principles, which govern persons who exercise functions pursuant to the legislation. These principles, in effect, reflect the general principles found in Article Three of the Convention:[56]

a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
b) Non-discrimination;
c) Full and effective participation and inclusion in society;
d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
e) Equality of opportunity;
f) Accessibility;
g) Equality between men and women; and
h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

For example, in New South Wales[57] the principles state that:

(a) the welfare and interests of such persons should be given paramount consideration;
(b) the freedom of decision and freedom of action of such persons should be restricted as little as possible;
(c) such persons should be encouraged, as far as possible, to live a normal life in the community;
(d) the views of such persons in relation to the exercise of those functions should be taken into consideration;

(Austl.);*Guardianship and Management of Property Act 1991* (ACT) (Austl.); *Guardianship and Administration Act 1993* (SA) (Austl.).

[56] Convention on the Rights of Persons with Disabilities, *supra* note 4.

[57] Sue Field, this panel member, currently resides in New South Wales.

(e) the importance of preserving the family relationships and the cultural and linguistic environments of such persons should be recognized;
(f) such persons should be encouraged, as far as possible, to be self-reliant in matters relating to their personal, domestic and financial affairs;
(g) such persons should be protected from neglect, abuse, and exploitation; and
(h) the community should be encouraged to apply and promote these principles.[58]

In practice the various tribunals, when hearing matters relating to guardianship, underpin their decisions using a person-centered approach by reference to the principles outlined above. However, it may be argued that the power of tribunals to make plenary orders in respect of financial matters is in fact a breach of Article Twelve of the Convention.[59]

C. The Reality

If a tribunal appoints one of the statutory authorities as Financial Manager or Guardian, the policy governing their role is to utilize an assisted or supported decision-making process wherever possible.[60] But not all decision making for persons with impaired

[58] *Guardianship Act 1987* (NSW) s 4 (Austl.), states that "it is the duty of everyone exercising functions under this Act with respect to persons who have disabilities to observe the following," and then lists the principles above.
[59] Convention on the Rights of Persons with Disabilities, *supra* note 4 at art. 12(5) (Article Twelve, entitled "Equal Recognition before the Law," explains that "[s]ubject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, *to control their own financial affairs* and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property" (Emphasis added).
[60] Supported decision-making has gained momentum through the Convention on the Rights of Persons with Disabilities. Article Twelve of the Convention obliges State parties to recognize that people with disabilities enjoy equal legal capacity with others, including the right to be recognized as a person before the law and have one's decisions legally validated. *See* Queensland Gov't Office of the Pub. Advocate Sys. Advocate, *A Journey Towards Autonomy? Supported Decision-Making in*

capacity is directed, in the first instance, by the various tribunals. For example, for medical and dental decisions, should there not be a formal guardian appointed (either by the tribunal or the person themselves prior to loss of capacity) then, using a hierarchical structure,[61] there is a provision in the legislation for a "person responsible."[62] In descending order, this can be the spouse in a close and continuing relationship,[63] someone who cares for the person,[64] or a close friend or family member.[65] However, it is at the level of guardianship on a daily basis that the theory and best of intentions often collide. Although the best interests of the person requiring assistance may be paramount in the eyes of the person assisting, a lack of knowledge associated with the principles, and the lack of an ability to put them into effect, may result in a situation of substituted rather than assisted decision making. In these situations, the person with an impaired capacity may in fact have all of their daily living decisions made for them.

Publications such as the 'Capacity Toolkit[66] assist in overcoming this knowledge deficit. The Toolkit defines six basic principles to be followed when assisting persons with an impaired capacity; these principles include the following:

Theory and Practice, QUEENSLAND GOV'T (Feb. 2014), www.justice.qld.gov.au/__data/assets/pdf_file/0005/249404/Decision-making-support-for-Queenslanders-with-impaired-capacity-A-review-of-literature-March-2014.pdf.

[61] *Guardianship Act 1987* (NSW) s 33(A) ¶ 4 (Austl.). The top of the hierarchy is the appointed guardian. There is a hierarchy of persons from whom the person responsible for a person other than a child or a person in the care of the Secretary under section thirteen is to be ascertained. That hierarchy begins, in descending order: (a) the person's guardian, if any, but only if the order or instrument appointing the guardian provides for the guardian to exercise the function of giving consent to the carrying out of medical or dental treatment on the person. *Id.*

[62] *Guardianship Act 1987* (NSW) s 33(A).

[63] *Id.* Provided that the spouse is not under a guardianship order. *Id.* at s 33(A) ¶ 4(b)(ii).

[64] *Guardianship Act 1987* (NSW) s 3(D)(1) (Austl.). This section of the Guardianship Act does not extend to caring for a person in a professional capacity. *Guardianship Act 1987* (NSW) s 3(D)(1) defines a person having the care of another person as someone who regularly (a) provides domestic services and support, or (b) arranges for such services and support, but does not receive remuneration from the person or any other source.

[65] *Guardianship Act 1987* (NSW) s 33(A) ¶ 4(d).

[66] N.S.W., Attorney General's Dep't, *Capacity Toolkit* (2008), *available at* http://www.justice.nsw.gov.au/diversityservices/Documents/capacity_toolkit0609.pdf.

1. Always presume a person has capacity;
2. Capacity is decision specific;
3. Don't assume a person lacks capacity based on appearances;
4. Assess the person's decision-making ability—not the decision he or she makes;
5. Respect a person's privacy; and
6. Substitute decision making is a last resort.

Support for private guardians can also be found with the various offices of the Public Guardians who have Private Guardian Support Units.[67] These units provide a confidential pro bono service for legally appointed guardians (that is, appointed either by the person themselves prior to losing mental capacity, or by the relevant Guardianship Tribunal).

D. Promising Practices

In South Australia, a Supported Decision-Making Project was undertaken from 2010 through 2012,[68] which provided a "non-statutory supported decision making agreement" with the aim of maximizing the autonomy of people with a disability and is consistent with Article Twelve of the Convention.[69] Upon evaluation of the project, it was found that "the project provided specific benefits to most participants . . . [which] included increased

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[67] Private Guardian Support Unit, *An Information and Support Service for Guardians Appointed in NSW* (May 2010), *available at* www.publicguardian.justice.nsw.gov.au/Documents/pgsu_brochure_final_may_2010.pdf. The Private Guardian Support Unit is a "free and confidential service available to guardians" that does not "supervise the actions or decisions of guardians," but rather offers information on "the rights and responsibilities a guardian has to the person under guardianship," decision-making best practices, and resources available to people with disabilities. *Id.*

[68] Off. of Pub. Advocacy, *Resources: Supported Decision Making*, OFF. OF THE PUB. ADVOC., http://www.opa.sa.gov.au/resources/supported_decision_making (last visited Oct. 3, 2016) [hereinafter Off. of Pub. Advocacy, *Resources*]; Off. of Pub. Advocacy, *Annual Report 2012*, OFF. OF THE PUB. ADVOC. 54–67, http://www.opa.sa.gov.au/resources/annual_report (last visited Oct. 3, 2016) (click on "Annual Report 2011–2012").

[69] Off. of Pub. Advocacy, *Resources*, *supra* note 68.

confidence in decision making, improved decision making skills, and a feeling of greater control in a person's life."[70]

New South Wales is currently undertaking the state's first supported decision-making trial related to financial management. The pilot "aims to develop and test a range of options that enhance decision making control an individual has in their life."[71] The overall goal will be to "reflect the United Nations Convention on the Rights of People with Disabilities."[72] There is light at the end of the tunnel—and it's not an oncoming train!

V. TRANSPONDER QUESTIONS, INTERACTIVE PARTICIPANT RESPONSES, AND FACULTY ANSWERS WITH COMMENT

A. Summary of the Transponder System and its Operation During the Plenary General Session

As described in the introduction, one of the requirements of the panelists participating in this plenary general session was to prepare 2 questions with multiple choice answers. Moderator Professor Rebecca C. Morgan and Facilitator Professor Roberta K. Flowers organized all questions and possible answers in a transponder system. The transponder system is a mechanical and software system that allows all participants to enter anonymous answers through remote devices when instructed to do so. They are given ample time to respond and as they make their selection the percent of voting participants is tallied until it reaches 100%, or time is called by the facilitator.

After each panelist gave oral comments lasting approximately 7 minutes, their prepared questions and multiple

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[70] *Id.*
[71] N.S.W. Trustee & Guardian, *Annual Report 2012–2013*, N.S.W. TRUSTEE & GUARDIAN 38 (2012–2013), *available at* http://www.tag.nsw.gov.au/verve/_resources/NSW_Trustee__Guardian_Annual_Report_2012-13[1].pdf.
[72] *Id.*

answers were presented to the participants and they responded. The tabulations of the answers were instantaneous once the facilitator closed the voting.

Each panelist then provided their opinion as to the right answer and commentary. While anecdotal, the exercise as a whole provided insight into participant understanding of person-centered guardianship and supported decision-making in the countries of panelist as well as their own countries.

Appendix A, attached to this Article is a spreadsheet organized by Professors Morgan and Professor Flowers taken from the data in the transponder system that shows the participant answers. Below are answers and comments from the panelists.

1. Q&A–Dr. Prof. Arai

1. What shall a guardian obtain for sale on principal's behalf with regard to a building used for the principal's residence ?

Possible Answers:

1. Nothing
2. Permission of the Local Authority
3. Permission of the Family Court

Correct Answer: **(3)** Permission of the Family Court

Previously, the powers of the guardian were not limited. But in the current law the powers of the guardian are limited, especially when he or she sells the principal's residence. The idea behind this is an emphasis on protecting livelihoods. When the guardian sells it without the permission of the Family Court, the transaction is absolutely void.

2. How often has the advisership been utilized?

Possible Answers:

1. Guardianship 5%
   Curatorship 10%
   Advisership 85%

2. Guardianship 10%
   Curatorship 40%
   Advisership 50%

3. Guardianship 85%
   Curatorship 10%
   Advisership 5%

Correct Answer: **(3)** Guardianship 85%, Curatorship 10%, Advisership 5%

Advisership is the most recommendable category of the statutory guardianship. It is conformable with the VN Convention. But it has not been well used. How should we increase the use of advisership? That is our challenge.

2. Q&A–Professor Blankman

1. A women with a severe intellectual disability is not able to take care of her interests and a guardianship measure is needed. She lives in an institution and has a brother who visits her weekly. Her level of development equals a 3 year old girl. Now there are several options under Dutch law. Suppose you are a judge. What would you decide?

Possible Answers:

1. She is entitled to receive the best and most extensive protection that is available and for that reason I would favor full

guardianship. This measure results in loss of legal capacity, but that is not really a problem. She does not notice and does not mind.

2. I would give her both a protective trust and a personal guardianship. The combination of the two guardianship provisions result in limitation of her legal capacity. Since she will not be able to enter into contracts that are harmful to her physical or financial situation, full guardianship is not needed.

3. Because her brother is authorized under the Medical Treatment Act to represent her and no appointment is needed for that, as a judge I would only provide her with a protective trust to make sure that her financial interests are taken care of and the necessary payments are made.

Correct Answer: **(2)** I would give her both a protective trust and a personal guardianship. The combination of the two guardianship provisions result in limitation of her legal capacity. Since she will not be able to enter into contracts that are harmful to her physical or financial situation, full guardianship is not needed.

2. *Under Dutch guardianship law preference is given to partners and close family members when the court is asked to appoint a guardian. The recently introduced quality requirements for guardians do not apply to guardians who are partner or close family member (family guardians). Which thesis is the most correct one in your opinion?*

Possible Answers:

1. It is correct that Dutch guardianship law has this preference. The important role of partners and family members should even be strengthened: the requirement of willingness as a condition to be appointed should be skipped and the law should formulate that a partner or close

family member is obliged to take up the role of guardian. Only a valid excuse will prevent him or her from being appointed.

2. The preference under Dutch guardianship law is correct but quality requirements should apply to all guardians.

3. This preference should be cancelled. There is no research to prove or indicate that abuse by professional guardians or guardians from outside the family occurs more often than abuse by family members and partners. As for quality requirements no distinction should be made between professional guardians and family guardians.

4. This preference is correct and universal. Quality requirements should only apply to partners and family members when the adult has substantial assets.

The correct answer I would say, is 4, but if most of the participants would favor answer/thesis 2, I could comment on that within a few minutes.

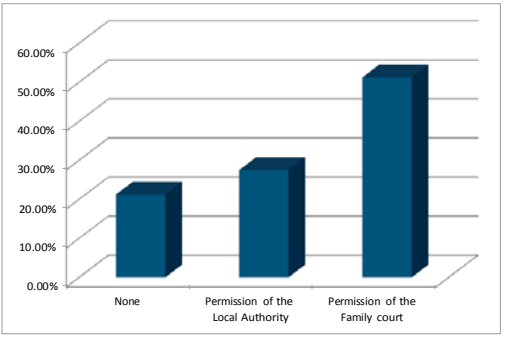
VI. CONCLUSION

This Article presents the comments and writing of panelists from a plenary general session of the 3rd World Congress on Guardianship. In addition to the comments, the article provides the outcome of participant involvement with interactive questions discussed during the session. The session suggested that more is known about person-centered and supported decision-making by those immersed in guardianship around the world. Person-centered guardianship and supported decision making are changing the experience of aging across the world and it is only a matter of time before this practice becomes the global norm.

APPENDIX A

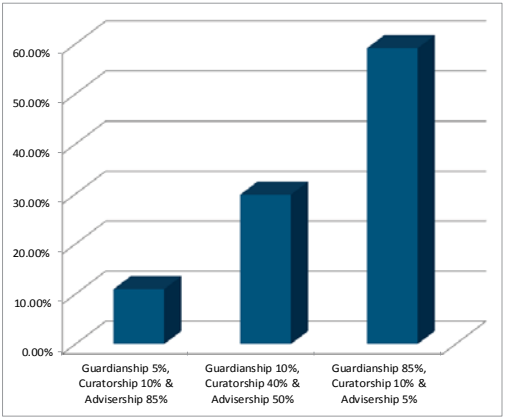
5. What authority, if any, must a guardian obtain to sell the principal's residence ? (Multiple Choice)

	Responses	
	Percent	Count
None	21.25%	34
Permission of the Local Authority	27.50%	44
Permission of the Family court	51.25%	82
Totals	**100%**	**160**



6. How often has the advisership been utilized (Multiple Choice)

	Responses	
	Percent	Count
Guardianship 5%, Curatorship 10% & Advisership 85%	10.98%	18
Guardianship 10%, Curatorship 40% & Advisership 50%	29.88%	49
Guardianship 85%, Curatorship 10% & Advisership 5%	59.15%	97
Totals	**100%**	**164**



Question 7

Woman, severe intellectual disability (developmental level of 3 year old), not able to care for her interests & guardianship needed. Lives in institution & brother visits weekly. Several options under Dutch law. As judge, what would you decide?

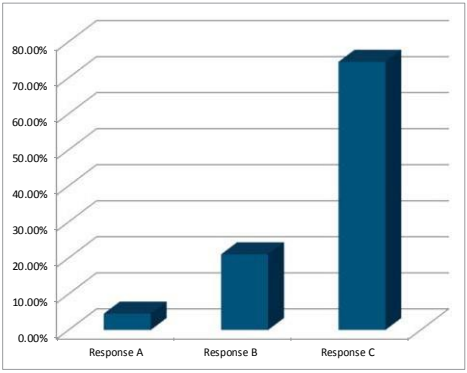
Transponder Response to Question 7

	Responses	
	Percent	**Count**
Response A	4.55%	8
Response B	21.02%	37
Response C	74.43%	131
Totals	**100%**	**176**

Response A: Entitled to best & most extensive protection available; favor full guardianship. Results in loss of legal capacity, but she doesn't notice & doesn't mind

Response B: Protective trust & personal guardianship. Results in limitation of legal capacity. Since not able to enter into harmful contracts, full guardianship not needed

Response C: Since brother authorized to represent under Medical Treatment Act, only provide with protective trust to protect financial interests & make necessary payments



Question 8

Under Dutch guardianship law, preference given to partners & close family members when court is asked to appoint guardian. New quality requirements for guardians do not apply to guardians who are partner or close family member (family guardians). Which thesis is most correct?

Transponder Response to Question 8

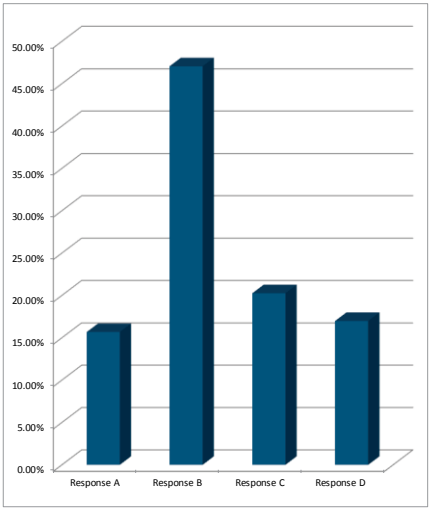
	Responses	
	Percent	**Count**
Response A	15.69%	24
Response B	47.06%	72
Response C	20.26%	31
Response D	16.99%	26
Totals	**100%**	**153**

Response A: Correct Dutch guardianship law has this preference. Important role of partners & family should be strengthened: requirement of willingness as condition to be appointed should be skipped & law should formulate partner or close family member obliged to take up guardian role. Only valid excuse prevents appointment.

Response B: Preference under Dutch guardianship law is correct but quality requirements should apply to all guardians.

Response C: Preference should be cancelled. No research to prove or indicate abuse by professional guardians or guardians from outside family occurs more often than abuse by family & partners. Quality requirements-no distinction made between professional & family guardians.

Response D: Preference is correct & universal. Quality requirements only apply to partners & family when adult has substantial assets.



Question 9

Tom 85, diagnosed with dementia. Lifelong heavy smoker, he has suffered diminished blood flow particularly to lower left leg over last few years. Doctor recommends above knee amputation. As legal guardian for medical & dental treatment decisions, what would you do?

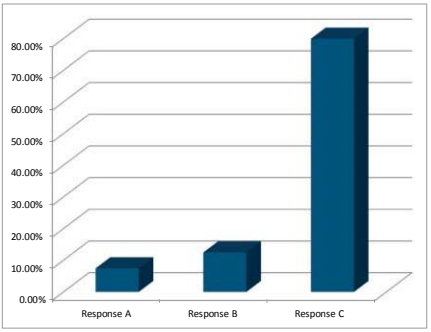
Transponder Response to Question 9

	Responses	
	Percent	**Count**
Response A	7.50%	12
Response B	12.50%	20
Response C	80.00%	128
Totals	**100%**	**160**

Response A: Tell Tom he is having operation to make his leg better.

Response B: Tell doctor this is medical decision, so do whatever he/she thinks necessary.

Response C: Spend time with Tom to get his understanding of what is happening, and support his decision – whatever it is.



Question 10

Phillipa, 25, suffered a brain injury from motor vehicle accident. In a sexual relationship with 40-year-old male, also with acquired brain injury. Health professionals think testing for sexually transmitted diseases "in Phillipa's best interest." As legal guardian with accommodation & community services function, what do you do?

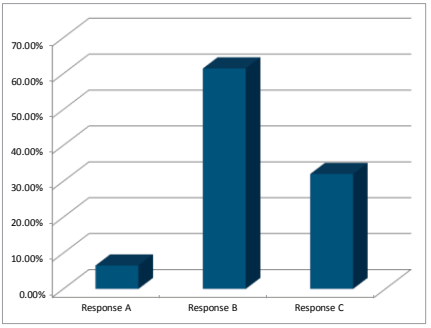
Transponder Response to Question 10

	Responses	
	Percent	**Count**
Response A	6.54%	10
Response B	61.44%	94
Response C	32.03%	49
Totals	**100%**	**153**

Response A: Agree with health professionals, and schedule tests as soon as possible.

Response B: Discuss situation with Phillipa, and support decision as her legal substituted decision maker – whatever the decision.

Response C: Do none of the above--not within your function.



Question 11

What does Sweden provide its incapacitated adults?

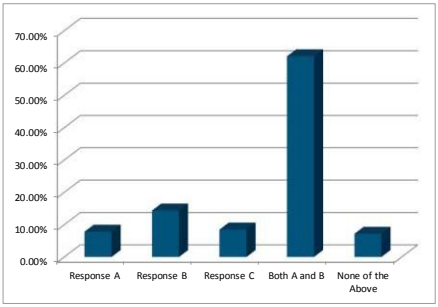
Transponder Response to Question 11

	Responses	
	Percent	**Count**
Response A	7.84%	12
Response B	14.38%	22
Response C	8.50%	13
Both A and B	62.09%	95
None of the Above	7.19%	11
Totals	**100%**	**153**

Response A: Person-centered guardianship

Response B: Supported decision-making through judicial process

Response C: Supported decision-making without judicial process



Question 12

The guardian or supporting person of the incapacitated adult has the authority to do which of the following?

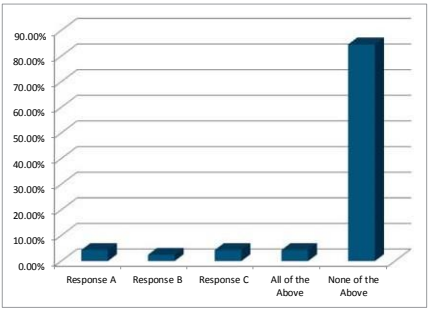
Transponder Response to Question 12

	Responses	
	Percent	**Count**
Response A	4.32%	7
Response B	2.47%	4
Response C	4.32%	7
All of the Above	4.32%	7
None of the Above	84.57%	137
Totals	**100%**	**162**

Response A: Involuntarily place the incapacitated adult in a locked institution.

Response B: Restrict the incapacitated adult from smoking, drinking or using mind altering

Response C: Restrict the incapacitated person from marriage or birthing babies.



Question 13

Canadian practice suggests that supported decision-making works best with:

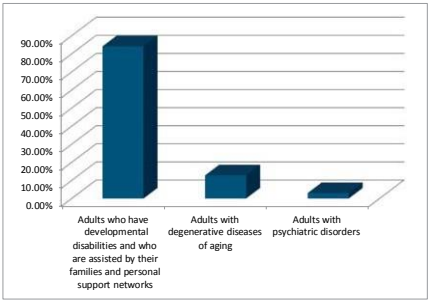
Transponder Response to Question 13

	Responses	
	Percent	**Count**
Response A	84.15%	138
Response B	12.80%	21
Response C	3.05%	5
Totals	**100%**	**164**

Response A: Adults who have developmental disabilities and who are assisted by their families and personal support networks

Response B: Adults with degenerative diseases of aging

Response C: Adults with psychiatric disorders



Question 14

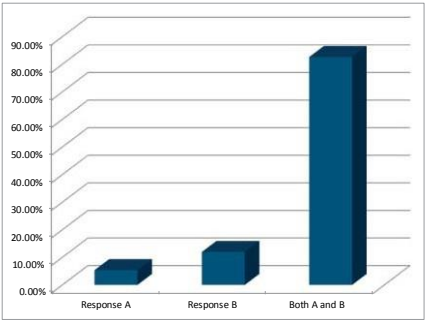
In some Canadian jurisdictions, supported decision-making is:

Transponder Response to Question 14

	Responses	
	Percent	**Count**
Response A	5.39%	9
Response B	11.98%	20
Both A and B	82.63%	138
Totals	**100%**	**167**

Response A: An option that must be considered by courts before a guardianship order is made

Response B: A relationship that can be created through agreements between adults and their families and support networks



Question 15

Why is it important to champion self-direction & person-centeredness with regard to guardianship?

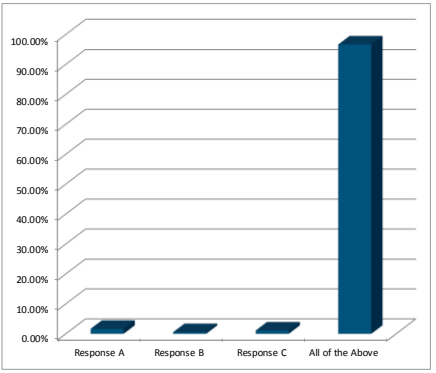
Transponder Response to Question 15

	Responses	
	Percent	**Count**
Response A	1.68%	3
Response B	0.56%	1
Response C	1.12%	2
All of the Above	96.65%	173
Totals	**100%**	**179**

Response A: Because everyone deserves to have positive control over life

Response B: Because complexities of coordinating and managing supports and services for older adults require thorough knowledge of individual wishes

Response C: Because physical, emotional, and mental health needs of people are fluid and need to be continuously assessed in making decisions



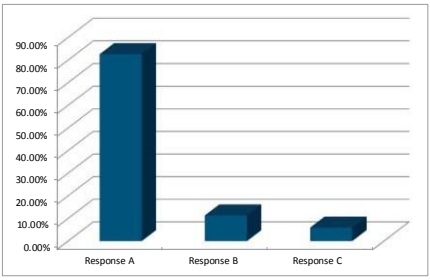
Question 16

Persons with dementia may be able to indicate preferences related to daily care but not make decisions about complex treatment choices. This concept is known as:

Transponder Response to Question 16

	Responses	
	Percent	**Count**
Response A	82.63%	138
Response B	11.38%	19
Response C	5.99%	10
Totals	**100%**	**167**

Response A: Decision-specific capacity
Response B: Decision-making capacity
Response C: Competence



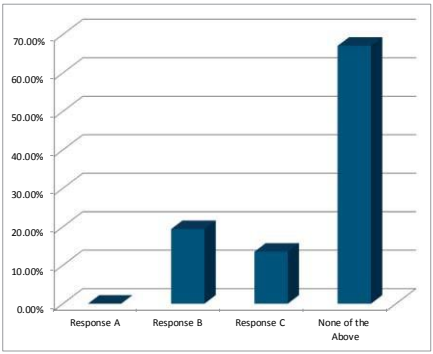
Question 17

The distinct difference between Person-Centered guardianship & Supported Decision-Making is?

Transponder Response to Question 17

	Responses	
	Percent	**Count**
Response A	0.00%	0
Response B	19.41%	33
Response C	13.53%	23
None of the Above	67.06%	114
Totals	**100%**	**170**

Response A: Person-Centered guardianship receives governmental funding
Response B: Supported Decision-Making is primary approach for serving vulnerable persons in most countries
Response C: Person-Centered guardianship is usually judicial action that takes away individual rights of the person adjudicated incapacitated



STEPPARENTS VERSUS STEPCHILDREN: USING MEDIATION TO AVOID CONTESTED GUARDIANSHIPS IN BLENDED FAMILY SITUATIONS

Tye J. Cressman*

I. INTRODUCTION

Worldwide, legal systems have long wrestled with issues of how to best care for people who do not have the capacity to make decisions for themselves. Most systems to address these concerns have developed presumptions that certain populations, such as minors, do not have the legal capacity to make certain decisions, such as medical decisions.[1] However, after a minor reaches an appropriate age, the process for stripping away some or all of that person's rights because of alleged incapacity necessarily becomes more difficult, because free societies require a balancing of interests: those of all free persons desiring autonomy and self-determination, versus the interests of society in protecting those persons (by appointing others to care for their best interests).[2] This balancing is difficult under the best circumstances, but becomes infinitely more difficult when various family members vie for the role of guardian or the person who is responsible for making decisions for the incapacitated person.

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[1] Susan D. Hawkins, *Protecting the Rights and Interests of Competent Minors in Litigated Medical Treatment Disputes* 64 FORDHAM L. REV. 2075, 2116–17 (1996).

[2] Jamie L. Leary, *Review of Two Recently Reformed Guardianship Statutes: Balancing the Need to Protect Individuals Who Cannot Protect Themselves Against the Need to Guard Individual Autonomy* 5 VA. J. SOC. POL'Y & L. 245, 284–85 (1997).

The balancing of interests is particularly difficult in the context of blended families. *Blended families* is the term used here for families where at least one child is not the biological or adopted child of the alleged incapacitated person's current spouse; such families present a potentially maximized level of these conflicting interests. The rise of divorce in many societies since World War II, combined with increased longevity and rising rates of dementia, introduces an increasing and natural conflict—namely, where a healthier spouse seeks appointment as guardian over an ailing spouse who has children from a prior marriage.[3] This situation, ripe for conflict, is not an ideal scenario for adversarial legal systems to handle, rather, it is often best resolved by more nuanced legal solutions, including mediation. This Article discusses generally the benefits of mediation and applies them to the increasingly common case of contested guardianships in the context of blended families.

II. GUARDIANSHIPS AND CONSERVATORSHIPS, GENERALLY

A guardianship proceeding is a legal process initiated by one party to assume some or all of the decision-making rights of another party "who, for reasons other than being a minor, is unable to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or self-care, even with appropriate technological assistance."[4] Generally, the party initiating the litigation (the "Petitioner") seeks to assume the decision-making rights of the other party (the "alleged incapacitated person") in one or both of the following ways:

> (1) Rights over the *person*—some or all of the alleged incapacitated person's rights to health care, personal choices, and living conditions;

[3] Jeremy Greenwood & Nezih Guner, *Marriage and Divorce Since World War II: Analyzing the Role of Technological Progress on the Formation of Households* (Nat'l Bureau of Economic Research, Working Paper No. 10772, 2004), *available at* http://www.nber.org/papers/w10772.pdf.
[4] SUSAN J. BUTTERWICK ET AL., EVALUATING MEDIATION AS A MEANS OF RESOLVING ADULT GUARDIANSHIP CASES 2 (2001), *available at* http://www.tcsg.org/mediation/SJI_01.pdf.

> (2) Rights over the person's *estate*—some or all of the alleged incapacitated person's rights to receive and use his or her income or assets.

In many jurisdictions, such an action is referred to as a conservatorship,[5] however for purposes of this Article, both the rights of the *person* as well as rights of the *estate* are referred to as guardianships, collectively.

The proceeding is initiated by the filing of a complaint or petition alleging facts proving the alleged incapacitated person's incapacity. Generally, the opinion of at least one medical professional (given to a reasonable degree of medical certainty) is required to prove incapacity by a "clear and convincing standard."[6] Afterward, the action turns to the fitness of the proposed guardian(s), generally decided under a "best interests" standard.[7]

A. Contested Guardianships

Contested guardianships between family members typically arise in one of several ways:

> (1) spouse versus spouse—where a spouse seeks appointment as guardian for a non-willing spouse;
> (2) child versus parent—where a child seeks appointment as guardian for a non-willing parent;
> (3) child versus child—where two or more children seek appointment as guardian for a willing or non-willing parent; and
> (4) child versus stepparent—where a child seeks appointment as guardian for a willing or non-willing

[5] Unif. Guardianship & Protec. Proc. Act §§ 102, 314 (1997).
[6] Unif. Guardianship & Protec. Proc. Act §§ 304, 311 (1997).
[7] Unif. Guardianship & Protec. Proc. Act § 311(a)(1).

parent, and the healthier spouse does not consent or is also seeking appointment.

This Article focuses on the fourth of these possible situations because the Author feels that for the above contested guardianship scenarios, mediation presents the most possible benefit to blended families, where the healthier spouse may not be the natural parent of the child or children seeking appointment as guardian for the child or children's natural parent.

III. STATISTICS THAT SUPPORT THE SAMPLE PROBLEM (UNITED STATES AND WORLDWIDE)

While the United States leads other industrialized nations in its divorce rate, the prevalence of divorce is common to other leading nations as well.[8]

	1980 Marriage Rate	**1980 Divorce Rate**	**1990 Marriage Rate**	**1990 Divorce Rate**	**2000 Marriage Rate**	**2000 Divorce Rate**
United States	15.9	7.9	14.9	7.2	12.5	6.2
United Kingdom	11.6	4.1	10.0	4.1	8.0	4.0
Canada	11.5	3.7	10.0	4.2	7.5	3.4
France	9.7	2.4	7.7	2.8	7.9	3.0
Germany	N/A	N/A	8.2	2.5	7.6	3.5
Sweden	7.1	3.7	7.4	3.5	7.0	3.8
Japan	9.8	1.8	8.4	1.8	9.2	3.1

*Rates are per 1,000 population aged 15–64 years.

[8] U.S. CENSUS BUREAU, STATISTICAL ABSTRACT OF THE UNITED STATES: INTERNATIONAL STATISTICS, 823, 840 tbl.1336. (2012), *available at* https://www.census.gov/prod/2011pubs/12statab/intlstat.pdf.

In the United States, historically, most men will remarry within just five years of divorce, while just slightly less than half of women will remarry within five years of divorce.[9] This relatively consistent remarriage figure has resulted in a significant number of blended families being created over the course of the past half-century.

The prevalence of the modern blended family type is significant. By some estimates, as many as eighteen percent of adults aged 50–64 and twenty-two percent of adults aged 65 and older have a stepchild.[10] Twenty-three percent of persons aged 30–49 have a stepparent and that number jumps to thirty-three percent for persons 18–29 years of age.[11] It is clear that such blended families are a major component of the current familial landscape, with thirty nine percent of persons aged 50–64 having at least one or more steprelative.[12]

As to the issue of dementia in older adults, numerous studies have concluded that dementia rates generally increase with age, although exact figures vary considerably.[13] However, the majority of studies conclude that for adults aged greater than 80 years, the rate of dementia well exceeds ten percent of the worldwide population:[14]

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[9] ROSE M. KREIDER & U.S. CENSUS BUREAU, REMARRIAGE IN THE UNITED STATES 6 (2006), *available at* https://www.census.gov/hhes/socdemo/marriage/data/sipp/us-remarriage-poster.pdf (citing U.S. Census Bureau data from 1996, 2001, and 2004).

[10] Social & Demographic Trends, *A Portrait of Stepfamilies*, PEW RESEARCH CTR. (Jan 13, 2011), http://www.pewsocialtrends.org/2011/01/13/a-portrait-of-stepfamilies/.

[11] *Id*.

[12] *Id*.

[13] Alzheimer's Assoc., *2015 Alzheimer's Disease Facts and Figures*, ALZHEIMER'S ASSOC. 7, 9, 16 (Mar. 2015), https://www.alz.org/ facts/ downloads/facts_figures_2015.pdf (stating that age is the greatest risk factor for Alzheimer's disease, the most common cause of dementia).

[14] Marcos Antonio Lopes et al., *Systematic Review of Dementia Prevalence, 1994 to 2000*, 3 DEMENTIA & NEUROPSYCHOLOGIA 230, 234 (2007), *available at* http://www.redalyc.org/pdf/3395/339528999002.pdf.

Age Range	Dementia Rate
65–69	1.2%
70–74	3.7%
75–79	7.9%
80–84	16.4%
85–89	24.6%
90–94	39.9%
95+	54.8%

Encouragingly, there are recent studies indicating that dementia rates may be declining,[15] however, such reports are preliminary at this point. Also, indicators of an overall decline in the number of people with dementia does nothing to contradict the strong correlation between higher ages and dementia rates.[16]

For purposes of this Article, it is clear that a significant number of persons of advancing age will face two possibilities: (1) the person's likelihood of suffering from dementia will increase with age,[17] and (2) there is a strong possibility the person has also remarried, potentially resulting in a blended family unit.

For many blended families, these two possibilities could lead to the difficult situation where guardianship for the aged person may be required as a result of a dementia-related illness. Those eligible to serve as guardian or conservator may be steprelatives, who are

[15] *E.g.*, Perminder S. Sachdev, *Is the Incidence of Dementia Declining*? 2014 ALZHEIMER'S AUSTRALIA NUMBERED PUBLICATIONS, April 2014, at 1, 14 Apr. 2014, *available at* https://www.fightdementia.org.au/files/NATIONAL/documents/Alzheimers-Australia-Numbered-Publication-39.pdf. See also: Langa KM, Larson EB, Faul JD, Levine DA, Kabeto MU, Weir DR, *A Comparison of the Prevalence of Dementia in the United States in 2000 and 2012. JAMA Intern Med*. Published online November 21, 2016 at doi:10.1001/jamainternmed.2016.6807.
[16] Maria M.Corrada et al., *Dementia Incidence Continues to Increase with Age in the Oldest Old: The 90+ Study*, 67 ANNALS OF NEUROLOGY, 114, 117–20 (2010).
[17] Alzheimer's Assoc., *supra* note 13.

potentially less likely to defer to each other as fiduciaries or guardians. These possibilities return to the fact scenario at the heart of this Article: when an incapacitated person's healthier spouse is not the natural parent of the incapacitated person's children. This type of situation is ripe for a contested guardianship proceeding. Further, the complexity of the family dynamics in place make the typical judicial resolution of such contest much less suitable.

Reliable data relating to the role of gender, age, poverty, wealth, and other factors in guardianship proceedings is available, but there is no statistical data to suggest that guardianships are more often contested in blended family situations.[18] However, the Author, a practitioner in the field of elder law, can attest to the fact that guardianship cases, where the natural child or children of an incapacitated parent are seeking appointment as guardian instead of the parent's healthier spouse (the children's stepparent), are often the most difficult to find resolution outside of the courtroom in the negotiation setting. Further, when litigation is sought to decide on the appropriate person to serve as guardian, courts must implement a binding "all or nothing" choice between the current spouse as guardian or the children of the incapacitated parent.[19]

The unsatisfactory result speaks to the limitations inherent to adversarial legal system resolutions. Either the court will appoint the healthier spouse, who, following the trial, is unlikely to make further communication with the incapacitated parent easy or comfortable for the stepchildren, or the court will appoint a child, or

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[18] Joseph A. Rosenberg, *Poverty, Guardianship, and the Vulnerable Elderly; Human Narrative and Statistical Patterns in a Snapshot of Adult Guardianship Cases in New York City* 16 GEO. J. POV. L. & POLICY 315, 322 (2009).

[19] Mary F. Radford, *The Use of Mediation in Adult Guardianship Cases*, NAT'L GUARDIANSHIP ASS'N INC. 3 (2007), http://www.guardianship.org/training_modules/Mediation_and_Guardianship.pdf [hereinafter Radford, *The Use of Mediation*]; *see* Mary F. Radford, *Is the Use of Mediation Appropriate in Adult Guardianship Cases?*, 31 STETSON L. REV. 611, 641–44 (2002) [hereinafter Radford, *Is the Use of Mediation Appropriate*].

children, to serve as guardian for the parent, which greatly disrupts the existing marital relationship between the incapacitated parent and their spouse. Whichever the result, the family dynamic is permanently fractured, resulting in hurt feelings and irreparably destroyed relationships.[20] If a primary consideration of the guardianship proceeding is to best honor the wishes and safety of the incapacitated person, the court is placed in an impossible situation to start, because the incapacitated person would never have wanted this at all.[21]

IV. INHERENT ISSUES AND CONFLICTS FACED BY BLENDED FAMILIES

Even in their infancy, blended family relationships present complex family dynamics. The evil stepmother from Cinderella and Snow White is a popular trope from children's literature that looms over many families, especially those where second marriages occurred after a child's adolescence has passed. Without the necessary bonding that occurs during children's formative years in the household with both natural parent and stepparent, the familial "glue" necessary to create and strengthen such bonds was never applied, nor given the proper opportunity to set. Nonetheless, such family relationships can continue without incident for decades until an intervening disaster, such as a natural parent's diagnosis of dementia, forces the blended family to confront issues that they are potentially ill-equipped to handle.

This often becomes apparent in earlier phases for families, such as second-marriage spouses consider their estate planning, trying to work out disposition decisions that protect each other while benefiting their respective children from prior marriages in the future, upon both of their deaths. Inheritance for children may or may not play a role in future disputes, but it is often the first time that second-marriage couples confront the possibility that, in the

[20] Radford, *The Use of Mediation*, *supra* note 19, at 6–8; Radford, *Is the Use of Mediation Appropriate*, *supra* note 19 at 666–67.
[21] Radford, *Is the Use of Mediation Appropriate*, *supra* note 19 at 666–67.

future, one of them—the current healthier spouse—may be forced to deal with the other spouse's children in a potentially adversarial setting.

The ubiquity of powers of attorney appointing current spouses as agents for each other inserts another trust-dynamic into the situation, since such boilerplate documents generally will include clauses naming the primary agent as the principal's guardian or conservator in the case of a guardianship proceeding. Aside from such clauses, the agency relationship presents additional difficulties as the healthier spouse is often named and left to make health care and financial decisions for the ailing spouse, which may or may not be the same decisions that would be made by the ailing spouse's natural children.

The healthier spouse of an ailing spouse with children from a prior marriage is placed in a naturally difficult situation. The healthier spouse may have married the ailing spouse either when the children were young or when the children were older, and, depending on the circumstances, may or may not have played a role in their upbringing. While the healthier spouse likely had no control over the circumstances leading to the ailing spouse's prior divorce, he or she might be unfairly blamed for it. The healthier spouse may even fear the ailing spouse's children.

From a long-term care planning point of view, the healthier spouse may have good reason to fear the children. The spouse's planning interests and goals may differ from theirs if they were to have control of the healthier spouse's decision-making. For a spouse suffering from dementia, the long-term care options have a direct and significant impact on the healthier spouse's ability to live comfortably. Long-term care can be very expensive, and the choice of options have a major impact on the income and assets of a healthier spouse.

Imagine the scenario for a female spouse with a home and $250,000 in savings between the couple: if her husband were to enter skilled care at a cost of $8,766 per month, Medicaid would not begin paying for care until their respective assets were reduced to $119,220,[22] depending on income. In addition, once her spouse qualified for Medicaid, some or all of his income may be paid to the nursing home, leaving her with significantly reduced assets *and* a significantly reduced income.[23] She may be very uncomfortable with another person making the health care and financial choices for her spouse. The fear of long-term care is heavy for many healthier spouses; it can become much worse when they also have to fear whether the decision-maker for an ailing spouse has their best interests in mind.

A child may view such stepparent's fears as the stepparent "going after dad's money" since the Medicaid Long-Term Care spousal protection rules invite planning at the time of nursing home entry to maximize available resources for the benefit of the spouse remaining at home.[24] In reality, the stepparent is quite concerned about ongoing finances for her own care, which is quite reasonable, from their point of view. The child, on the other hand, may see these concerns as selfish and as not paying proper heed to the ailing parent's health needs. Both sides are right in their own way, and now each side has considerable reason to distrust the other's motives. The result for many blended families is an adversarial situation where the parties' positions are intractable, since both parties perceive themselves as being right.

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[22] Medicaid, *2015 SSI and Spousal Impoverishment Standards*, MEDICAID (Jan. 2015), http://www.medicaid.gov/medicaid-chip-program-information/by-topics/eligibility/downloads/2015-ssi-and-spousal-impoverishment-standards.pdf. The Community Spouse Resource Allowance for 2015 is $119,220. *Id.*

[23] 42 U.S.C. § 1396r-5(d) (2012). Sometimes referred to as the "Patient Pay Liability" of the spouse entering a skilled nursing facility. *Id.*

[24] *Id.* at § 1396r-5(c).

V. TRADITIONAL SOLUTION: CONTESTED GUARDIANSHIP

Carrying the above situation to its likely judicial conclusion, both parties (child and healthy spouse) may seek guardianship of the incapacitated spouse. Both parties will retain attorneys to advise them of their rights, and one party or the other (or both) will file petitions for appointment as guardian for the incapacitated party. Even at this point, prior to any hearing on the matter, the following facts are likely true: (1) the parties can no longer communicate with each other; (2) the parties have expended personal resources on legal fees or retainer fees; and (3) the child or children's access to the ailing parent has been significantly limited or cut off.

Upon the filing of the guardianship action, a hearing date will be set, often for several months in the future. In emergency situations, either party often has the right to seek an emergency order regarding guardianship. More legal fees expended throughout this process, and the party "in possession" of the incapacitated parent likely denies communication to the adverse party.

A. Effects of Litigation on the Alleged Incapacitated Person and Blended Family

In a contested guardianship proceeding, all parties suffer.[25] Because it is difficult to obtain reliable feedback from incapacitated persons, gauging an incapacitated person's satisfaction with the contested guardianship process is equally challenging. However, there are several basic characteristics of the guardianship process that likely ensure that the process is a painful one for the alleged incapacitated person at the center of the litigation.

[25] Radford, *The Use of Mediation*, *supra* note 19, at 3.

The first characteristic is that guardianship usually involves litigation between family members because the laws of most states, based on the Uniform Guardianship Act, creates a priority list of persons who may be appointed as guardian, including Agents under Powers of Attorney, spouses, adult children, parents, and co-habitating adults.[26] While this preferential order is logical, it also ensures that a party of higher priority on such a list must be proven unfit as guardian by a person of lower priority desiring to be appointed guardian.[27] These basic components of guardianship law encourages family members to raise negative characteristics about each other.

The incentive for inter-family acrimony identified as the first characteristic is naturally compounded by the second characteristic: unless excused, the alleged incapacitated person is to be present during any proceedings.[28] He or she will witness the two components of any guardianship proceeding. The first will be the family's arguments for why the alleged incapacitated person should be found incapacitated, including expert testimony regarding the person's alleged incapacity.[29] The second will be the family's arguments for who should serve as guardian. If the second issue is contested, then evidence regarding the relative unfitness of the proposed guardians (discussed in Section IV) will be held in the presence of the alleged incapacitated person.[30]

The third and most important characteristic of guardianship is its detrimental effect on the life of the alleged incapacitated person, both before, during, and after the guardianship hearings. In the months leading up to the filing of the petition, the ailing spouse is usually isolated from one or all of the other parties seeking guardianship, must meet with lawyers, and must endure listening to people talk *about* him or her but not *to* him or her. By its nature, a guardianship hearing involves the deprivation of independence and

[26] *Id.* at 16.
[27] Unif. Guardianship & Protec. Proc. Act § 310(b).
[28] Unif. Guardianship & Protec. Proc. Act § 308 (1997).
[29] Unif. Guardianship & Protec. Proc. Act § 311.
[30] Unif. Guardianship & Protec. Proc. Act § 306 (1997).

personal liberty; through the procedural steps listed above, the process typically results in a loss of autonomy and dignity as well.[31]

The healthier spouse's sense of fear throughout the guardianship process may be even greater than the alleged incapacitated person. What will his or her life look like if the ill spouse's children gain control? What will happen to their shared finances? Could the children move the ward away from the healthier spouse without his or her consent? The uncertainty to these questions leaves the healthier spouse with no option other than to be named guardian to protect his or her own interests, as well as the interests of the ailing spouse.[32]

Other predictable consequences will follow. From the onset of the litigation, the healthier spouse has the incentive to limit any interaction between the ailing spouse and his or her children, because the children, if acting as Petitioners in the guardianship matter, will bear the burden of proving their parent incompetent in the guardianship proceeding. Any information gleaned by the children from visiting their ailing parent which reflects negatively on the healthier spouse may be used against him or her in the proceeding.[33] For litigation strategy purposes, the healthier spouse must cut off the children's access to the alleged incapacitated spouse. As a result, the ailing spouse is further isolated from sources of support at a time when the love and support from family is likely most needed. Often the children of the ailing spouse are adults with children of their own, who are not necessarily present, but often observing and absorbing the secondary effects of contested litigation, via their parents.[34] The alleged incapacitated spouse's grandchildren—future generations of family—may also be

[31] Rosenberg, *supra* note 18, at 323.
[32] Unif. Guardianship & Protec. Proc. Act § 315 (1997).
[33] Unif. Guardianship & Protec. Proc. Act § 311(a).
[34] Robert A. Grey, *All We Are Saying Is Give Mediation a Chance*, 10 ELDER L. ATT'Y, Fall 2000, at 75, 75–76.

prevented from visiting the alleged incapacitated person during the litigation process, and maybe even after it is finished, depending on the result. Such are the real-life consequences to relying on adversarial legal systems to resolve family disputes in guardianship settings.

B. Benefits of Mediation in Contested Guardianship Proceedings

The above scenarios are common to elder law practitioners, and are unacceptable in light of better options for resolution, such as mediation.[35] The benefits of mediation are well documented in various settings.[36] The most commonly cited benefits to mediation for clients in the guardianship arena are identified below:[37]

> (1) *Non-adversarial*. Rather than respective parties battling to achieve success for one or the other, mediation frames the issue as "we *all* have this problem, and we will *all* work towards a solution to it."[38]
>
> (2) *Flexible*. Solutions can be tailored to the exact needs of the parties involved in the situation, rather than adhering to traditional win-lose judicial dichotomies.[39]
>
> (3) *Self-determination*. Parties accept or reject solutions to problems, rather than having those solutions imposed on them by a judge.[40]

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[35] Radford, *The Use of Mediation*, *supra* note 19, at 4. Mediation is an alternative form of dispute resolution "whereby a neutral facilitator encourages the parties to work through their problems and structure their own solutions." *Id.* Other options for resolution include arbitration and private negotiation. *Id.* at 5.

[36] *See generally* Teresa W. Carns & Susan McKelvie, *Alaska's Adult Guardianship Mediation Project Evaluation*, ALASKA JUDICIAL COUNCIL (Mar. 2009), *available at* http://www.ajc.state.ak.us/sites/default/files/imported/reports/adultguard.pdf.

[37] *Id.* at 6.

[38] *Id.*

[39] *Id.*

[40] *Id.*

> (4) *Efficiency*. The time required of all parties is often less, the resolution is often more expedient (because parties are not depending on the Court's calendar), and the resulting legal bills and cost to all parties is generally less.[41]
>
> (5) *Allows parties to identify the "root causes" of the issues*.[42] Judicial solutions providing a win-lose result rarely address the causes that brought the family to litigation in the first place.[43] Mediation provides the opportunity for safe discussion by family members.[44]
>
> (6) *Allows preservation of family bonds*.[45] In a contested guardianship, most opponents will be family members. The ability of mediation to work toward the root causes of the dispute increase the likelihood that family bonds will be maintained.

In mediation, rather than litigate the disputed matter, the parties collaborate to resolve it together. A skilled mediator can return all parties to the basic point that all issues revolve around: what is best for the incapacitated person.[46] Because the issues faced are complex and nuanced, the healthier spouse and their stepchildren could work to develop solutions tailored to their needs.[47] Specifically, if one of the issues raised by the children is visitation, flexible schedules for seeing the parent can be developed. If inheritance is an issue, then the parties can work towards a mutually

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[41] *Id.*
[42] *Id.* at 7.
[43] BUTTERWICK ET AL., *supra* note 4, at 2.
[44] Radford, *The Use of Mediation*, *supra* note 19, at 6.
[45] *Id.* at 7.
[46] *Id.* at 6.
[47] *Id.*

agreeable post-nuptial agreement. Better yet, parties who design solutions for themselves, rather than having dichotomous solutions largely devoid of context imposed upon them, are be more inclined to adhere to those solutions.[48] Furthermore, mediation involves less time in court and attendant attorneys' fees.

Likely, the best aspect of mediation in these circumstances is that all parties have an opportunity to be heard in a private forum, where a skilled mediator can work towards the major reasons that the parties are engaged in litigation.[49] Often, litigation is simply the most obvious remedy available, where complex, rooted issues find surface-level resolution.[50] However, having opposing parties simply *discuss* the underlying issues which may be otherwise ancillary to the matter of incapacity itself, may provide significant relief to the parties and create the opportunity to craft solutions tailored to those ancillary issues. Adversarial systems cannot reach these root issues, but mediation can.

VI. GUARDIANSHIP MEDIATION IN THE UNITED STATES AND WORLDWIDE

Significant studies evaluating the use of mediation to resolve guardianship disputes have been conducted in the United States since at least the mid 1990s.[51] Pioneered in the United States by The Center for Social Gerontology (TCSG) and several mediation and elder law professionals, these studies have yielded useful and telling research regarding the applicability, utility, and limitations of mediation in guardianship settings.[52] Despite some success in guardianship mediation programs, use of such programs has not spread greatly within the United States.[53]

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[48] *Id.*
[49] BUTTERWICK ET AL., *supra* note 4, at 4.
[50] *Id.* at 17.
[51] *Id.* at 8.
[52] *Id.* at 8–11.
[53] *Id.* at 123. As of writing, only pilot programs for mediation in guardianship settings have been conducted in Florida, Ohio, Wisconsin, Oklahoma, and Alaska.

The United States legal system has historically favored legal frameworks based on adversarial models. Its use is commonplace in guardianship proceedings, primarily because of the importance of legal rights being removed from a person in the guardianship setting. While mediation has been a viable option for decades, it is rarely used to resolve disputes.[54]

In Western Europe, despite the passage of Directive 2008/52/EC by the European Union Parliament, mediation has not gained any widespread popularity for resolving conflicts.[55] Directive 2008/52/EC created a promising framework for international cooperative mediation among European Union countries by promulgating certain directives which member countries would ideally adopt, including: (1) identifying parameters for mediation in cross-country conflicts;[56] (2) training and development of mediators in respective countries;[57] and (3) identifying several canons of mediation, including confidentiality[58] and voluntary participation.[59] Other European countries, including France, have incorporated portions of Directive 2008/52/EC into their own alternative dispute resolution statutes as they have been passed in recent years.[60] While the development of these laws is promising, their use continues to involve primarily commercial disputes.

In 2004, Japan passed the Act for Promotion and Use of Alternative Dispute Resolution, which has been in force since 2007, and since its passage, over 80 dispute resolution centers have been

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[54] *Id*.
[55] Constantin-Adi Gavrila, *What Went Wrong with Mediation?*, KLUWER MEDIATION BLOG (Feb. 6, 2014), http://kluwermediationblog.com/2014/02/06/what-went-wrong-with-mediation/.
[56] Council Directive 2008/52/EC on certain aspects of mediation in civil and commercial matters, OJ L 136/3 (2008).
[57] *Id.* at art. 4 ¶ 2.
[58] *Id.* at art. 7.
[59] *Id.* at art. 3.
[60] *See* 2 CARLOS ESPLUGUES, SR., CIVIL AND COMMERCIAL MEDIATION IN EUROPE: CROSS-BORDER MEDIATION 485 (2014).

started in Japan.[61] Despite this somewhat widespread implementation, it is reported that most centers report one or less disputes being resolved each year.[62] Such dispute resolution is focused on commercial disputes rather than family-related disputes.[63]

In 2010, Russia passed its own integrated mediation law, which sought to normalize standards for parties wishing to engage in mediation.[64] The Russian mediation law was very comprehensive, broadly identifying matters for which mediation could be used, identifying a few specific legal matters for which it could not be utilized, setting standards for training and certification of mediators, and identifying stages of litigation at which mediation could be implemented.[65]

The good news is that many countries have some legislative framework for the implementation and use of mediation in private legal matters, including family law. However, the overwhelming reports from each country are that it remains not well utilized and is still seen as the rare alternative to the generally accepted approach of adversarial justice. This is disappointing because, as discussed in Section V, Subsection B, mediation has considerable benefits to participants, especially in the guardianship setting.

VII. BARRIERS TO SUCCESS IN MEDIATION SETTINGS

Among the findings by TCSG was the discovery that mediation, as an alternative to judicial guardianship proceedings, was underutilized, even when such mediation systems were presently available.[66] This finding is deflating towards the possibility of comprehensive use of mediation, if it gained more

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[61] Hideaki Irie, *An Overview on the Current Status of Japanese Private Dispute Resolution*, JCAA NEWSLTR., Nov. 2010, at 1, 1, *available at* http://www.jcaa.or.jp/e/arbitration/docs/news25.pdf.
[62] *Id.*
[63] *Id.*
[64] Sergey Yuryev, *Legal Alert: Mediation in Russia*, CMS.LAW (Aug. 2010), https://cms.law/en/RUS/Publication/Mediation-in-Russia.
[65] *Id.*
[66] BUTTERWICK ET AL., *supra* note 4, at 130.

widespread availability. Thus, even if mediation is available, it becomes clear that certain barriers must be overcome.

First, judges involved in resolving such conflicts must be aware of mediation opportunities and must view them as a viable alternative to court litigation. Thus, better awareness by the judiciary and a willingness for judges to cede control of such contested matters to mediators (including non-lawyer mediators) who the can resolve the conflicts is key.[67]

Second, lawyers involved in such conflicts must view mediation as a useful tool toward case resolution, and not an alternative to litigation.[68] Mediation is a voluntary process, requiring a buy-in by both parties' legal advocates to produce success. Awareness is required, but also required is faith by the parties' counsel that the process is worthy and desirable.

Finally, skilled mediators are necessary because knowledge of guardianship law is essential to providing valuable solutions for a family in the midst of a guardianship proceeding. Studies suggest that the failure of mediation solutions in the contested guardianship context are often the result of mediators who have little knowledge of elder law.[69] Mediators typically use two approaches in dispute resolution which include the facilitative approach and the evaluative approach.[70] The facilitative approach involves giving the parties a voice and allowing a forum for discussion, where parties are encouraged to develop their own solutions.[71] An evaluative mediation model would involve a mediator who could hear the arguments and issues of both parties and develop solutions to problems based on the likelihood of success for the respective

[67] *Id*. at 138.
[68] *Id*.
[69] *See id*. at 140.
[70] Radford, *The Use of Mediation*, *supra* note 19, at 13.
[71] *Id.*

parties.[72] Both approaches have value, although, based on the previously mentioned studies, the evaluative model may be more helpful in contested guardianship disputes because it would allow the mediator, when appropriate, to "insert his or her own opinion into the process to protect the interests of the weaker party."[73]

VIII. MODEL FOR MEDIATION IN BLENDED FAMILY SITUATIONS

The model to be applied to increase the use of mediation in blended family situations should mirror the barriers to success presented by TCSG report, namely: (1) developing a buy-in and educating judges and members of the bar; (2) promoting implementation of mediation prior to filing of guardianship petitions; and (3) developing programs which are organizationally and structurally integrated into the probate court setting.[74]

As noted in the TCSG report, buy-in from and education of local probate judges and lawyers is necessary[75] since court-based programs created more referrals to mediation programs than community-based programs.[76] To that end, any mediation program would ideally be approved by probate judges in a given area, and the local bar association would educate its members as to the value of mediation in guardianship cases.

Many of the benefits of mediation cited earlier may be lost once litigation is initiated, therefore, promoting mediation prior to the filing of a guardianship petition is ideal.[77] The problem arises because while a judge may recommend parties to mediation, all parties must agree to move forward prior to filing such a petition on their own initiative.[78] Part of the attorney education referenced in

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[72] *Id.*
[73] *Id.* at 14.
[74] BUTTERWICK ET AL., *supra* note 4, at 123.
[75] *Id.* at 137.
[76] *Id.*
[77] *Id.* at 123.
[78] *Id.* at 135.

the above paragraph must result in developing a buy-in from probate attorneys regularly practicing in this area, so that they may, in turn, encourage clients to consider mediation as a pre-filing step that ought to be taken.

Finally, structural and organizational integrity is an important component to the successful use of mediation as an alternative to litigation.[79] The preliminary structural component is proper screening to ensure that only cases appropriate for mediation are referred to the program.[80] Inappropriate screening procedures may result in lower success rates for mediations which, in turn, may result in a lower value by necessary stakeholders in the mediation program.[81] Such programs must decide whether the program should (or is able) to accept pre-petition cases as well as post-petition cases, since intake and screening will be different based on the distinction. The concerns arising from the availability of mediators and the ability to pay mediators[82] may be addressed in the following ways: (1) developing a list of trained mediators willing to perform mediations at a fixed hourly rate; and (2) making it clear in program materials that mediator costs are to be paid equally by participating parties. In pre-petition mediation cases, if probate attorneys within the local bar have been convinced of the value of mediation in such settings, payment of such costs may be acceptable; in post-petition cases, judges may order payment of mediator costs to be borne equally by the parties, as is done in other legal settings, such as child custody mediation.

[79] *Id.* at 127.
[80] *Id.*
[81] *Id.* at 128.
[82] *Id.* at 129.

IX. CONCLUSION

The problem presented by contested guardianships in blended families is clear to many who practice elder law, and this problem will persist until more appropriate models for resolution are created and effectively encouraged. The value of mediation in many other contexts is well documented and should produce even more valuable results in the family-based area of contested guardianship if proper mechanisms and personnel can be established to ensure success for the most important parties—the incapacitated persons—who are often the most overlooked.

THE RESTORATION OF CAPACITY FOR PERSONS UNDER GUARDIANSHIP WITH DEVELOPMENTAL DISABILITIES IN FLORIDA

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I. OVERVIEW OF RESTORATION OF CAPACITY STUDY AND WORK GROUP PROJECT[1]

A. Purpose and Need for Study

Guardianship is a process in which a court appoints someone to exercise certain legal rights of an individual who has been adjudicated incapacitated. The legislative intent of guardianship is to preserve and protect property and to provide for the health and safety of persons who have been determined to be unable to do so for themselves. Guardianship is the most restrictive form of assistance and should be imposed as a last resort. In the United States, guardianship law is determined by each state.

Many conditions underlying incapacity, such as dementia, are unlikely to improve over time and the guardianships for those individuals routinely remain in place for the remainder of the

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[1] The following Article derives from a presentation at the 3rd World Congress on Adult Guardianship, May 30, 2014, in Washington D.C. The panel consisted of Karen Campbell, Phoebe Ball, Melinda Coulter, and Amelia Milton. Funding for the research was provided by the Florida Developmental Disabilities Council and the Guardian Trust.

person's life. But, in many instances, a person with an acquired disability (such as the effects of a head injury) or a person with a developmental disability (such as Down syndrome) can be expected to gain or regain capacity over time with training, life experience, and rehabilitation.

Florida provides for greater due process than many states. In order to ensure that individuals faced with guardianship do not have their civil rights restricted unnecessarily, Florida law provides alleged incapacitated persons have (1) an attorney appointed to represent them, (2) a three-person examining committee, including a physician, to determine which rights they lack capacity to exercise, (3) consideration by the court of less restrictive alternatives, and (4) the right to attend a hearing to determine their capacity and to present evidence and cross-examine witnesses.[2]

Furthermore, for those individuals under guardianship, Florida law provides that guardians annually report on whether less restrictive options are available and if restoring rights is appropriate.[3] Florida law also provides a process for restoration of rights that is less stringent than the process for entering into guardianship.[4]

Despite the progressive statutes in Florida concerning the restoration of rights for persons under guardianship, there has been little research conducted on the extent of restoration activity. This Article reports the activities of the first year of a potential three-year project funded by the Florida Developmental Disabilities Council and Guardian Trust (FDDC). The major goal of the first year was to develop and implement a research methodology that estimates the amount of restoration of rights taking place in Florida and to document barriers to restoration, specifically for persons with developmental disabilities who are under guardianship. The project team consisted of two attorneys, a parent of a person with a

[2] FLA. STAT. § 744.331 (2015).
[3] FLA. STAT. § 744.3215 (2015).
[4] FLA. STAT. § 744.464 (2015).

developmental disability, two staff members from the Florida Agency for Persons with Disabilities, and a three-person research and evaluation team.

Additionally, with the guidance of the FDDC, a Stakeholders Work Group was constituted with the following two purposes: (1) examine the current state of guardianship restorations among persons with developmental disabilities, and (2) determine whether there is a need for a program to assist persons in gaining restoration of their legal rights.

The Stakeholders' Work Group was made up of a diverse group of individuals who represent the legal community, individuals under guardianship, psychologists, individuals who have had their legal rights restored, family members of persons with developmental disabilities, Exceptional Student Education personnel, the judiciary, and guardians.

Over a series of three meetings, two face-to-face meetings and one webinar meeting, the Stakeholders' Work Group reviewed the research design and methodology, reviewed the research findings, deliberated over various options for addressing the findings and recommended a pilot project implementation plan.

II. GUARDIANSHIP AND RESTORATION OF CAPACITY

A. Progression of Guardianship

Guardianship is an ancient system that developed over centuries of western civilization as a means of protecting vulnerable citizens who are deemed to be unable to manage their own affairs due to disability, illness, or age. Guardianship predates not only modern civil rights laws, such as the Americans with Disabilities

Act, but also the United States Constitution and the Magna Carta.[5] Guardianship springs from the doctrine of *parens patriae*, which gave the crown the authority to exercise "royal prerogative over its subjects unable to protect themselves, but with the singular objective of protecting the subjects' properties for the crown."[6] This broad authority was elaborated by the U.S. House Subcommittee on Health and Long-Term Care, Select Committee on Aging:

> The typical ward has fewer rights than the typical convicted felon--they can no longer receive money or pay their bills. They cannot marry or divorce. By appointing a guardian, the court entrusts to someone else the power to choose where they will live, what medical treatment they will get and, in rare cases, when they will die. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen…[7]

In response to investigative reporting that revealed serious abuses of the guardianship system in the United States,[8] state guardianship laws have been revised to provide greater due process, limitations on the scope of guardianship, and increased monitoring of existing guardianships to prevent exploitation and abuse. In Florida, sweeping changes were made to its guardianship statutes in 1989.[9]

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[5] A. Frank Johns & Vicki Joiner Bowers, *Guardianship Folly: The Misgovernment of Parens Patriae and the Forecast of Its Crumbling Linkage to Protected Older Americans in the Twenty-First Century—A March of Folly? Or Just a Mask of Virtual Reality?*, 27 STETSON L. REV. 1, 6–29 (1997) (discussing the first forms of guardianship and its progression through history).

[6] A. Frank Johns, *Person-Centered Planning in Guardianship: A Little Hope for the Future*, 2012 UTAH L. REV. 1541, 1542 (2012).

[7] *Abuses in Guardianship of the Elderly and Infirm: A National Disgrace: Hearing Before Subcomm. on Health and Long-Term Care of the H. Select Comm. on Aging*, 100th Cong. 1–6 (1988) (statement of Claude Pepper, Chairman, Subcomm. on Health and Long-Term Care).

[8] Fred Bayles & Scott McCartney, *Guardians of the Elderly: An Ailing System Part I: Declared 'Legally Dead' by a Troubled System*, ASSOCIATED PRESS (Sept. 19, 1987), http://www.apnewsarchive.com/1987/Guardians-of-the-Elderly-An-Ailing-System-Part-I-Declared-Legally-Dead-by-a-Troubled-System/id-1198f64bb05d9c1ec690035983c02f9f.

[9] The changes were made in Florida Statutes Chapter 744.

B. International Best Practices for Guardianship and Restoration

Guardianship reform internationally has been forward-looking, prescriptive, and accountable. The recommended reforms have been system-oriented. Nations and sub-nations are expected to demonstrate their support of the rights of persons with diminished capacity through sweeping legislative action that reflects a person-centered, less restrictive, and non-paternalistic philosophy. Although the cornerstone of guardianship reform has been the reduction of statutory guardianship through legal and community based alternatives, there have been few recommendations directly referring to the restoration of rights to persons already under guardianship.[10] As we will demonstrate below, several principles of the reform are central to strategies for restoration of rights of persons under guardianship, namely, supplanting substituted decision-making with supported decision-making, improving record-keeping and reporting for persons under guardianship, and replacing the practice of plenary guardianship with limited guardianship.

The United Nations Convention on the Rights of Persons with Disabilities[11] (CRPD), held in 2006, has been described as a "paradigm shift, for it treats people with disabilities as subjects and no longer as objects of care."[12] The CRPD recognized that alternatives to guardianship should be considered whenever possible. The most controversial article in the CRPD has been Article 12, which states that "States Parties shall take appropriate

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[10] One notable exception is legislation in Alberta, Canada, where the "adult is able to terminate the [guardianship] agreement . . . at any time." Shih-Ning Then, *Evolution and Innovation in Guardianship Laws: Assisted Decision-Making*, 35 SYDNEY L. REV. 1, 133 (Mar. 2013) (citing Adult Guardianship and Trusteeship Act, R.S.C. 2008, c A-4.2 (Can.)).

[11] Convention on the Rights of Persons with Disabilities (New York, 13 Dec. 2006) 2515 U.N.T.S. 3, *entered into force* 3 May 2008, *available at* https://treaties.un.org/doc/Publication/UNTS/Volume%202515/v2515.pdf. [hereinafter CRPD].

[12] Volker Lipp & Julian O. Winn, *Guardianship and Autonomy: Friends or Foes?*, 5 J. INT'L AGING L. & POL'Y 41, 43 (2011).

measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity."[13] This has been broadly interpreted to mean that statutes designed to provide protection to individuals with disabilities through the assignment of a guardian or agent need to be rewritten to recognize the basic rights of individuals to make decisions on their own behalf whenever possible. For instance, Sally Hurme has concluded that maximizing the rights of persons with disabilities while minimizing restrictive interventions has been the convergent theme in new policies and declarations worldwide.[14]

Perhaps the most significant development resulting from Article 12 that will affect people currently in guardianship, as well as those who may be able to find alternatives to guardianships that were not previously available or accessible, has been the mandate to shift from "substituted decision-making" to "supported decision-making."

> With supported decision-making, the presumption is always in favour of the person with a disability who will be affected by the decision. The individual is the decision maker; the support person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preferences of the individual. Even when an individual with a disability requires total support, the support person(s) should enable the individual to exercise his/her legal capacity to the greatest extent possible, according to the wishes of the individual….[15]

[13] CRPD, *supra* note 11 at art. 12, ¶3.
[14] Sally Balch Hurme, *World Congress to National Summit: Moving Guardianship Excellence to Reality*, 6 J. INT'L AGING L. & POL'Y 1, 4 (2013).
[15] DEP'T OF ECON. & SOC. AFF. ET AL., FROM EXCLUSION TO EQUALITY: REALIZING THE RIGHTS OF PERSONS WITH DISABILITIES 89 (2007), *available at* http://www.un.org/disabilities/documents/toolaction /ipuhb.pdf.

As of April 6, 2015, 159 state and nations have signed the CRPD agreement and 153 have ratified the agreement.[16] One obstacle to turning "wards" over to community support may be the risk-averse nature of modern societies, as well as important privacy concerns.[17] Since the adoption of the CPRD in 2006, parties to the agreement have initiated guardianship reform legislation, with varying levels of approval. In some cases, it has proven difficult for state and national reforms to embody the requirements of the CRPD. For example, the first two nations to bring their statutes before the Commission, Tunisia and Spain, were found not to be in compliance, having virtually ignored the technical definition of "supported decision-making."[18] However, other nations have fought to preserve the principle in their ongoing legislative reform. A report on the South Australian Public Advocate argument stated,

> The minimisation of guardianship not only depends on supported decision making reform, but reform to our service systems, so that they are based on true personalisation and choice, reform to our adult protection systems so that they provide a right to safety rather than a welfare response, and a commitment to overcome inequity and discrimination.[19]

[16] Current status may be found at www.un.org/disabilities.
[17] Then, *supra* note 10, at 133.
[18] Lipp & Winn, *supra* note 12, at 50–51.
[19] Terry Carney & Fleur Beaupert, *Public and Private Bricolage—Challenges Balancing Law, Services, & Civil Society in Advancing CRPD Supported Decision-Making*, 36 U. NEW S. WALES L. J. 1, 175 (2013) (quoting John Brayley, *The Future of Supported and Substitute Decision Making*, paper presentation at the World Congress of Adult Guardianship, in Melbourne, Australia (Oct. 16, 2012), *available at* http://www.opa.sa.gov.au/resources/supported_decision_making.

Another report discusses the successful "co-decision-making" models in Japan, Norway, Denmark, and several throughout Canadian provinces.[20]

Another component of the international reforms has been a call for replacing statutes requiring plenary guardianships[21] with legislation allowing for limited guardianships. Although restoration of rights is typically not addressed in these discussions, like supported decision-making, limited guardianship is an important strategy for restoration as well, in that it allows for persons to exercise capacity in areas unaffected by other disabilities they may have.

The need to eliminate plenary guardianship laws has been reiterated throughout the reform community. The European Commissioner for Human Report called on member states "to abolish mechanisms of full incapacitation and plenary guardianship."[22] The World Congress on Adult Guardianship Law held its first conference in Yokohama, Japan, in 2010. The "Yokohama Declaration," Article I.3(4) also condemns plenary guardianship:

> Measures of protection should not be all-embracing and result in the deprivation of capacity in all areas of decision-making, and any restriction on an adult's capacity to make decisions should only be imposed where it is shown to be necessary for his or her own protection, or in order to protect third parties.[23]

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[20] Then, *supra* note 10, at 151.

[21] Plenary guardianships remove all the rights of the incapacitated person.

[22] Robert Dinerstein, *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 HUMANS RIGHTS BRIEF 2, 12 (2012).

[23] Makoto Arai, *World Wide Guardian Practice* (May 28, 2014), *available at* http://www.guardianship.org/IRL/Resources/Handouts/Comparative%20Perspectives%20-%20World%20Wide%20Guard.%20Practice.pdf; Yokohama Declaration, The World Congress on Adult Guardianship Law, art. 1 § 3(4) (Oct. 4, 2010), *available at* http://www.international-guardianship.com/yokohama-declaration.htm [hereinafter Yokohama Declaration].

Finally, a third theme reflected in the current guardianship reforms that bears on the restoration of rights is improved record-keeping and tracking of persons receiving support. Monitoring persons under guardianship and their guardians provides greater assurance that legal adjustments may be made when persons regain capacity, or are discovered to have been mistakenly adjudicated incompetent. Article I, section 3.5 in the Yokohama Declaration states that "measures of protection should be subject to periodic and regular review by an independent authority wherever appropriate."[24] When such systems are in place, the possibility of an individual becoming "forgotten" is greatly reduced.

Improved data systems can also track the activities and qualifications of the support persons themselves, such as guardians, persons delegated specific powers, companions, and others. Inclusion Europe, an advocacy organization for the rights of persons with disabilities, states in its position paper that record-keeping is an essential component of supported decision-making:

> Selection and registration of support persons. Jurisdictions need a registration system to reassure those who come into contact with persons with disabilities that the supporters are authorized to assist them. Such a system can also facilitate the training individuals will need.[25]

Reliable data systems are also necessary for evaluating the success of guardianship reforms. For example, data from England and Wales showed that the number of guardianships had decreased since the introduction of guardianship reforms:

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[24] Yokohama Declaration, *supra* note 23 at art. 1 § 3(5).
[25] Dinerstein, *supra* note 22, at 10.

> In the year 2010 there were 836 guardianship cases open, and for the fifth consecutive year there had been a decrease in the number of cases. Also in 2010, for the eighth consecutive year, guardianship was conferred on the local authority in 99% of new cases. It is possible that the Deprivation of Liberty Safeguards and supervised community treatments, both of which were introduced by the Mental Health Act of 2007, may have had an impact on the use of guardianship.[26]

C. National Best Practices for Guardianship and Restoration

Nationally, a groundswell of support has occurred for examining guardianship from a human rights perspective. The Third National Guardianship Summit, held in Utah in 2011, generated many ideas for improvements in guardianship theory and in practice. The topics covered included an overview of status of and need for standards in guardianship, surrogate decision-making, the need for person-centered planning, specific discussions of various areas of guardianship decision-making, and increased monitoring. While not legally binding, many of these ideas were subsequently incorporated into the National Guardianship Association's Standards of Practice. These standards emphasize the need to include the individuals under guardianship in decision-making and engaged in person-centered planning at every opportunity. Additionally, they establish that the guardian has a responsibility, standards which already mirror Florida Statutes Chapter 744, to facilitate the individual's gaining or regaining functional capacity and his or her ability to seek restoration.[27]

Following the Summit, many states sought revisions of their statutes. Illinois made one particularly interesting change that allows

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[26] DENZIL LUSH, *Guardianship in England and Wales*, in COMPARATIVE PERSPECTIVES ON GUARDIANSHIP 137, 152 (A. Kimberley Dayton ed., 2014).

[27] NGA Standards available at http://guardianship.org/documents/Standards_of_Practice.pdf.

the court to modify or revoke letters of guardianship based on a verified petition signed by the person under guardianship and the guardian, which indicates that the person has regained capacity.[28] While this new process may make it easier for restorations to occur when the guardian is supportive, the restoration process may not be as easy when the guardian is not supportive. Illinois law also provides that a petition for restoration not supported by the guardian must be supported by clear and convincing evidence, which is a high standard of proof for the person under guardianship to meet, a higher standard than the standard required in Florida.[29]

Michigan has also significantly revamped its guardianship system and there are several changes to the Michigan statute that are notable. One is that courts are required to review the continued need for a guardian one year after appointment and every three years thereafter.[30] Another statutory requirement is that the individual under guardianship is entitled to an independent evaluation by a physician or professional of his or her choice, which will be paid for by the state if the person is indigent; and, the individual is entitled to a trial by jury on the issue of incapacity.[31] Finally, Michigan law gives priority to the person's choice of guardian, even over relatives.[32]

In addition to the statutory changes outlined here, which are designed to increase the self-determination of individuals either by raising the bar for imposing guardianship in the first place or granting more autonomy and authority to individuals once they are under guardianship, there are some efforts underway to assist individuals with having their rights restored. As an example,

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[28] 755 ILL. COMP. STAT. § 5/11a-20(b-5) (2015).
[29] *Id.*
[30] MICH. COMP. LAWS § 700.5309 2000).
[31] *Id.* at § 700.5304.
[32] *Id.* at § 700.5313.

Disability Rights North Carolina includes on their website detailed instructions on how to petition the court for restoration.[33]

The Quality Trust for Individuals with Disabilities launched the "Jenny Hatch Justice Project" in 2013. The Quality Trust provided legal representation to Jenny Hatch, a 29-year old woman with Down syndrome living in Virginia, who fought to have the guardianship of her parents lifted so she could live where and how she wanted. The case brought national attention to the issue of people with developmental disabilities having their rights restricted under guardianship. Also, it brought together national leaders and scholars on guardianship reform to develop new paradigms that would replace guardianship with more person-centered models based on the principles of self-determination.[34]

D. The Guardianship Process in Florida

In Florida, the process for creating guardianships is established in the Florida Guardianship Law, Chapter 744, of the Florida Statutes. The legislative intent emphasizes the preservation of autonomy, including the affirmative requirement that guardians provide opportunities for the individual under guardianship to regain their abilities to the extent possible.[35] The process is as follows:

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[33] *Grounds for Removal and Replacement of Guardian*, DISABILITY RIGHTS NORTH CAROLINA (2008), http://www.disabilityrightsnc.org/sites/default/files/Guardianship%20Removal%20Information%20Packet.pdf.

[34] *The Jenny Hatch Justice Project*, JENNYHATCHJUSTICEPROJECT.ORG, http://www.jennyhatchjusticeproject.org/home (last visited Oct. 22, 2016).

[35] Florida has developed an alternative process specifically designed to meet the needs of persons with developmental disabilities—guardian advocacy. The authority given by the court and the responsibilities defined in the statutes are the same. The differences between guardianship under Florida Statutes, Chapter 744 and Chapter 393 are: first, advocacy is only available to individuals with to individuals with at least one of the five developmental disabilities defined by Florida Statutes, Chapter 393; second, in order to appoint a guardian advocate, the statutes do not require a determination of incapacity; and third, a guardian advocate need not be represented by an attorney unless required by the court or if the guardian advocate is delegated any rights regarding property other than the right to be the representative payee for government benefits. For these reasons, guardian advocacy is usually considered to be less expensive, less intrusive and easier to implement than guardianship. In this Article, we focus on restoration of rights of persons under plenary or limited guardianship, under Florida Statutes, Chapter 744.

1. A petition is filed with the court to determine the person's incapacity. The petition must include a description of the alleged incapacity and a list of the rights the person allegedly cannot exercise.[36]
2. The court appoints an attorney to represent the alleged incapacitated person (AIP), gives notice of the petition, and appoints a three-member examining committee.[37] At least one person on the committee must be a physician.[38]
3. The examining committee submits a report detailing the physical, mental and functional condition of the AIP and a list of the rights that the committee recommends should be removed.[39]
4. A hearing is held to give the person an opportunity to challenge the imposition of the guardianship.[40] If the person is found by the court to be incapacitated, the court must first determine whether there are less restrictive alternatives before appointing a guardian.[41]

If a guardian is appointed, the court determines whether the guardianship should be plenary (all delegable rights removed) or limited (only certain rights removed).[42] The guardian is required to submit an annual guardianship report which must address the issue of restoration of rights to the person under guardianship and include the following: (a) a summary of activities during the preceding year that were designed to enhance the capacity of the person under

[36] FLA. STAT. § 744.3201 (1997).
[37] FLA. STAT. § 744.331(2)-(3) (2015).
[38] *Id.* at § 744.331(3).
[39] *Id.*
[40] *Id.* at § 744.331(5).
[41] *Id.* at § 744.331(6)(b).
[42] *Id.* at § 744.344(1) (2015).

guardianship; (b) a statement of whether that person can have any rights restored, and (c) a statement of whether restoration of any rights will be sought.[43] Also, the court, at its discretion, may require reexamination of the person under guardianship by a physician at any time.[44]

E. The Restoration Process in Florida

Under the Uniform Guardian and Protective Proceedings Act (UGPPA), guardians have an affirmative duty to encourage the person under guardianship to participate in decisions and assist the person in regaining capacity.[45] Under Florida law, individuals under guardianship or guardian advocacy who gain or regain capacity are entitled to seek restoration through a well-defined process that includes due process protections (see Table 1).[46]

Any interested party, including the individual under guardianship, may file a petition called a "Suggestion of Capacity" with the court where the guardianship is filed.[47] A Suggestion of Capacity simply must state that the person has regained the ability to exercise some or all of the rights that were removed and a good faith reason for the belief.[48] The court will appoint a physician to evaluate whether the person has regained some capacity.[49] If the physician recommends no or limited restoration, or a timely objection is filed, the court will set a hearing and appoint an attorney to represent the individual under guardianship.[50] The process is substantially similar for individuals under guardian advocacy, Chapter 393.12 of the Florida Statutes, except that the court relies on reports and other relevant information about the person's abilities rather than appointing an examining physician.

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[43] FLA. STAT. § 744.3675(3) (2006).
[44] *Id.* at § 744.3675(4)
[45] Unif. Guardianship & Protec. Proc. Act § 314(a) (1997).
[46] FLA. STAT. § 744.464 (2015).
[47] *Id*.
[48] *Id*.
[49] *Id*.
[50] *Id*.

Table 1

Restoration of Rights Process in Florida

	Guardian Advocacy **Chapter 393.12(12), Florida Statutes**	**Guardianship** **Chapter 744, Florida Statutes**
Suggestion of Capacity	Any interested person, including the person under guardian advocacy, may file a Suggestion of Capacity which must state that the person has regained the ability to exercise some or all of the rights that were given to the guardian advocate, along with evidentiary support or a statement of the good faith reason for the belief.	Any interested person, including the person under guardianship, may file a Suggestion of Capacity stating that the person is currently capable of exercising some or all of the rights which were removed.
Physician's Review	Since the guardian advocacy process does not include an examining committee (which involves the evaluation by a physician), the restoration of rights process does not require an examination by a physician.	The court will immediately appoint a physician to examine the ward and submit his report within 20 days.
Court Action	If no evidentiary support is attached, the court must immediately set a hearing wherein the court can consider all reports and testimony relevant to the person's decision-making abilities.	If an objection is timely filed, or if the medical examination suggests that full restoration is not appropriate, the court shall set the matter for hearing. If the ward does not have an attorney, the court shall appoint one to represent the ward.
Order for Restoration of Capacity	At the conclusion of the hearing or review of the evidence submitted, the court will enter an order denying the suggestion or restoring some or all of the individual's rights.	At the conclusion of the hearing or review of the physician's report, the court will enter an order denying the suggestion or restoring some or all of the individual's rights.

F. Structural Barriers to Restoration

Individuals under guardianship may encounter barriers to restoring rights that have been removed. These barriers can include the unavailability of rehabilitative and supportive services to help gain capacity; and guardians not supporting or encouraging the regaining of some or all rights, starting the restoration process, proving that capacity has been restored, family members or other interested parties objecting to any suggestion of capacity, and appealing the court's decision if rights are not restored.

The legal system is not the only barrier to restoration. Unless the individual under guardianship has access to rehabilitation and education that aims to build capacity and a guardian who has included him or her in making decisions, the individual is likely to be ill-equipped to demonstrate his or her functional capacity to make and carry out decisions. The availability of services in the community can also have a profound impact on an individual's ability to regain his or her rights. Person-centered planning could take the place of guardianship for many individuals with developmental disabilities if the services and supports they require are available in the community. Persons under guardianship generally have three options for beginning the restoration process:

1. to communicate directly to the court, e.g., through writing a letter or speaking up at a hearing;
2. to contact an advocate or an attorney on their own, (this may be more difficult if the right to contract has been removed under guardianship); or
3. to rely on the guardian or the attorney for the guardianship to either file the suggestion of capacity or communicate with the court that restoring rights is desired.

These options can create barriers to beginning the process of restoring rights. For example, it may not be easy to communicate directly with the court. An individual has to know the name of the judge handling the guardianship and then find the judge's contact information.

Additionally, if an individual is successful in filing a "suggestion of capacity," the court is required to appoint a physician. Persons under guardianship may have a difficult time proving to their physician that they have gained or regained the ability to manage their affairs, or the physician may not be familiar with developmental disabilities and lack knowledge of support and services available.

The statute also requires the guardian be given notice and any other interested persons which could be other family members.[51] This can turn capacity restoration into adversarial proceedings. An individual has to demonstrate that he or she has regained abilities when there may be someone on the other side who is trying to show just the opposite.

Another barrier to restoration is providing proof of capacity. The level of proof required to show capacity is not presently spelled out in the statute. Florida is one of "[t]hirty-three states [that] do not provide a specific evidentiary standard. There is little case law in the area of restoration and it is not entirely clear what standard of proof should apply."[52] Although there is one Florida case that seems to indicate that preponderance of the evidence is the appropriate standard in a Suggestion of Capacity action, this is by no means universally understood.[53] However, regardless of the actual standard

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[51] *Id.* at § 744.464(2)(c) (2015).

[52] Jenica Cassidy, *State Statutory Authority for Restoration of Rights in Termination of Adult Guardianship*, 34 BIFOCAL 123, 125 (2013).

[53] *See* In re Guardianship of Branch, 10 Fla. L. Weekly Supp. 23, 25 (Fla. Cir. Ct. 2002) (citing Beal Bank, SSB v. Almand & Assocs, 780 So. 2d 45 (2001)).

of proof, it seems probable that once one has been determined to lack capacity, courts may view the suggestion that the person has gained or regained ability to exercise sound judgment somewhat skeptically, particularly if they fear harm will come to the person if they allow them to continue without a guardian. This concern is highlighted in a situation where a guardian stated, "nobody will be focused on Mrs. Doe's desire to live at home when she dies in a fire trying to boil water at 2 a.m. They will want to know why I did not provide for her safety."[54]

One final legal barrier is that if the person wants to appeal a denial of a suggestion of capacity, he or she cannot continue to retain their attorney without a court order if he or she has the right to contract removed.

III. RESEARCH DESIGN AND METHODOLOGY

A. Goals and Objectives

The goals of the research were to estimate the extent of restoration activity and to identify barriers to restoration of rights for individuals with disabilities in Florida. Court records in Florida are not currently organized in such a way that detailed guardianship data can be readily generated at the state or even circuit level.[55] The Office of the State Courts Administrator (OSCA) only reports the number of guardianships filed in a given year and the dispositions of those cases (see Figure 1). The state does not keep a record of the total number of persons under guardianship, whether the guardianship is plenary or limited, the nature of the disability of the person under guardianship, and a host of other data crucial to informed decisions about system changes. Additionally, there is neither central reporting of the number of suggestions of capacity filed nor restoration outcomes in general.

[54] Naomi Karp et al., *Choosing Home for Someone Else: Guardian Residential Decision-Making*, 2012 UTAH L. REV. 1445, 1466 (2012).
[55] The court's e-filing system does not currently include the data discussed above.

Figure 1
Example of report available from
Florida Office of the State Courts Administrator (OSCA)

Summary Reporting System (SRS)
Summary for the month of July 2011 through June 2012
State Total - Probate

	Probate	Guardian ship	Trust	Baker Act	Substance Abuse	Other Social	Total
Cases Filed	**47,884**	**6,207**	**902**	**33,121**	**9,175**	**4,345**	**101,634**
Cases Disposed							
Dismissed Before Hearing	21,592	668	213	16,858	2,910	624	42,865
Disposed by Judge	23,696	3,255	479	7,199	4,859	1,820	41,308
Disposed by Non-Jury Trial	222	1,783	2	6,706	1,089	1,476	11,278
Other	156	76	31	2,241	43	52	2,599
Total Disposed	**45,666**	**5,782**	**725**	**33,004**	**8,901**	**3,972**	**98,050**

Since case-by-case data was not available, information on restoration of capacity activity was collected from two groups of individuals with specific knowledge about guardianship. One group was comprised of legal and human service professionals who work in the area of guardianship and who would likely come in contact with persons seeking restoration of capacity. These included attorneys, clerks of the court, judges, court monitors, agency staff, and professional guardians. The second group was composed of self-advocates as well as family members of persons with disabilities, some of whom were legal guardians or guardian advocates.

Different techniques were used to reach the target groups. Web-based surveys were used to contact attorneys, clerks of the court, agency staff, family members, and guardians. Family members and persons with disabilities were interviewed in focus groups in both rural and urban settings.

Permission was also sought to review court records in several districts to document restoration activity as reported in guardians' court-mandated annual guardianship plans. Finally, points-of-intake for restoration requests were identified and a point of intake system was developed to track phone inquiries regarding the restoration of capacity. Thus, the research design would rely on a broad range of sources to obtain data on the status of restoration of capacity activity in the state (see Table 2).

Table 2
Data sources

Method	**Target**
Web-based surveys	Attorneys, clerks of the court, agency staff, guardians, families of persons under guardianship
Focus groups	Persons under guardianship and their families
Case file reviews	Restoration proceedings
Point-of intake tracking	Tracking inquiries about restoration

B. Sources of Data

1. Web-Based Survey Returns and Findings

Separate survey instruments were developed for professionals involved in the guardianship process and family members of persons under guardianship. The areas covered in the

survey of professionals included extent of restoration of capacity activity in their offices and practices, procedural issues regarding restoration, and outcomes of restoration inquiries. The survey of guardians included items about their professional experience and training, current numbers of persons for whom they serve as guardian, information about restoration of capacity procedures with which they have been involved, and their familiarity with Florida law. Family members of persons with disabilities were also asked their familiarity with Florida law, as well as their relationship to the person with disabilities.

Generating comprehensive lists of these professionals for the purpose of canvassing or even drawing a random sample proved to be impracticable. The process would have required: lists of organizations dealing with guardianship and restoration, permission from each organization to conduct the research, and creation of email contact lists for staff involved in guardianship, and in particular, restoration.

Each of these steps would be time-consuming and often problematic. Most offices did not organize their files in a way that would make retrieval of restoration information straightforward; thus, requests for this information would have added a burden to staff. Finding initial email contacts for certain professional groups was also more difficult than anticipated. For example, there is no central list of email addresses for the clerks of court in Florida's circuits, and many clerks list only their phone numbers—not their email addresses—on their websites. Additionally, concerns about client confidentiality needed to be addressed at every level.

Since comprehensive email lists across agencies could not be obtained, convenience sampling techniques were used to answer questions on the status of restoration of capacity: email lists were obtained from professional contacts both inside the research team

and Stakeholders' Work Group; agency personnel were represented by staff at the Florida Agency for Persons with Disabilities; a statewide training workshop on less restrictive alternatives (Lighting the Way to Guardianship and Other Decision-Making Alternatives) to guardianship provided a large email list that included attorneys, guardians, family members, and other professionals; Finally, clerks of court were contacted individually through information provided on their websites.

While non-probability techniques such as convenience sampling provide a wealth of information, they do not meet the criteria for statistical inference because they are not based on random samples and they do not lend themselves to generalizing from sample findings to a larger population. Consequently, it is not possible to report statewide estimates of restoration activity in Florida, such as numbers of suggestions of capacity filed, and numbers of successful restorations.

On the other hand, using multiple sources of data—surveys, focus groups, case file reviews—presents a richer and more realistic understanding of the complex issues surrounding guardianship, restoration of capacity, and ultimately self-determination of persons with disabilities. Surveys were distributed from March through May of 2013. Email invitations were sent to potential respondents to alert them of the survey two days in advance of the mailing. There were 256 usable surveys returned to the team from an original list of 1,405 emails sent, a return rate of 18 percent.[56] All four targeted groups were well represented in the sample (see Table 3).

[56] Return rates are less critical in non-probability samples than in random or stratified samples, as sample findings are not generalized to an entire population.

Table 3 **Survey returns**	
Target group	**Number returned**
Agency staff	77
Attorneys	108
Clerks of the court	24
Guardians	47
Total	**256**

Survey respondents reported very little restoration activity, consistent with the professional experience of the Stakeholders' Work Group. Among attorneys, clerks, and agency staff, only 62 percent reported that their office receives inquiries about restoration; the median number of inquiries among those who received them is two per year. Some of these may result in the filing of a suggestion of capacity and the appointment of an attorney to represent the person under guardianship. But, according to the sample data, few of these inquiries seem to get that far. Among 38 attorneys responding to this item, 26 had not pursued a restoration case in 2012, and another six had pursued just one (see Figures 2 to 4).

Figure 2
Do individuals contact your office to seek information about the restoration of rights for persons under guardianship (n=149)

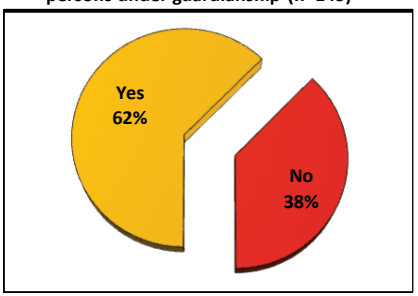


Figure 3

Approximately how many contacts about the restoration of rights for persons under guardianship have you had in the past 12 months? (n=144)

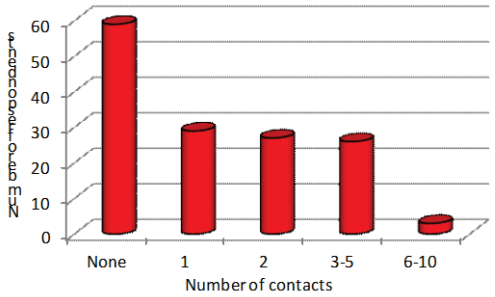
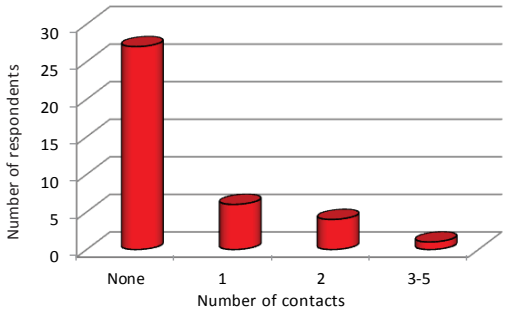
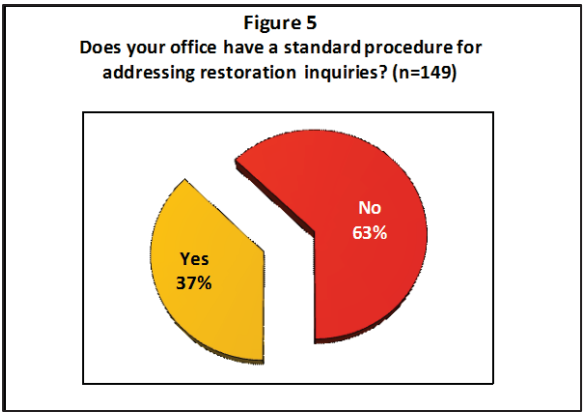


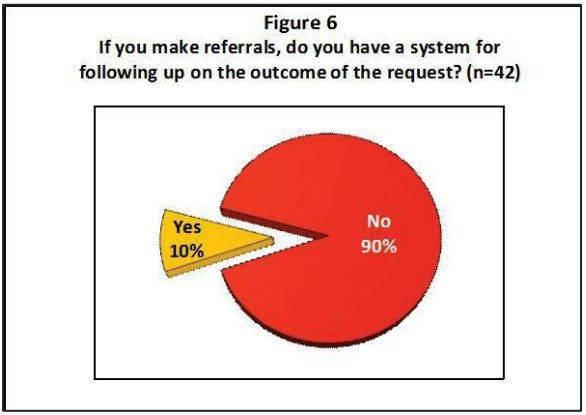
Figure 4

How many restoration cases did you pursue in 2012? (n=38)



In the offices and practices of this sample of attorneys, clerks, and agency staff, inquiries into restoration of capacity have not generally necessitated the creation of unique procedures for handling them. Less than one in three respondents reported having standard procedures for addressing restoration inquiries, and only one in ten had mechanisms for tracking these inquiries further along the process. The majority of cases were referred to attorneys and legal services, although a significant number were sent to public guardians or directly to the court (see Figures 5–6).





Information received from guardians provided insight into not only their own training and experience, but also the knowledge of the persons for whom they serve as guardians. About half of the guardians responding to the survey served as guardian for only one person, most likely family guardians. Another third were professional guardians, serving as guardian for between three and "more than ten" persons.

Guardians responding to the survey reported more experience with restoration of capacity than attorneys, clerks and

agency staff. More than 25 percent had at least one person who expressed an interest in having his or her rights restored. Similarly, nearly 20 percent had initiated a restoration process (see Figures 7–8).

Figure 7
Have any persons for whom you serve as guardian expressed an interest in haviing some or all of their rights restored? (n=42)

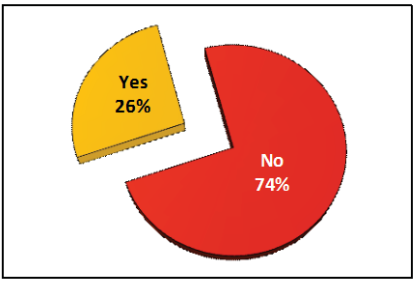
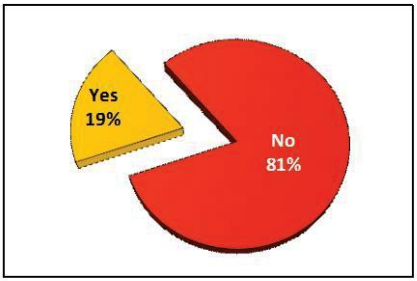


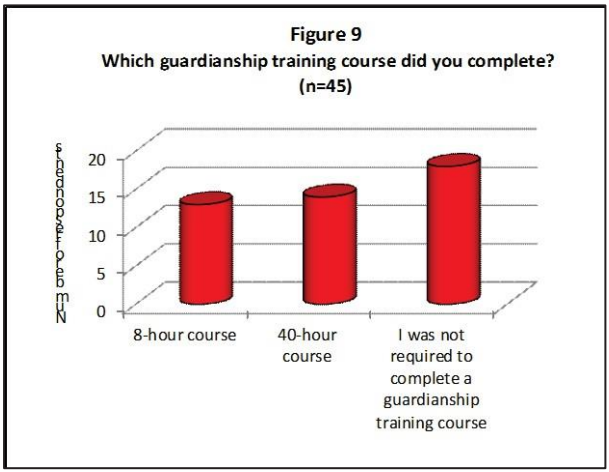
Figure 8
Have you ever initiated a process for restoration of rights for a person under guardianship? (n=42)



Responses from guardians raised serious concerns about their training and the extent to which persons under guardianship understand their rights. In Florida, family guardians (those who serve one or two persons) are required by law to complete an eight-hour guardianship training course,[57] and professional guardians (those who serve three or more) are required to complete a forty-

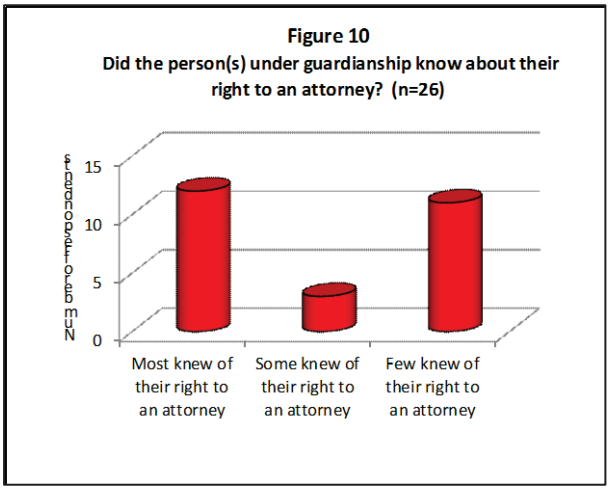
[57] FLA. STAT. § 744.3145(2) (2015).

hour guardianship training course.[58] Both courses include information on a guardian's legal responsibilities, their charge to seek training or activities that would lead to the least restrictive environment for persons under guardianship, and the duty to report this activity in annual guardianship reports. However, more than one third of the guardians responding to the survey reported receiving no training at all (see Figure 9).



Persons under guardianship were not universally aware of their right to an attorney. Only 47 percent (12 of 26) of the guardians reported that their clients knew of their right to an attorney. Nearly the same number (11 of 26, or 42 percent) reported that few of the persons for whom they served as guardian knew of their right to an attorney (see Figure 10). The lack of awareness among persons under guardianship of their legal rights is a cause for concern. Working towards the restoration of rights once they have been removed, and the associated training in skills that foster independence and self-determination, are cornerstones of a person-centered system.

[58] *Id.* at § 744.1085(3).



What we have learned from these respondents is that restoration of capacity is rare in their professional experience. Whether this is an indication of a system that is not working properly or simply the result of proper placement into guardianship is impossible to determine except on a case-by-case basis. Existing documents cannot tell us if a person has been improperly adjudicated as incapacitated or has developed skills that would warrant the restoration of some or all of their rights.

Findings from the surveys show that, although inquiries about restoration are not uncommon, respondents were aware of very few cases in which persons under guardianship with developmental disabilities had any rights restored. Furthermore, there is widespread lack of education and knowledge among families of persons with disabilities and guardians regarding the rights of persons under guardianship and the duties of guardians themselves, the consequences of which are two-fold. First, persons with disabilities, families and guardians may be unaware that there are mechanisms in place for restoring some or all of the rights of persons under guardianship in Florida, and that a primary responsibility of the guardian is to seek ways to accomplish that goal. Second, restoration is only the potential outcome of a more important process—assisting the person under guardianship to

develop the skills for self-determination and independent living. We have concluded that there is a need for outreach and education to persons under guardianship, their families and their guardians. Data collected from the focus groups also highlight that the need is urgent.

2. Focus Groups

Information was gathered from three focus groups: two in urban and one in rural settings. The urban focus groups took place in Orlando and Tampa, Florida, and the rural focus group was conducted in Gadsden County, Florida an area with a high African-American population. The Florida Agency for Persons with Disabilities (APD) provided assistance in locating and confidentially mailing focus group invitations to clients currently being served or on the waiting list for the Medicaid Home and Community-Based Services (HCBS) waiver, excluding those persons currently residing in an intermediate care facility for the developmentally disabled (ICF/DD). Focus group participants are referred to as "families" for the purpose of this study. A family consisted of one or more persons with a developmental disability under guardianship or guardianship advocacy in Florida, and one or more family members or legal guardian of the person under guardianship.

Table 4 shows the total amount of participants grouped by families in each of the three focus groups. Each family consisted of one person under guardianship with a developmental disability, and at least one family member/guardian. Of the 14 total participant families, 64 percent (nine families in total) participated in the rural focus group in Gadsden County, Florida, while 36 percent (five families in total) participated in the urban focus groups in Orlando and Tampa, Florida.

Table 4
Focus group mail outs and participation

	Invitations mailed by APD	**Invitations returned as undeliverable**	**Number of families confirmed**	**Number of families participating**
Orlando	150	20	10	2
Tampa	200	19	5	5
Gadsden County	258	10	15	9

Participants were divided into two separate rooms; one room contained persons with a developmental disability under guardianship, and the other room contained the family member/guardian of the person with a developmental disability. Both groups were asked a set of open-ended questions about their experiences with guardianship. A survey was also completed by the family member/guardian to collect demographic information about the person under guardianship (see Figure 11).

Figure 11
Number of participant families in focus groups by location (16 total families)

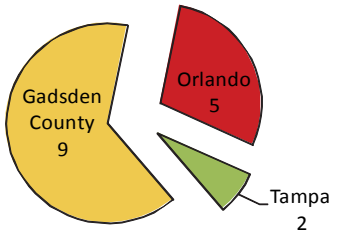


Figure 12 illustrates the gender of the persons under guardianship with a developmental disability who participated in the focus groups. Of the 14 total participants, 64 percent (nine people in total) were male and 36 percent (five people in total) were female.

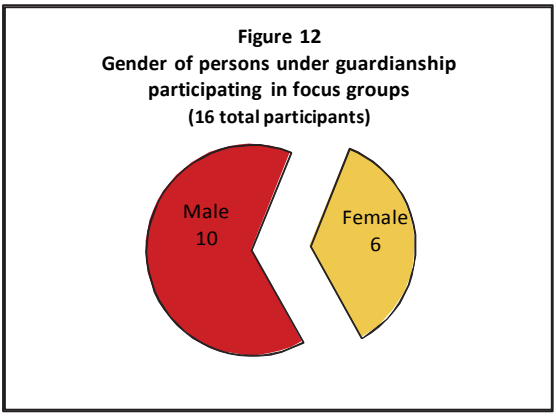
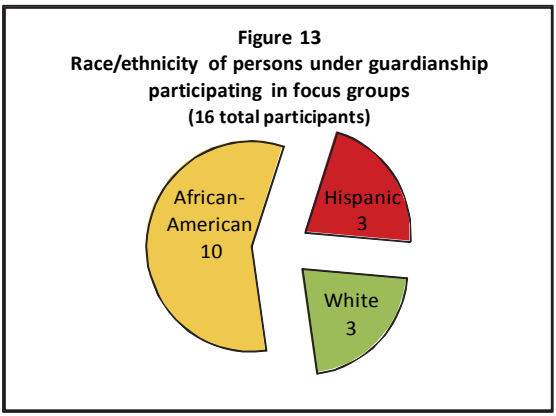


Figure 13 illustrated the race/ethnicity of the persons under guardianship with a developmental disability that participated in the focus groups. Of the 14 total participants, 57 percent (eight total participants) self-identified as African-American, 21.5 percent (three total participants) as Hispanic, and 21.5 percent (three total participants) as white.



Participants in the family/guardian groups were asked the following series of questions:

- How did you learn about guardianship? What has been your experience with guardianship?
- Do you know that once a person has a guardian, the law says that the individual can try to get some or all of their rights back?
- What activities are you doing to help the person under guardianship towards more independent living?
- Do you talk with your family member about restoration of rights?

Persons under guardianship groups were asked the following series of questions:

- Do you know you have a guardian that helps you?
- Who is your guardian?
- What does your guardian help you with?
- Do you live on your own? Do you want to live on your own?
- Do you manage your own money?
- Do you know that the law says that you can try to get some or all of your rights back?
- Have you wanted any of your rights back?

3. Focus Group Findings

Most family members/guardians were unaware that they could pursue restoration of rights, or felt that this option was not applicable to their family members under guardianship. When asked about whether the guardians answered the question on their annual reports about activities towards restoration, guardians noted that they had not explored restoration of rights with their family members. One participant was working with the person under guardianship to build independence and work towards restoration,

and one individual under guardianship had successfully regained all of his rights with the exception of choosing his residential setting.

Participants in the focus groups for persons with developmental disabilities were generally also unaware of the option to pursue restoration of some or all of their rights. Although unaware of restoration of capacity, participants stated interest in building independence by obtaining jobs, bank accounts, independent living, and more financial responsibility.

In all three focus groups, participants noted difficulty in obtaining public services or information for resources. One focus group participant reported attempting to contact a legal aid organization on multiple occasions and had not received a response. Participants were also unaware of the Agency for Persons with Disabilities (APD) database of resources and were unfamiliar with the Florida Developmental Disabilities Council's resources.

Although the focus group invitations specifically asked for persons under guardianship in Florida, some participants in the focus groups were unaware of the difference between a court-appointed guardian and acting as a representative on behalf of the person without court approval. Some participants were unaware of the difference between a plenary and a limited guardianship. A few family members believed that if they were the parent of the person with a developmental disability, they were the "guardian," despite their child being 18 or older. Two participants who had pursued guardianship or less restrictive alternatives to guardianship chose to do so because of difficulties faced by not being able to make decisions for the person with a disability who had reached the age of 18.

Three focus group participants noted difficulties in navigating the legal process in Florida. One participant stated that

although multiple attempts had been made to find an attorney to represent them, finding an affordable attorney or an attorney that would represent them pro bono had been unsuccessful. Another participant stated that the process was too expensive and that it was not economically feasible to pursue guardianship for her family member.

Members of the focus groups noted that they had been made aware of guardianship in Florida through their family member's school district. Many had been told that guardianship was the only way to ensure protection of their family members and assist in decision-making after their family member had turned 18 years of age. One focus group member, a special education teacher, stated that there was little input from family members in the development of their students' Individual Education Plan (IEP)[59] or Individual Transition Plan (ITP).[60] That same focus group member stated that multiple attempts to contact family members and assist them in finding less restrictive alternatives to guardianship had resulted in few responses from families.

The most common response in the focus group was the lack of knowledge of less restrictive alternatives to guardianship. Most focus group participants were unaware that there were resources available to assist family members in planning and decision-making other than those found in the Florida legal system. Of the focus group members who were aware of alternatives to guardianship, two were professional state workers, one at the Florida Department of Education and one at the Florida Agency for Persons with Disabilities.

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[59] The Individualized Education Program (IEP) is a written plan developed for each public school student who receives special education and related services, which is required by the Individuals with Disabilities Education Improvement Act of 2004. The IEP is developed by a committee of parents or guardians, teachers, school administrators, related services personnel, and the child, when appropriate. The IEP must include the child's present level of educational performance, special education and related services needed, annual educational goals, and a plan for measuring the child's progress.

[60] The IEP must include an Individual Transition Plan (ITP) by the time the student reaches the age of sixteen. The ITP outlines goals and services needed for the child to transition into adulthood.

4. Florida Court Case File Reviews

The goal of reviewing individual guardianship case files was two-fold: first, it would be the most accurate way to determine the frequency and outcomes of restoration activity, and second, it would provide a snapshot of activities being performed to advance an individual's independence. Included in a guardian's annual report to the court is a required section about the activities undertaken by the guardian that advance the individual's goal of greater independence. This information is critical in understanding the extent to which persons under guardianship are being provided with the knowledge and skills to develop some or all of the capacities that would lead to greater self-determination. There is no current data collection on the frequency and outcomes of restoration activity; therefore, individual case review was the only means of collecting data on the number of restorations and outcomes.

Three different counties in Florida were approached to gain access to their individual case records: two urban (Palm Beach and Orange) and one rural (Gadsden). Court personnel in all three circuits were initially receptive to participating in the project. Although none of these requests were denied, only two were approved in time for inclusion in the report.

Palm Beach County performed a limited review of a random sample of open guardianship files. It was not possible to grant persons outside the court access to the files. The senior auditor of the circuit reviewed 76 randomly selected open guardianship files for persons over the age of 18. Among these, over two thirds were of persons with age-related disabilities. Nine of the 76 files (11.8%) selected were of persons with developmental disabilities. After reviewing the files, the senior auditor reported his findings that there were "no cases where the guardianship plan recommended the restoration of any rights."

In rural Gadsden County, court staff reviewed 15 open guardianship files. Of these, eight persons under guardianship were minors and two were elderly. Among the remaining five, three had developmental disabilities. Over the 15 cases, six had no annual report filed and nine had no restoration plans recorded. None had a suggestion of capacity filed.

The results from the case file reviews triangulated findings from the web-based surveys of guardianship professionals and families of persons under guardianship, as well as the professional experience of the Stakeholders' Work Group members, which concluded that restoration activity is rare at best.

5. Point of Intake System

To better assess the demand for restoration of capacity in the community, three different agencies that receive inquiries about restoration of capacity were approached: the Statewide Public Guardianship Office at the Department of Elder Affairs, Florida Legal Services, and Disability Rights Florida. The goal of having a point-of-intake system at an agency that receives requests for information about guardianship was to determine the number of requests addressing restoration of capacity.

Two barriers arose when attempting to collect data from the identified points of intake named above. The Statewide Public Guardianship Office at the Florida Department of Elder Affairs was unable to provide intake tracking as disclosing the nature of the disability could potentially violate HIPAA confidentiality regulations. Additionally, Florida Legal Services works primarily with local legal aid offices that individually prioritize guardianship on a local level and therefore had no central point of intake available to collect the data.

Finally, data was collected from Disability Rights Florida, the statewide designated protection and advocacy system for individuals with disabilities in the State of Florida. Disability Rights

Florida receives more than 7,000 requests for assistance per year from or regarding people with disabilities from across the state of Florida.

These calls can sometimes include complaints about abuse, neglect or exploitation from individuals under guardianship who do not agree with the actions of their guardians and want their rights restored. Although Disability Rights Florida does receive calls pertaining to restoration of rights, it is only able to provide legal services to assist with restoration in a limited number of cases due to time and expense involved. For the point-of-intake research methodology, a system was developed to monitor incoming calls to the organization. When a call involved questions about guardianship, the caller was asked several additional questions to determine whether information on restoration of rights was being sought. Of approximately 3,500 calls to the organization during the six-month period from June 2013 to November 2013, only eight calls involved restoration.

C. Summary of Data Collection Findings

- Overall, there was very little restoration activity reported by respondents. Fewer than two out of three attorneys, clerks, and agency staff, received inquiries about restoration. The median number of inquiries among those who receive inquiries was two per year. More than 25 percent of guardians had at least one person who expressed an interest in having his or her rights restored, but this was over the full course of their professional experience.
- Few of these inquiries appeared to have developed into restoration proceedings. Among 38 attorneys responding to this item, 68 percent

had not pursued a restoration case in 2012, and another 16 percent had pursued just one.

- Training of guardians was inconsistent. Despite the fact that Florida law requires guardians to complete either an eight-hour or forty-hour course, more than one third had apparently had this requirement waived or not enforced and received no training at all.
- There is a need for outreach and education to persons under guardianship and their families. Fewer than half knew of their right to an attorney. Families were uninformed about the resources for fostering greater independence and self-determination in their family members with disabilities. This finding appeared in both the survey and focus group research.
- Focus group respondents were not clear on the difference between a legal guardian and a caregiver or family member. Several focus group family members identified themselves as "guardians" when in fact they had not gone through the process to become a legal guardian.
- Focus group respondents reported difficulties in navigating the legal process or in obtaining public services. This often stemmed from a lack of resources and an overtaxed system. Family members were not aware that while they may have difficulty finding attorneys to establish guardianship, the restoration process permits the appointment of a court-appointed attorney for the alleged incapacitated person.
- Families reported that they were advised to pursue legal guardianship when their dependent children turned 18 years of age. As a result, families did not consider or pursue alternatives to guardianship, such as durable power of attorney.

IV. STAKEHOLDERS' WORK GROUP

Three Stakeholders' Work Group meetings were held over the course of the first year of the project. Stakeholder membership consisted of a judge, attorneys with experience in guardianship, a circuit court guardianship monitor, self-advocates, a family guardian, a special education teacher, the deputy director of Florida Legal Services, two neuropsychologists, and members of affiliated agencies with experience in guardianship and restoration of capacity.

The first Stakeholders' Work Group meeting took place in Orlando, Florida, on June 7, 2013. The stakeholders were presented with the data that had been collected by the project work group during the research phase of the project. With that knowledge, stakeholders were asked about their personal experience with guardianship and restoration. Stakeholders were also asked to assist in designing a feasible outline for a project to assist persons with disabilities, their families, and the legal community with restoration of rights. The Work Group concluded that through the use of education, awareness of restoration would increase, and activities assisting in building capacity would lead to more successful restorations on a larger scale. While the suggestion arose about the use of more pro bono attorneys, it was the opinion of some of the stakeholders that an increase in workload for attorneys was not a sustainable approach for increasing the number of restorations.

In subsequent discussion, the Stakeholders' Work Group recognized that there was not an existing "place" where those inquiring about restoration of capacity could easily access information. Members concluded that the most effective way to address restoration of capacity would be further outreach and education through an easily accessible website. Since some people

would not have Internet access, having the materials in manual form would also be beneficial.

The Stakeholders' Work Group recommended that a pilot project be developed in the second funding year. The pilot project would develop and test the website and manual that include: an easy-to-understand explanation of the restoration of capacity process in Florida, a database of useful available resources, new tools to be developed, examples of a suggestion of capacity, person-centered planning information, and resources for the building of independence.

The second Stakeholders' Work Group meeting took place in Tampa, Florida, on October 11, 2013. Stakeholders were presented with the outline for the pilot project for restoration of capacity based on their recommendations in the previous meeting. From the suggestions made, stakeholders were asked to assess the functionality of the pilot project, as well as the feasibility of the pilot project. Stakeholders were asked to assist in identifying additional materials not addressed by the model, and if in their opinion, the program would assist individuals in gaining knowledge about the restoration of rights process in Florida.

Members of the Work Group noted that data collection was difficult for the restoration of capacity project and that a supplemental component of the pilot project should be to increase data tracking on guardianship and identify those groups that could facilitate the collection of data to further enhance the tracking of guardianship and restoration status, such as the Agency for Persons with Disabilities, Quality Council on Leadership. Stakeholders also noted that the Florida courts e-filing system does not currently collect information pertaining to guardianship restoration of rights and the nature of the disability, and suggested that the Work Group write a letter to request that a change be made to collect such data.

A final suggestion by the Stakeholders' Work Group was to raise awareness about the pilot project to groups currently assisting

in rewriting Florida Statutes, Chapter 744 on guardianship. Presentation of the data collected and pilot project materials will be provided to groups identified by the Stakeholders' Work Group to assist in facilitating systems change for restoration of capacity.

The third Stakeholders' Work Group meeting was convened as a webinar on December 14, 2013. The final outline of the pilot project and an implementation plan for the projected years two and three of the restoration of capacity project were presented. Stakeholders were asked for any final comments related to the project. Stakeholders were given a draft of the final report outline and provided input into its final presentation.

A. Pilot Project Design

The proposed pilot project recommended by the Stakeholders' Work Group will be composed of three components designed to increase awareness of the legal process of restoration in Florida:

1. Develop a website and accompanying manuals tailored to persons under guardianship and their families, self-advocates, guardians, the legal community, educators and other interested parties;
2. Advocate for the improved collection of data on guardianship and persons with developmental disabilities by the courts and state agencies;
3. Develop training workshops for persons under guardianship and their families, self-advocates, guardians, educators, and the legal community.

B. Website and Manuals

In year two of the proposed pilot project, the website and accompanying manuals will be developed, including new tools identified in the research findings. The website and manuals are intended to be a key resource for persons seeking information about restoration of capacity, and a supplemental set of information to the Council's "*Lighting the Way to Guardianship and Other Decision-Making Alternatives*" handbook.
The following tools were identified by the Stakeholders group, and further elaborated by the project team:

- An easy-to-understand explanation of the restoration process in Florida
- A directory of resources and activities for self-determination, independent living, and least-restrictive alternatives available for decision making assistance
- Directories of relevant agencies and legal offices
- Instructions on developing a Progressive Capacity Restoration Plan which identifies activities and goals towards building independence and acquiring abilities
- Resources for physicians that focus on assessing functional abilities in addition to, or instead of, medical assessments only
- Resources for attorneys to assist in the restoration process including relevant statutory law, relevant case law, sample briefs and legal pleadings

Two manuals will be developed, one for persons under guardianship, families, guardians, educators, and other interested parties; and the other for attorneys and other legal professionals. These manuals will contain the same material as the website for those persons that cannot access the website. The manuals will also

be offered as part of the workshop trainings in year three of the proposed pilot project.

C. Improved Data Collection

In year two of the proposed pilot project, the Stakeholders' Work Group identified the following three opportunities for improved data collection on restoration of rights:

- Questionnaire for Situational Information (QSI)—APD Needs Assessment
- Rewrite of the guardianship statute (Chapter 744, F.S.)
- E-filing with the Florida courts

The Questionnaire for Situational Information (QSI) conducted by the Florida Agency for Persons with Disabilities is a portion of the assessment instrument used to determine a person's Medicaid allocation. Additional items added to the assessment instrument pertaining to legal representatives, guardianship, and restoration of rights may assist in increasing data collection.

The Stakeholders' Work Group has suggested that any group working to rewrite the Florida guardianship statutes include a mandate for improved data collection, as well as communicating the importance of less restrictive alternatives to guardianship. Changes to the guardianship statutes should also include improving the examining committee process and qualifications of examining committee members.

The judicial system does not currently gather data on guardianship and people with developmental disabilities. For example, it is impossible to know the nature of incapacity in guardianship cases or the number of restorations filed during a

particular period without examining individual court files. Key contacts in the judicial system should be identified and informed of the importance of collecting these data elements on a statewide basis and advocate for changes in current policy. Similarly, thousands of individuals with disabilities and their families receive supportive services in Florida, but data on the use of decision-making supports are currently not collected. Identifying existing opportunities where data can be collected will be beneficial.

Additionally, the Florida court system should include detailed information in their e-filing system pertaining to guardianship and restoration of rights for better tracking of persons under guardianship.

D. Training Workshops

In year three, a minimum of three live workshops will be conducted in strategically selected locations throughout the state in an effort to reach as many individuals as possible. Each live workshop would be conducted over two days; One day for persons under guardianship, families, guardians, educators, and one day for interested parties, and the other for attorneys and others in the legal community. The website and manuals developed in year two will contain the information and resources that will be used for the live workshops, and will:

a. focus on raising awareness of the rights of persons under guardianship, including the right to a continuing review of the appropriateness of the guardianship and the legal process for restoring rights;
b. focus on building independence and autonomy for persons under guardianship;
c. provide training to guardians on their responsibilities to engage in activities that build independence and work towards restoration; and

d. provide resource materials for attorneys representing persons seeking restoration of rights and resources for the judiciary, clerks of court, service providers and other interested parties to assist persons seeking restoration.

The first day of the workshop will be entitled "Building Independence," and will be designed for persons under guardianship, their families, guardians, educators, and other interested parties. This workshop will offer training in the new tools developed, and identifying activities for self-determination, filing a Suggestion of Capacity, and identifying resources for independent living.

The second day of the workshop will be a legal workshop which will present a review of restoration of capacity and will assist in the use of the website and manual. Continuing Legal Education units will be offered in this workshop. Legal workshops will offer training on tools developed to improve the examining committee process, self-determination and person-centered planning, examples of successful Progressive Capacity Restoration Plans, different models of assessment instruments (psychological assessments, functional assessments, activities of daily living, etc.).

V. CONCLUSION

Restoration of rights among persons with developmental disabilities in Florida appears to be a rare occurrence despite the availability of a statutory scheme designed to recognize and facilitate regaining capacities. Raising awareness among individuals under guardianship and guardianship professionals is needed to address this issue.

KOREAN GUARDIANSHIP AS A POLICY FOR THE PROTECTION OF ADULTS WITH IMPAIRED DECISION-MAKING ABILITIES

Professor Cheol Ung Je*

I. INTRODUCTION

In Korea, close relatives within family have traditionally been responsible for the protection of adults with dementia, developmental disabilities, brain injury, and mental illness, who temporarily or permanently lack the mental capacity to make decisions in relation to their property, personal welfare, or medical treatments (hereinafter "Adults with impaired decision making abilities"). Family law therefore has dealt with relevant legal matters. Traditionally, a family member is appointed as a guardian for the person's representation in property matters, as well as in personal care and medical treatments, if agency is required.[1] The society and the state do not intervene to protect him or her unless he or she is impoverished or has no relatives.[2]

The need for social intervention to secure the adult with impaired decision making abilities' proper protection has, however, increased. This paper first describes the background of such a change, namely the social and legal environment leading to the

* Professor at Hanyang University, Republic of Korea. This work was supported by the research fund of Hanyang University (HY-2014).

[1] Minbop [Order of a Guardian for a Person in Full Incapacity or in Limited Incapacity], Art. 933 (R.O. Korea). This law was abolished by Law No. 10429 in 2011.

[2] *E.g.*, The Korean National Basic Living Security Act [Standard for Public Benefits], Article 3, is applied to secure the minimum level of living but only in cases in which there are not any relatives responsible for their care.

introduction of social responsibility for such a protection. It then explains the adoption of major policy, namely the new adult guardianship law and its main features. Thereafter, it introduces the current situation after the implementation of the new adult guardianship law. Lastly, it focuses on remaining tasks to secure proper protection of adults with impaired decision making abilities.

II. BACKGROUND FOR THE ADOPTION OF A POLICY FOR SOCIAL RESPONSIBILITY

A. Unpopularity of Guardianship

Among the Korean population, which is more than 50 million people,[3] the number of adults with impaired decision making abilities is approximately more than one million, as shown in table 1.[4]

Table 1
The Number of Persons with Impaired Decision Making Abilities[5]

Number/ Type	Persons with Dementia	Persons with Brain Injury	Persons with Developmental Disabilities	Persons with Mental Illness
Registered Number	540,755	257,797	190,163	94,638

Adults with impaired decision making abilities use guardians to represent them in legal transactions because alternatives to guardianship or augmentative and alternative

[3] Statistics Korea, *Statistics on Korean Population*, http://www.index.go.kr/potal/main/EachDtlPageDetail.do?idx_cd=1007 (last visited Oct. 24, 2016).
[4] The Korean Ministry of Health and Welfare, *2013 Statistics on Disabilities*.
[5] "The Number of Persons with Impaired Decision Making Abilities," The Korean Ministry of Health and Welfare, 2013 Statistics on Disabilities

communication methods and skills for such adults are not yet developed. That being said, adult guardianship has been very unpopular in Korea, as reflected in the low number of adults, roughly six thousand people, under guardianship.[6]

Table 2
The Number of Applications for, and Permission of, Adult Guardianship[7]

Year	Application	Permission
2001	323	176
2002	421	208
2003	433	250
2004	473	274
2005	529	291
2006	663	303
2007	747	334
2008	804	391
2009	944	493
2010	1,024	515
2011	1,290	617
2012	1,342	705
2013.7.1–2014.9.30	1,851	1,206
Total	10,884	5,763

[6] There have not been any official statistics on the current number of adults under guardianship in Korea, which has presumably been due to prevailing thought that guardianship is a concerned family matter and that society should abstain from intervention into family matters. The current number of adults under guardianship is, therefore, an estimated one, based on the fact that major users of guardianship services have been adults with dementia, who have much more property than other disabled persons, but who are too old to properly manage their financial and property affairs, and the fact that the number of accumulated permission orders for more than 13 years may value approximation

[7] "The Number of Applications for, and Permission of, Adult Guardianship," The Korean Supreme Court, Judicial Statistics 2002–2013.

Less than 10 per 100,000 of the population are under adult guardianship in Korea, which is a low number, even when compared to other East Asian countries: for instance, about 138 per 100,000 of the population in Japan were under adult guardianship in 2013.[8] In Taiwan, where the new adult guardianship law came into force as of November 23, 2009, the number of guardianship applications reached 4,530 in 2010; of those, a guardian was appointed in 2,477 cases. In 2011, the number of relevant applications was 4,485, among which 2,724 cases were permitted to open guardianship. In 2012, the number of relevant applications in Taiwan was 5,925, among which guardianship was opened in 2,806 cases. In 2013, the number of application increased to 7,573, among which guardianship was opened in 3,625 cases.[9]

There can be many factors explaining such an unpopularity of adult guardianship in Korea. The most plausible reason can be family-centered Confucianism, which has for long prevailed in Korean society.[10] Family centered Confucianism has made family members[11] and relatives[12] be favorably treated in many aspects.

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[8] Makato Arai, *Guardianship in Japan Under the Adult Guardianship Law of 2000 in* COMPARATIVE PERSPECTIVES ON ADULT GUARDIANSHIP 167 (Kimberley Dayton ed., 2014). There are three types of statutory guardianship in Japan: guardianship, which corresponds to full guardianship in Korean law in terms of power and authority of guardians in relation to financial and property matters, and curatorship and advisorship, which are similar to limited guardianship in Korean law. Continuing power of attorney in Japan is available instead of statutory guardianship. *Id.* In Japan, the number of applications for guardianship, for curatorship, and for advisorship was reported to be 28,472, 4,268, and 1,264, respectively in the year 2012. In the same year, persons under guardianship, under curatorship, and under advisorship were 136,484, 20,429, and 7,508, respectively. Yasuhiro Akanuma, *Overview and Characteristics of the Adult Guardianship System in Japan* in *The Adult Guardianship System* 24 (The New Asia Family Law Tripartite Conference, ed., 2014).

[9] Sieh-Chuen Huang, *An Introduction to Taiwan's Adult Guardianship and Recent Development*, in *The Adult Guardianship System* 118 (The New Asia Family Law Tripartite Conference, ed. 2014). Considering that the population of Taiwan, about 23 million, is less than half the population of Korea, the number of applications for guardianship in Taiwan is much larger than in Korea. *Id.*

[10] The political ideology of the last Korean dynasty, which ruled for about 500 years before Japan colonized Korea in 1910, was Confucianism, which deeply permeated into ordinary people's daily lives, but which began to weaken after industrialization in 1970s. *See generally* Nicolas Levi, *The Impact of Confuscianism in South Korean and Japan*, 26 ACTA ASIATICA VARSOVIENSIA 7-16 (2013).

[11] According to Art. 779 of the Korean Civil Code (hereinafter KCC), family members are the spouse, lineal blood relatives, brothers, and sisters. Spouses of the lineal blood relatives, lineal blood relatives of the spouse, and brothers and sisters of the spouse are numbered to family members if they share living accommodation. Minbop [Scope of Family Matters], Art. 79 (R.O. Korea).

[12] The scope of relatives is very broad in Korea. Minbop [Scope of Relatives], Art. 777 (R.O. Korea).

On the one hand, even remote relatives have rights to intervene in very personal affairs such as marriage[13] and adoption;[14] close relatives are responsible for maintenance of their relatives in poverty[15] and have power to admit relatives who are under their maintenance and who are mentally ill to a psychiatric hospital or facility without their consent.[16] Such a privilege of relatives is extended to immunity from criminal prosecution: for instance, deceit, theft, and misappropriation of property between close relatives cannot be convicted, and such a crime between remote relatives can be prosecuted only with direct complaint from victims.[17]

On the other hand, it has been very naturally acceptable to Koreans that family members can make decisions in relation to financial matters as well as personal welfare matters on behalf of adults with impaired decision making abilities, even without any

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KCC provides that blood relatives within the eighth degree of kinship, affinity relatives within the fourth degree of kinship, and spouse are relatives. *Id.*

[13] Close relatives within the fourth degree of kinship are eligible to apply to a competent family court for cancellation of double marriage. Minbop [Claimant for Annulment of Marriage in Violation of Marriageable Age, etc.], Art. 817 (R.O. Korea). They may also apply for cancellation of a marriage between relatives. Minbop [Claimant for Annulment of Bigamy], Art. 818 (R.O. Korea).

[14] Lineal blood relatives and their spouses among lineal blood of immediate kinship are eligible to apply to a competent family court for cancellation of adoption. Minbop [Affiliation], Art. 885 (R.O. Korea). Even remote relatives are eligible to apply for revocation of adoption. Minbop [Person Entitled to Claim for Dissolution of Adoptive Relation], Art. 906 (R.O. Korea).

[15] Lineal blood relatives and their spouses are responsible for maintenance of each other in poverty. Minbop [Duty to Furnish Support], Art. 974 (R.O. Korea).

[16] *See* Korean Mental Health Act, Art. 24 (R.O. Korea); *see also* Cheol Ung Je, *Korean Guardianship in* COMPARATIVE PERSPECTIVES ON ADULT GUARDIANSHIP 195 (Kimberley Dayton ed., 2014).

[17] Art. 328 of Hyongbup [Korean Criminal Act] provides such an immunity or privilege is extended to the crime of obstructing another's exercising rights. Hyongbop, Art. 328 (R.O. Korea). Art. 344 provides the same privilege to the crime of larceny and robbery. Hyongbop, Art. 344 (R.O. Korea). Art. 354 extends to the crime of fraud, unlawful profit, and extortion. Lastly, Art. 361extends to the crime of embezzlement and breach of fiduciary duty. Hyongbop, Art. 354 (R.O. Korea).

authority or without any legal provision granting such an authority. Such a transaction by an unauthorized relative agent could be done under the non-transparent financial and property market environment where a non-identified principal could buy and sell financial goods and real property.

B. Changed Social Environment

Such a legal and social environment has set the living conditions of adults with impaired decision making abilities in contradiction; the purpose is their protection by family members and relatives, but the probability of neglect and abuse by those same family members and relatives is considerable. In reality, the latter aspect has become more conspicuous, as large extended family culture began to disband.[18] The decrease of family responsibility for the protection of adults with impaired decision making abilities can be supported by the fact that the latter are left alone either in the communities or in accommodation institutions, as shown in the three tables below.[19] In other words, it has traditionally been considered that the elderly and intellectually or mentally disabled adults should be cared for by family members, while in reality, they are abandoned without any family support.

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[18] Elder abuse has been serious social problems in Japan and the Prevention of Elderly abuse and Assistance of Care Givers of Elder People Act was enacted in 2005. *See* Japanese Ministry of Labor, Health and Welfare, *A Survey Result for Compliance Status of Act Related to the Prevention of Abuse Against Elders and the Assistance for Caretakers of Elders, available at* http://www.mhlw.go.jp/file/04-Houdouhappyou-12304500-Roukenkyoku-Ninchishougyakutaiboushitaisakusuishinshitsu/h24chousakekka.pdf (last visited Oct. 24, 2016). Interestingly, Japanese law on the power, responsibility, and privilege in criminal cases of relatives is very similar to Korean law except that the scope of relatives in Japan is narrower than in Korea: namely relatives are confined to those to the sixth degree of kinship. From such a similarity, it can be deduced in Korea as well that similar social phenomena of abuse of adults with impaired decision-making abilities are likely to take place.

[19] The National Mental Health Commission, *Statistics on Mental Health 2005-2009*; The Ministry of Health and Welfare, *Statistics on Accommodation Facilities for Disabled Persons*; The Ministry of Health and Welfare, *2013 Statistics on the Elderly*.

Table 3
The Number of Involuntarily Admitted Patients (Unit: Persons)[20]

Types/Year	2005	2006	2007	2008
Psychiatric Hospitals	58,150	63,760	68,253	69,702
Psychiatric Accommodation	14,049	14,296	14,609	14,235
Total	72,199	78,056	82,862	93,937

Table 4
The Number of Facilities and Accommodated Persons with Intellectual Disabilities[21]

	2007	2008	2009	2010	2011	2012	2013
Facilities	131	144	172	196	226	278	293
Accommodated Persons	9,325	9,192	9,539	14,338	10,788	11,748	12,001

[20] "The Number of Involuntarily Admitted Patients," The National Mental Health Commission, Statistics on Mental Health 2005–2009.
[21] "The Number of Facilities and Accommodated Persons with Intellectual Disabilities," The Ministry of Health and Welfare, Statistics on Accommodation Facilities for Disabled Persons

Table 5
The Number of Elderly Living Alone in the Communities[22]

Age/Year	2007	2008	2009	2010	2011	2012
Total	887,118	943,666	999,194	1,055,650	1,124,099	1,186,831
65-69	257,136	266,581	271,173	273,476	275,471	280,913
70-74	263,044	274,664	286,198	297,723	308,492	319,666
75-79	205,556	222,727	240,876	258,999	276,760	292,911
80-84	113,218	124,618	138,241	154,036	172,152	191,514
85+	48,164	55,076	62,706	71,416	91,224	101,827

Coincidently, the social atmosphere or social customs that relatives believe they are entitled to representing adults with impaired decision making abilities without any legal authority has recently been changing slowly but steadily. On the one hand, since the mid-1990s, many laws have been made so that financial transactions and real property transactions are to be done only under the real owner's name.[23] Such a change of social and legal environment began to be further accelerated by the money laundry prevention statutes,[24] and the protection of individual information statutes,[25] which were either enacted or revised since 2000. Since then, the law that any person cannot do legal transactions on behalf of others without legal authority, such as withdrawal of their relatives' money from bank accounts, began to materialize in the market.

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[22] "The Number of Elderly Living Alone in the Communities," The Ministry of Health and Welfare, 2013 Statistics on Elderly

[23] Act on the Registration of Real Estate under Actual Titleholder's Name (Law No. 10682, 1995) (R.O. Korea); Act on Real Name Financial Transactions and Confidentiality (Law No. 12711, 1997) (R.O. Korea).

[24] Act on Special Cases Concerning the Prevention of Illegal Trafficking in Narcotics Etc. (Law No. 10854, 1995) (R.O. Korea); Act on Reporting and Using Specified Financial Transaction Information (Law No. 11411, 2001) (R.O. Korea); Act on Regulation of Punishment of Criminal Proceeds Concealment (Law No. 12842, 2001) (R.O. Korea); Act on Prohibition against the Financing of Terrorism (Amended by Presidential Decree No. 24083, 2012).

[25] The Personal Information Protection Act was enacted in 2011. Personal Information Act (Law No. 11990, 2011).

Such a changed social environment has urged policy makers and legislators to reform current systems to secure proper protection for the adults with impaired decision making abilities instead of leaving such tasks to traditional advocates, namely family members. In other words, social responsibility for the protection of such adults was inevitable.

C. The Reformation of Guardianship Law as a Major Policy for Social Responsibility

Policy makers and legislators rarely go beyond accustomed legal framework, which is the very case for Korean legislators' reformation work to secure social responsibility for the adults with impaired decision making abilities. In this regard, the Japanese experience was a model for the reformation work because Japan has undergone the change of social environment before Korea.

In Japan, there are about 550,000 adults with intellectual disabilities; about 3.2 million adults are mentally disabled, and more than 4.6 million are adults with dementia.[26] Among them, adults under guardianship were numbered 176,564 in 2013.[27] That

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[26] *See* Cabinet Office, Government of Japan, *Disability Statistics in Japan*, 2012, *available at http://www8.cao.go.jp/shougai/whitepaper/h24hakusho/zenbun/pdf/h1/2_1.pdf;* Ministry of Health, Labor and Welfare, *Comprehensive Strategy for Dementia*, 2012, *available at* http://www.mhlw.go.jp/file/04-Houdouhappyou-12304500-Roukenkyoku-Ninchishougyakutaiboushitaisakusuishinshitsu/01_1.pdf (last visited Oct. 24, 2016). A Japanese author argues that in 2012, about 8.4 million people are potential demanders for guardianship service, because about 4 million elderly are demented, 550.000 are intellectually disabled, and 3.23 million people are mentally disabled. *See* Nobuyuki Koike, the Introduction and the circumstances of the revision of the Adult Guardianship System in Japan, in: *The Adult Guardianship System,* ed., by the New Asia Family Law Tripartite Conference, p.5, 2014.

[27] *See*, Family Bureau Under Japanese Supreme Court, *Overview of Adult Guardianship Related Cases (from April 2000 to March 2001), available at*

means that about 138 per 100,000 of the population in Japan were under adult guardianship. Moreover, the appointment of third parties as guardians, especially professional guardians has, year to year, increased to the extent that more than half of newly appointed guardians recently came from professionals such as lawyers, Japanese judicial scriveners, social workers and accountants, as shown in table 6.[28] Lastly, local authorities have become more and more involved in the application for guardianship and supported vulnerable adults so as to be served by citizen guardians and guardian corporations subsidized by them.

Table 6
The Composition of Newly Appointed Guardians[29]

	Relatives	Friends etc.	Professionals	Citizen Volunteers subsidized by Local Authorities	Total
2010	16,758(58.5%)	956(3.3%)	10,892(38%)	0	28,606
2011	16,420(55.6%)	205(0.6%)	12,805(43.3%)	92(0.3%)	29,522
2012	15,661(48.5%)	161(0.4%)	16,323(50.6%)	118(0.3%)	32,263
2013	14,064(42.1%)	129(0.3%)	18,983(56.9%)	167(0.5%)	33,343

It seemed to occur to Korean policy makers that the Japanese experience could serve as a solution. In other words, reformation of the adult guardianship system arose as a major policy for the state to intervene in the protection of adults with impaired decision making abilities, which was traditionally regarded as a family matter.

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http://www.courts.go.jp/vcms_lf/H28.1kouhou.pdf (last visited Oct. 24, 2016).

[28] Japanese Supreme Court, *Judicial Statistics on Adult Guardianship by Japanese Supreme Court from 2010 to 2013*.

[29] "The Composition of Newly Appointed Guardians," Judicial Statistics on Adult Guardianship by Japanese Supreme Court from 2010 to 2013

D. Another Element of Respecting Human Rights

On the other hand, the awareness of human rights of disabled persons in Korea has been raised since the beginning of the twenty-first century, particularly since the establishment of the national Human Rights Commission of Korea (NHRCK) in 2001.[30] Recently the focus of the disability movement led by the civil society has begun to shift to intellectually disabled persons and to mentally disabled persons. It is mainly because many cases of financial abuse, physical abuse and sexual exploitation began to be exposed to the public. Such awareness was a driving force for Korea ratifying The United Nations Convention on Rights of People with Disabilities (UNCRPD) in 2008.[31] Since then major legislative measures have been taken so as to implement UNCRPD into domestic laws and practices.[32] The reformation of the traditional legal incapacity regime, namely, the Adult Guardianship Act 2011,[33] was influenced by such a social trend, as well. It means that the policy purpose of the reformation of the traditional guardianship system to add social responsibility where family

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[30] *See National Human Rights Council of Korea*, http://www.humanrights.go.kr/english/main/index.jsp.

[31] From 2003 on, National Human Rights Commission of Korea and many disability organizations paid attention to the preparation work of UNCRPD and introduced its codification process to Korea. See National Human Rights Commission of Korea, the reports on the attendance at the second, and sixth Ad Hoc Committee on a Comprehensive and Integral Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities, 2003 and 2006, *available at* http://www.humanrights.go.kr/03_sub/body02_3_4.jsp.

[32] *See* Act on the Prohibition of Discrimination against Disabled Persons (Law No. 10789, 2007) (R.O. Korea); Act on Activity Assistant Services for Persons with Disabilities (Law NO. 10518, 2011.

[33] The official title is "The Amendment of Some Provisions in the Korean Civil Act (Act No. 10429)." Amendment of Some Provisions in the Korean Civil Act (Act No. 10429, 2013). Since provisions related to guardianship are in the KCC, any reform to guardianship law has required an amendment to KCC. *Id.* The Adult Guardianship Act 2011 is however frequently used to succinctly indicate the legislative purpose.

responsibility was usually emphasized was supposed to guarantee that the everyday life of adults with impaired decision making abilities was to be normalized, that their remaining capacity should be respected, and that their right to self-determination should also be respected.

However, such an aspect of respecting human rights in the reformation of guardianship was compromised by the strong power of traditional culture and prejudice against adults with impaired decision making abilities.[34] It means that the Adult Guardianship Act is a result of compromise between respecting the principles of the UNCRPD and resisting a change toward respecting the human rights of persons with impaired decision making abilities, as will be demonstrated later.

III. THE MAIN FEATURES OF THE ADULT GUARDIANSHIP ACT 2011 AND ITS PERFORMANCE

A. From Family Responsibility to Family Court's Responsibility

Under the legal incapacity regime, any close relative within the fourth degree of kinship and a public prosecutor were eligible to initiate judicial procedure for a declaration of legal incapacity of an adult with impaired decision-making abilities.[35] When a competent family court[36] declared that the person in the case for

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[34] *See The Adult Guardianship Study Group*, Study on Adult Guardianship Systems, NATIONAL COURT ADMINISTRATION, 2007. A good example is the proposal of reformation of the traditional legal incapacity regime by the Adult Guardianship Study Group of the Korean Supreme Court in 2007. *Id.* This proposal actually copied Japanese adult guardianship law of 2000 in many aspects, which significantly contravenes the Article 12 of UNCRPD in that guardianship, curatorship, and even advisorship deprive or restrict legal capacity of persons with impaired decision-making ability and in that any element of supported decision making system the Article 12 of UNCRPD recommends for adoption is hardly found. *See* Convention on Rights of Persons with Disabilities art. 12 (May 3, 2008), *available at* http://www.un.org/disabilities/default.asp?id=272.

[35] Minbop [Declaration of Limited Incapacity], Art. 9 (R.O. Korea); Minbop [Declaration of Full Incapacity], Art. 12 (R.O. Korea). These were revised by Law No. 10429, 2011.

[36] The case of declaration of legal incapacity was under the jurisdiction of family court, the function of which was discharged by 5 Family Courts, other District Courts and Branch Courts as the first

whom application for a declaration is made (hereafter the person in the case) is either in full incapacity or in limited incapacity, depending on the degree of deterioration of his/her mental capacity, a guardian was statutorily determined in the following order: a spouse if the person in the case is married, his/her parents, brothers and sisters, uncle and aunt, or cousins; if there was two or more eligible candidates in the same degree of kinship, the eldest has priority.[37] That being said, in an exceptional case where there was no statutory candidate, the competent family court had power to appoint a proper person as a guardian.[38]

A guardian whose ward was either in legally full incapacity (a person of Gm-Chi-San) or in limited incapacity (a person of Han-Jeong-Chi-San) was entitled to make any decisions in relation to financial matters.[39] Additionally, a guardian for the person who was in full incapacity had power to consent to marriage,[40] divorce,[41] and adoption,[42] and other important family related decisions by him or her.[43] While the guardian's power and authority was enormous, the revocation of a declaration of legal incapacity was permitted only if causes for such a declaration

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instance. Under the new adult guardianship law, guardianship cases are under the jurisdiction of family court as well. *See* Family Litigation Act, Art. 2 (Law No. 11949, 1990).

[37] Minbop [Order of a Guardian], Art. 935 (R.O. Korea). This was abolished by Law No. 10429, 2011.

[38] *See* Minbop [Appointment by a Court of a Guardian], Art. 936 (R.O. Korea). This was abolished by Law No. 10429, 2011.

[39] *See* Minbop [Statutory Authority of a Guardian to Represent a Ward], Art. 938 (R.O. Korea). This law was revised by Law No. 10429, 2011.

[40] *See* Minbop [Marriage Requiring Consent], Art. 808(2) (R.O. Korea).

[41] *Id; See also* Minbop [Adult Guardianship and Divorce by Agreement], Art. 835 (R.O. Korea).

[42] *See* Minbop [Adoption of Adult Ward], Art. 873(1) (R.O. Korea).

[43] A full guardian has power to consent to marriage, divorce, and action for denial of paternity. Minbop [Adult Guardianship and Action of Denial of Paternity], Art. 848 (R.O. Korea). A guardian also has the power to consent to adoption and dissolution of adoption. Minbop [Dissolution of Adoption Relation by Agreement for Adult Ward], Art. 902 (R.O. Korea).

disappeared, which was to be evidenced by a psychiatrist or psychologist report.[44] It meant that in most cases the status of legal incapacity used to last until the person under guardianship died, because causes for impaired decision-making abilities, namely dementia and developmental disabilities, hardly disappear. Nevertheless, the supervision system of the guardian was very poor. Theoretically ultimate responsibility for supervision of the guardian lay with a family council, the members of which were appointed by a competent family court from among relatives and persons specially acquainted with the ward, on the application of the ward, guardian, relatives, or others having interest in the welfare of the person in the case.[45] The installed family council had power to consent to the representation by the guardian of important transactions such as the running of a business, borrowing and lending money, disposal of land or any other valued property and litigation.[46] However, the supervision by a family council did not work in reality, because it could be organized, only if it was necessary to convene, but only the guardian—not other relatives—knew if such a necessity existed.[47] The traditional legal incapacity regime was family centered system, whereby there could hardly be any possibilities of family courts intervening into appointment of a guardian and his or her service.

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[44] *See* Minbop [Revocation of the Declaration of Limited Incapacity], Art. 11 (R.O. Korea); Minbop [Revocation of the Declaration of Full Incapacity], Art. 14 (R.O. Korea). These were both revised by Law No. 10429, 2011; Regulations on Family Litigation Act [Revocation of Declaration of Limited Incapacity and Full Incapacity], Art. 38 (R.O. Korea), which was revised by the Regulation of Korean Supreme Court, No. 2467, 2013.

[45] See Minbop [Appointment of Family Council Members], Art. 963 (R.O. Korea). This was abolished by Law No. 10429, 2011.

[46] A family council could be installed only when any eligible relatives or a guardian applied to a family court for the appointment of its members, meaning that there could be a guardian without a family council. Even if it was installed, a guardian had no duty to report to get the consent of the family council on the transaction. It means that in reality it was not until a member of family council noticed that the ward had been seriously neglected or abused that the competent family court was able to intervene in the guardian's work. *See* Cheol Ung Je, *supra* note 16, at 194–96.

[47] Minbop [Organization of a Family Council], Art. 960 (R.O. Korea), which was abolished by Law No. 10429, 2011, provided that it was to be established in the cases where its resolutions were required, namely the cases where the legal authority of a guardian to represent a ward was restricted. *See* Minbop [Restriction of legal Authority of Representation and Power to Consent], Art. 950 (R.O. Korea), which was revised by Law No. 10429, 2011.

The Adult Guardianship Act aims at overcoming the drawbacks of the legal incapacity regime revealed, namely securing proper intervention of the family court. Under the new system, eligible applicants apply for the appointment of one or more guardians,[48] instead of applying for a declaration of legally full and limited incapacity. Unlike under the legal incapacity regime, a competent family court[49] consequently has discretion to appoint any person or any legal entity as a guardian or guardians with taking into consideration the desire and wish, health, living condition and property of the person in the case, their job and experience of one or more candidates recommended, and conflicts of interests of the candidates with the person in the case.[50] Moreover, a competent family court, if it finds it necessary, can, on its own motion, appoint a supervisory guardian,[51] which replaces the function of a family council under the traditional legal incapacity regime, direct guardians to take appropriate measures,[52] and replace guardians with other guardians.[53] The transit from legal incapacity regime to adult guardianship grants on family courts greater power and responsibility for the protection of adults with impaired decision making abilities. Thus, those who are under guardianship are theoretically supposed to be under supervision of competent family courts.

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[48] Minbop [Adjudication on Commencement of Adult Guardianship], Art. 9 (R.O. Korea); Minbop [Adjudication on Commencement of Limited Guardianship], Art. 12 (R.O. Korea); Minbop [Adjudication of Specific Guardian], Art. 14-2 (R.O. Korea).

[49] A guardianship case shall be subject to the jurisdiction of a family court at the domicile of the person in the case. *See* Family Litigation Act, Art. 44 (Law No. 11949, 1990).

[50] *See* Minbop [Appointment of Adult Guardians], Art. 936(4) (R.O. Korea).

[51] *See* Minbop [Appointment of Supervisors of Adult Guardianship], Art. 940-4 (R.O. Korea).

[52] *See* Minbop [Dispositions Concerning Guardianship Affairs by Family Court], Art. 954 (R.O. Korea).

[53] *See* Minbop [Replacement of Guardians], Art. 940, (R.O. Korea).

B. Intervention of Local Authorities for the Protection of Adults with Impaired Decision Making Abilities

Another reform for the protection of adults with impaired decision making abilities is that local authorities are added to one of eligible applicants for guardianship-related court procedures. It is because one of the functions allocated to local authorities is protection of vulnerable adults through the social benefit delivery system[54] is closely related to the newly conceived role of guardians.

C. Respecting the Remaining Mental Capacity

The greater power of family courts in guardianship cases and intervention of local authorities to apply for guardianship, however, do not necessarily guarantee that adults with impaired decision making abilities can be appropriately protected in the communities. For this purpose, it is important to respect their remaining mental capacity; otherwise, they are excluded from any activities and transactions by substituted decision makings of guardians. In this regard, it cannot be denied that the new adult guardianship law still contravenes at least Article 12 (3) and (4) of UNCRPD because persons under full guardianship are regarded as legally incapacitated except in trivial transactions and because full and limited guardianship in most cases are likely to last until persons under full and limited guardianship die, just as under legal incapacity regime.[55] Thus, full and limited guardianship cannot be revoked unless causes for the appointment of full and limited guardianship disappear.[56]

That being said, the new law actually achieves some important reforms of the traditional legal incapacity regime. A

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[54] *E.g.*, The National Basic Living Security Act, Art. 21-27 (Act No. 11248, 2012); Act on Welfare of Persons with Disabilities, Art. 32-50 (Act No. 10426, 2011); Act on Long-term Insurance for the Aged, Art. 31-37 (Act. No. 12067, 2013); the Basic Pension Act, Art. 10-14 (Act No. 10854, 2011).

[55] *See* Minbop [Replacement of Guardians], Art. 940, (R.O. Korea).

[56] *See* Minbop [Adjudication on Termination of Adult Guardianship], Art. 11 (R.O. Korea); *see* Minbop [Adjudication on Termination of Limited Guardianship], Art. 14 (R.O. Korea).

person under full guardianship recovers legal capacity to the effect that he or she can do legal transactions of purchase of necessities to the extent of a small value amount.[57] Moreover, he or she can make decisions by him- or herself in relation to personal welfare matters, such as medical treatment, residence, personal contacts with others, and everyday life matters,[58] except marriage, divorce, adoption and other important family related decisions.[59] Any substituted decision making by a full guardian in relation to such matters can be allowed only if a guardian reasonably believes that the ward actually lacks the capacity to make relevant decisions.[60] Although it is limited to personal welfare matters, the recovery of the right to self-determination of the person under full guardianship is a breakthrough in Korean legal history.

D. Respecting Autonomy and Self-Determination

The two types of guardianship newly introduced, namely specific guardianship and contractual guardianship, are alternatives

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[57] *See* Minbop [Acts of Adult Wards and Cancellation thereof], Art. 10(3) (R.O. Korea).

[58] *See* Minbop [Decisions, etc. on Personal Matters of Adult Wards], Art. 947-2 (R.O. Korea).

[59] Just as a guardian for a person in full incapacity under the legal incapacity regime, a full guardian has power to consent to such personal decision makings by the person under full guardianship. *See* Minbop [Full Guardianship and Engagement], Art. 802 (R.O. Korea); Minbop [Consent-required Marriage] Art. 808 (R.O. Korea); Minbop [Full Guardianship and Divorce by Agreement] Art. 835 (R.O. Korea); Minbop [Full Guardianship and Lawsuit on Denial of Paternity], Art. 848 (R.O. Korea); Minbop [Affiliation by Persons under Full Guardianship] Art. 856 (R.O. Korea); Minbop [Adoption by, and of, Persons Under Full Guardianship] Art. 873 (R.O. Korea); Minbop [Persons Eligible for Revocation of Adoption] Art. 886 (R.O. Korea); Minbop [Agreement-Based Revocation by Persons Under Full Guardianship] Art. 902 (R. O. Korea); Minbop [Persons Eligible for Judicial Revocation of Adoption] Art. 906 (R.O. Korea).

[60] Minbop [Decisions, etc. on Personal Matters of Adult Wards] Art. 947-2 Section 1 (R.O. Korea), provides that persons under full guardianship alone make decision on personal matters as long as they have capacity to do so. It is a very important development in the new guardianship law.

to traditional guardianship with the autonomy and self-determination of adults under guardianship being respected.

Regarding specific guardianship, it can be opened only for a pre-determined short period, such as for one year to five years, to do pre-determined tasks.[61] The main function of a specific guardian is to support decisions made by the person under specific guardianship; in addition, the specific guardian can be granted by a family court with authority of representation for specific transactions, if it finds it necessary.[62] In this regard, the authority of representation by the specific guardian for important transactions can be granted on the condition that the person under specific guardianship should be represented only with consent of the competent family court.[63] For instance, a specific guardian can represent the ward in a reconciliation contract against a tortfeasor with court consent.

On the other hand, contractual guardianship is very similar to the lasting power of attorney in the United Kingdom in that a contractual guardian has power and authority to represent a principal in personal welfare matters as well as in financial and property matters. That being said, there is a significant difference between contractual guardianship and lasting power of attorney: a contractual guardian begins to serve only if a competent family court appoints a supervisory guardian, which is mandatory.[64] A supervisory guardian cannot be a family member of a contractual guardian.[65] It means that there should be at least two guardians in service and one of them should be a third party of the principal.

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[61] *See* Minbop [Rights to Representation of Specific Guardians], Art. 959-11(1) (R.O. Korea).
[62] *See* Minbop [Appointment, etc. of Specific Guardians], Art. 959-9(1) (R.O. Korea).
[63] *See* Minbop [Legal Authority of a Specific Guardian to Represent] Art. 959-11, Section 2 (R. O. Korea).
[64] *See* Minbop [Meaning, Method, etc. of Contracting Guardianship] Art. 959-14(4) (R.O. Korea).
[65] *See* Minbop [Appointment of Supervisors of Voluntary Guardianship] Art. 959-15(5) (R. O. Korea); *see* Minbop [Grounds for Disqualification as Supervisors of Guardianship] Art. 940-5 (R.O. Korea).

E. Current Situation After the Implementation of Adult Guardianship Act 2011

After the implementation of the new Adult Guardianship Act, the expectation that third parties will serve as guardians seems to be unsuccessful: most guardians appointed in the year following the implementation of the new adult guardianship law came from among family members, as shown in table 7: Relatives account for more than 90 percent of appointed guardians. It means that many Koreans might still be reluctant to allow any third parties to intervene in another person's personal and financial matters. Moreover, it does not seem easy for contractual guardianship to be rooted in Korean society.

Table 7
Composition of Guardians Appointed After the Implementation of the new Adult Guardianship Act[66]

2013.7.1~ 2014.6.30	Full Guardianship	Limited Guardianship	Specific Guardianship	Contractual Guardian	Total
Total number of appointments	618	104	61	2	785
Relatives	601 (97.2%)	97 (93.2%)	19 (31.1%)		717(91%)
Professionals	11 (1.7%)	4 (3.8%)	5 (8.1%)		20(2.5%)
Citizens	6 (0.9%)	3 (2.8%)	37 (60.6%)	2 (100%)	48(6.1%)

Moreover, two new types of guardianship such as specific guardianship and contractual guardianship are still strange to many Koreans. That being said, in comparison with Japanese

[66] Judicial Statistics on Adult Guardianship from 1 July 2013 to 30 June 2014.

guardianship practice, it is conspicuous that the number of applications for the specific guardianship is constantly increasing and preferred over limited guardianship, as shown in Table 8: in Japan, persons under guardianship, or full guardianship, account for more than 80%, persons under curatorship, or limited guardianship, more than 12%, whereas persons under advisorship, similar to specific guardianship in Korea, account for 4.5%.[67] The preference of specific guardianship to limited guardianship can be explained by the disability movement of parents of an adult child with intellectual disabilities or autism. In other words, they hope to use specific guardianship as a tool with which to integrate their adult child with intellectual disabilities or autism into the communities.

Table 8
The Number of Guardianship Application (Unit: Cases, %)[68]

2014.1.1~ 2014.12.31	Full Guardianship	Limited Guardianship	Specific Guardianship	Supervisory Guardian for Contractual Guardian
Application	1,994 (77.2%)	223 (8.6%)	355 (13.7%)	8 (0.3%)

IV. REMAINING TASKS FOR THE PROTECTION OF ADULTS WITH IMPAIRED DECISION MAKING ABILITIES

The new guardianship system, modified by the intervention of local authorities for guardianship application and ultimate supervision by family courts of guardians, falls short of realizing appropriate social responsibility for the protection of adults with impaired decision making abilities. On the contrary, the policy of putting more weight on the guardianship system easily tends to shift

[67] NATIONAL COURT ADMINISTRATION, *Judicial Statistics on Adult Guardianship from July 1, 2013 to June 30, 2014.*
[68] Judicial Statistics on Adult Guardianship from 1 January 2014 to 31 January 2014

responsibility from individual families to individuals other than family members. For social responsibility to be realized, it is indispensable to share the burden for their protection among neighbors, promoting their integrated living within the communities. In other words, other systems and schemes in addition to guardianship are required, such as a scheme for safeguarding vulnerable adults and other alternatives to guardianship so as to respect the self-determination of adults with impaired decision making abilities and guarantee integrated living in the communities. In this regard, Korea seems just to be standing at the starting line. There, however, continues much effort to provide appropriate protection, as introduced below.

A. Actions for Abolishment of Disqualification Provisions

Korea has still held on to reminiscence of the legal incapacity regime, in terms of a person under guardianship being disqualified in relation to voting rights, rights to be public officers, lawyers, and teachers, rights to running a business, and rights to acquire many kinds of licenses as soon as he or she was declared legally incapable. There are more than 300 relevant legal provisions disqualifying persons under guardianship, which will continue to apply until June 30, 2018, when the guardianship that was installed under the legal incapacity regime officially terminates. [69] Meanwhile, a person under full guardianship and a person under limited guardianship are deemed to be a person who is in full legal

[69] *See* Minbop [Transitional Provision on Persons in Full Incapacity etc.], Art. 2 Schedule of Law No. 10429, 2011 (R. Korea).

incapacity [70] and a person who is in limited incapacity, [71] respectively, in terms of disqualification provisions. It means that disqualification provisions apply to persons under full or limited guardianship as well. Such a disqualification provision presupposes that persons under guardianship are to be excluded from the social activities and transactions, rather than integrated. Under such a provision, the protection of adults with impaired decision making abilities may remain half way between individual family responsibility and social responsibility, not to mention that such disqualification provisions contravene Article 12 (2) of UNCRPD.[72]

Since the Adult Guardianship Act 2011 came into effect, constant movements for the abolition of such disqualification provisions have continued to petition the Parliament for legislation.

B. Actions for Prioritizing Alternatives to Guardianship

In order to guarantee integrated living of adults with impaired decision making abilities in the communities, it is recommended that the adults with impaired decision making abilities' own decisions be respected even at the time of incapacity. This can be realized by various alternatives to guardianship. One of alternatives to guardianship is an advanced directive to life sustaining treatment at the stage of terminal disease. The Korean Supreme Court recently dealt with a case related to the withdrawal of life sustaining treatments in the plenary session.[73] The majority of the Korean Supreme Court in that case ruled on three major principles regarding the withdrawal of life sustaining treatments: first, a patient has the right to refuse and withdraw life sustaining treatments insofar as the patient in the case has arrived at a terminal stage of disease where recovery after further medical treatments

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[70] *See* Minbop [Relation to Other Acts], Art. 3, Schedule of Law No. 10429, 2011 (R.O. Korea).
[71] *See id.*
[72] *See* Convention on Rights of Persons with Disabilities art. 12 (May 3, 2008), *available at* http://www.un.org/
disabilities/default.asp?id=272.
[73] Supreme Court, May 21, 2009, Life-Sustaining Treatment Withdrawal, 17417.

cannot be expected; second, an advance directive to withdraw life sustaining treatments at such a terminal stage of disease must be respected insofar as a written direction of withdrawal has been provided to the treating doctors, subsequent to the explanation by doctors of the progress of the disease; lastly, even without an advance directive, desires and wishes of the patient in the case to withdraw life sustaining treatments should be respected insofar as such desires and wishes can be indicated by religion, world view, and desires and wishes expressed to family members, relatives and friends. In that actual case, it was disputed whether desires and wishes of the patient in the case to withdraw life sustaining treatments can be indicated by family member witnesses. The majority in that case was in the affirmative to the question. Since then, it has been disputed whether decisions in relation to the withdrawal of life sustaining treatments at the terminal stage of a disease can be made on behalf of the patient in the case by a unanimous request of family members or by any other responsible persons even though there has been no decision made, an advanced directive or indicated desires and wishes by the patient in the case.[74]

In this regard, a movement to use advanced directives to medical treatment and care has just been started by the Korean Initiative for Advance Directive. Such a movement can facilitate governmental measures to be taken.

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[74] In July 2013, National Committee on Bioethics proposed for legislation to the effect that even substituted decision by family members in unanimity should be allowed when there is no relevant advanced directive and no indicated desire and wish of the patient in the case, which triggered controversy among the society once again. At the time of reviewing this paper, January 8, 2016, Korean National Assembly enacted the Terminal Patients' Decisions on Hospice, Mitigating Treatments, and Life Sustaining Treatments Act, which will come into force in 2018.

C. Actions for Safeguarding Vulnerable Adults

Adults with impaired decision making abilities are exposed to abuse and neglect, even where they are cared for by relatives. According to reports by Elderly Protection Agency in Korea, more than 75% of abusers against the elderly are family members, as shown in table 9.[75] Intellectually and mentally disabled adults are similarly exposed to abuse and neglect. Safeguarding systems for vulnerable adults should be set up to prevent such abuse and neglect. For persons with developmental disabilities, the Protection of Rights of Persons with Developmental Disabilities and their Assistance Act (PRPDDA),[76] which came into force in November 2015, introduces a safeguarding system specific to them. The central agency is supposed to have power to investigate abuses and neglects and to refer the cases to competent enforcement agencies.[77]

In addition, the Parliament enacted law on protection and advocacy system for disabled persons including persons with developmental disabilities by way of reformation of the Welfare of Disabled Persons Act (WDPA)[78] in June, 2015; furthermore, experts working for the human rights of the elderly have petitioned to the Parliament that the prevention of elderly abuse law should be enacted, whereby investigation into any kinds of abuse and neglect shall be made and appropriate measures shall be taken.[79]

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[75] The Ministry of Health and Welfare, *2013 Elder Abuse Report.*

[76] *See* Law No. 12618, 2014 (R.O. Korea).

[77] *See* PRPDDA [Role of Central Agency for Persons with Developmental Disabilities], Art. 34, the Law No. 12618, 2014 (R. O. Korea).

[78] *See* WDPA [Establishment etc. of the Protection and Advocacy Agency for Disabled Persons], Art. 59-9, Law No. 13367, 2015 (R.O. Korea). This law will come into effect on January 1, 2017.

[79] As a result, the draft bill of the Special Act on the Punishment etc. of Elderly Abuse Crimes was put forward, in 2015, and deliberated at Korean National Assembly. The draft bill is available at http://likms.assembly.go.kr/bill/jsp/BillDetail.jsp?bill_id=PRC_C1I5K0M4N2F0U1L9L1X0T2A8G8L7O3.

Table 9
Relation Between Victims and Abusers of Elderly (Unit: Cases, %)[80]

Victims: Self Neglects	Relatives	Others	Institution	Total
375	3,092	253	293	4,013
9.3 %	77.0 %	6.3 %	7.3 %	100 %

In order for a safeguarding system to efficiently work, either civil litigation or guardianship application must be brought in order for incapacitated adults to be protected, even where there is no guardian or close relative. The Ministry of Justice has drafted a bill for the reformation of the Civil Procedure Act,[81] which was enacted in January 2016, and the Korean Supreme Court has drafted a bill for the reformation of the Family Law Procedure Act. From those, a civil litigation or guardianship application can be brought for incapacitated adults either by a litigation guardian or on the motion of a family court. With these bills in place, the protection of incapacitated adults would be better organized so that the deficits, which immunity of relatives from criminal prosecution in the case of proprietary crimes has brought about, can be largely overcome.

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[80] The Ministry of Health and Welfare, 2013 Elderly Abuse Report.

[81] *See* the newly revised Civil Procedure Act, Law No. 13952, which will come into force as from January 1, 2017, *available at* http://www.law.go.kr/lsSc.do?menuId=0&p1=&subMenu=1&nwYn=&section=&tabNo=&query=#undefined.

V. CONCLUSION

Since the early twenty-first century, Korea has become conscious about sharing the burden for the protection of adults with impaired decision making abilities between family and society so that it leads to the reformation of the adult guardianship law. Social responsibility, however, can be realized only by adjusting the social environment to their integrated living in the communities, for which proper safeguarding systems and various alternatives to guardianship are required, rather than the engagement of local authorities for guardianship application and the supervision by family courts of guardians. In this regard, Korea stands at the threshold and has already moved from family responsibility to social responsibility for adult guardian protection.

ADULT GUARDIANSHIP IN TAIWAN: A FOCUS ON GUARDIAN FINANCIAL DECISION-MAKING AND THE FAMILY'S ROLE

Sieh-Chuen Huang*

I. INTRODUCTION: THE SOCIAL BACKGROUND OF THE 2009 LAW REFORM

In Taiwan, guardianship has been a family affair for a long time. Until the amendment of the Civil Code in 2008, enacted in November 23, 2009, the guardian of a vulnerable person was restricted to his or her family members or the person recommended by the family council.[1] In other words, guardianship was far from public organizations.[2]

The fundamental change in population and family structure makes this regime difficult to continue, however, this is not only happening in Taiwan, but also in other East Asian countries. The first important demographic trend is aging; with the improvement of medical treatment and standard of life, life expectancy in East Asia has been remarkably extended.[3]

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[1] The provisions of the Civil Code regarding adult guardianship were first promulgated in 1931 and were not revised until the 2009 law reform, except Paragraph 2 of Article 1113. Civil Code of the Republic of China, art. 1111 (1931), 1, 164–65; Civil Code of the Republic of China, art. 1111 (2014), http://law.moj.gov.tw/Eng/LawClass/LawAll.aspx?PCode=B0000001 [hereinafter the 2009 law reform].

[2] Civil Code of the Republic of China, art. 1111 (1931), 1, 164–65; Civil Code of the Republic of China, art. 1111 (2014), http://law.moj.gov.tw/Eng/LawClass/LawAll.aspx?PCode=B0000001.

[3] World Health Org., *World Health Statistics 2014*, at 60–67 (2014), *available at* http://apps.who.int/iris/bitstream/10665/112738/1/9789240692671_eng.pdf?ua=1; *see also* Dep't of Statistics, Ministry of the Interior, *Life Tables for the Republic of China*, MINISTRY OF THE INTERIOR,

Table 1: Life Expectancies at Birth in East Asia[4]

Year	Taiwan		China		Japan		Korea	
	Male	Female	Male	Female	Male	Female	Male	Female
1990	71	77	67	71	76	82	66	73
2012	76	83	74	77	80	87	78	85

In 1957, the life expectancy in Taiwan was 59.73 years for males and 63.25 years for females.[5] In 2015, it was 77.01 years and 83.62 years, respectively.[6] Seniors in Taiwan now have sixteen to nineteen more years compared to their counterparts fifty-eight years ago.[7]

The second population trend is the decrease in number of births.[8] Crude birth rate refers to the number of childbirths per 1,000 people per year.[9] Generally speaking, birth rates ranging from ten to twenty percent are considered low, while rates from forty to fifty percent are considered high. The crude birth rates in East Asian countries have dropped drastically over the last forty years compared to the stable situations in the United States and Germany.[10]

DEP'T OF STATISTICS, http://www.moi.gov.tw/stat/english/life.asp (last updated Sept. 29, 2016).

[4] World Health Org, *supra* note 3; Dep't of Statistics, *supra* note 3.

[5] Dep't of Statistics, Ministry of the Interior, *Life Expectancy Since 1957*, MINISTRY OF THE INTERIOR, DEP'T OF STATISTICS, http://www.moi.gov.tw/stat/english/year.asp (last visited Nov. 18, 2016) (scroll to heading "[2 Population]" and select "2.11 Life Expectancy since 1957's" in XLS format); Dep't of Statistics, *supra* note 3.

[6] Dep't of Statistics, Ministry of the Interior, *supra* note 5.

[7] *Id.*

[8] *See* United Nations, Dep't of Econ. & Soc. Aff., Population Div., Fertility & Family Planning Section, *Annual Number of Live Births and Crude Birth Rate*, UNITED NATIONS, http://www.un.org/esa/population/publications/WFD2012/MainFrame.html (click "Data: Annual number of births Crude birth rate" and then select "Table in EXCEL-Format") (last visited Nov. 18, 2016); Dep't of Statistics, Ministry of the Interior, *Interior National Indicators*, MINISTRY OF THE INTERIOR, DEP'T OF STATISTICS, tbl.10, http://www.moi.gov.tw/stat/english/interior.asp (last visited Nov. 18, 2016); Dep't of Household Registration, Ministry of the Interior, *Statistics: History (End of 2015)*, MINISTRY OF THE INTERIOR, DEP'T OF HOUSEHOLD REGISTRATION, tbl.1, http://www.ris.gov.tw/en/web/ris3-english/history (last visited Nov. 18, 2016).

[9] United Nations, *supra* note 8 (click "Metadata: Annual number of births Crude birth rate").

[10] *Id.*; Dep't of Household Registration, *supra* note 8; Dep't of Statistics, *supra* note 8.

Table 2: Crude Birth Rate (%)[11]

Year	Taiwan	China	Japan	Korea	U.S.	Germany
1970	27.2	33.0	19.0	30.7 (1972)	18.2	13.5
1985	18.0	20.8	11.9	16.1	15.8	10.5
1995	15.5	17.0	9.5	15.4 (1996)	14.6	9.4
2005	9.1	12.4	8.4	9.3	14.0	8.3
2010	7.2	11.9 (2011)	8.4	9.8	13.5 (2009)	8.3

Total fertility rate refers to the average number of children born to each woman over the course of her life and is a frequently used indicator of fertility. The data clearly shows the total fertility rate in this region is far fewer than 2.1 children per woman, the so called replacement rate. Compared to data from the United States, East Asian countries have achieved the lowest level in the world.[12]

Table 3: Total Fertility Rate[13]

Year	Taiwan	China	Japan	Korea	U.S.	Germany
1970	4.00	5.74	2.1	4.27	2.45	2.02
1985	1.88	2.36 (1986)	1.73	1.66	1.84	1.39
1995	1.78	1.86 (1994)	1.39	1.66 (1996)	2.01	1.25
2005	1.12	1.33	1.22	1.14	2.04	1.33
2010	0.90	1.47 (2008)	1.35	1.31	2.08 (2008)	1.37

The decreased birth rate and the longer life expectancy have contributed to the aging population. Japan outweighs all other

[11] United Nations, *supra* note 8; Dep't of Household Registration, *supra* note 8; Dep't of Statistics, *supra* note 8.
[12] United Nations, Dep't of Econ. & Soc. Aff., Population Div., Fertility & Family Planning Section, *Age-Specific Fertility Rates, Total Fertility and Mean Age at Childbearing*, UNITED NATIONS, http://www.un.org/esa/population/publications/WFD2012/MainFrame.html (select "Data: Age-specific fertility rates Total fertility Mean age at childbearing" and then select "Table in EXCEL-Format") (last visited Nov. 18, 2016); Dep't of Household Registration, Ministry of the Interior, *Statistics: History (End of 2015)*, MINISTRY OF THE INTERIOR, DEP'T OF HOUSEHOLD REGISTRATION, tbl.7, http://www.ris.gov.tw/en/web/ ris3-english/history (last visited Nov. 18, 2016).
[13] United Nations, *supra* note 12; Dep't of Household Registration, *supra* note 12.

nations with the highest proportion of elderly people (23% of the population is over the age of sixty-five) and Taiwan will soon be an aged society, as seniors accounted for 11.99% of the population in 2014 and is forecasted to reach 14.0% in 2018.[14]

Table 4: Population Distribution (%) by Three-Stage Age Groups in East Asia[15]

Year	Taiwan			China			Japan			Korea		
	0–14	15–64	65–	0–14	15–64	65–	0–14	15–64	65–	0–14	15–64	65–
1980	32.5	63.5	4.0	35.4	59.5	5.1	23.6	67.4	9.0	33.9	62.2	3.9
1990	27.2	66.7	6.1	29.3	64.9	5.8	18.3	69.7	11.9	25.6	69.4	5.0
2000	21.4	70.2	8.5	25.6	67.5	6.9	14.6	68.2	17.2	21.0	71.7	7.3
2010	16.0	73.3	10.7	18.1	73.5	8.4	13.3	63.8	23.0	16.2	72.7	11.1

Aging is usually accompanied with a decline in cognitive processes. In an aging society, the number of elderly individuals gradually losing capacity to deal with personal affairs will increase, and therefore, the demand for guardianship services will rise. However, support for the elderly is weakening and shrinking due to low birth rates. For instance, in Taiwan, the average number of household members in 1991 was 3.94 persons, and in 2014, the number decreased to 2.8 persons.[16]

To conclude, the reduced size of the household makes it more difficult for the family to support elders. Statistically, the population of elders in Taiwan is increasing. Similar situations have arisen in Japan and Korea, where the social environment and legal

[14] Dep't of Household Registration, *supra* note 12 at tbl.2; Health Promotion Admin., Ministry of Health & Welfare, *2014 Health Promotion Administration Annual Report*, 80 (2014), *available at* http://www.hpa.gov.tw/BHPNet/Portal/file/FormCenterFile/20141024094922044 4/online_english/index.html#80.

[15] United Nations, Dep't of Econ. & Soc. Aff., Population Div., *World Population Prospects: The 2015 Revision*, UNITED NATIONS, https://esa.un.org/unpd/wpp/ (select "Download Data Files" then select "Percentage by Broad Age Groups—Both Sexes (XLSX, 6.48 MB)") (last visited Nov. 18, 2016).

[16] Dep't of Statistics, Ministry of the Interior, *Number of Villages, Neighborhoods, Households and Resident Population*, MINISTRY OF THE INTERIOR, DEP'T OF STATISTICS, http://sowf.moi.gov.tw/stat/month/m1-01.xls (last visited Nov. 18, 2016).

systems are similar to those in Taiwan. This directs the government to reconsider and improve the adult guardianship system.

This Article aims to clarify the current state and the characteristics of adult guardianship in Taiwan. In order to provide an overview of Taiwan's adult guardianship, Part II will introduce the 2009 law reform of the Civil Code and the social response. Part III analyzes court cases regarding a guardian's disposition of a ward's real property to examine standards for guardian financial decision-making in practice. Part IV will discuss the changes necessary for adult guardianship in Taiwan

II. LEGISLATIVE REFORM OF ADULT GUARDIANSHIP

A. From Adjudication of Interdiction to Guardianship and Assistance

Prior to the 2009 law reform, adjudication of interdiction was the legal instrument used to protect a vulnerable person.[17] A person "declared an interdict" would become completely legally incompetent, meaning that the person was deprived of capacity in all areas of decision-making.[18] Thus, an interdict could not even make simple purchases.[19] On the other hand, there was no legal protection for persons with mild cognitive impairments, so they were at risk of being swindled. The "all-or-nothing" model of the 1931 Civil Code was criticized as being inflexible and unable to adapt to the gradual deterioration of dementia.[20] According to the 1931 Civil Code, the guardian was the surrogate of the ward to

[17] Civil Code of Republic of China, art. 14 (1931).
[18] *Id.* at art. 15; De-Kuan Liu, *Chengnian jianhufa zhi jiantao yu gaige [Reconsidering and Reform of Adult Guardianship]*, 62 NAT'L CHENGCHI L. REV. 229, 230 (1999).
[19] Chen-Erh Lin, *Minfa zongze jinzhichan xuangao xiuzheng caoan: chengnian jianhu zhidu zhi pingxi [The Draft of Revision on Adjudication of Interdiction on Civil Code General Principle: Focusing on Adult Guardianship]*, 58 L. MONTHLY, 2008, at 31, 32–33.
[20] XUN-XIN HONG, ZHONGGUO MINFA ZONGZE [GENERAL PRINCIPLES OF CHINESE CIVIL CODE] 91–92 (3d. ed. 1981); Shyue-Ren Teng, *Gaoling shehui zhi chengnian jianhu [Guardianship over Adults in the Aged Society]*, 3 CENT. POLICE U. L. REV. 335, 338 (1998); Liu, *supra* note 18, at 229–30; Shyue-Ren Teng, *Riben zhi xin chengnian jianhu zhidu [New Guardianship in Japan]*, 5 CENT. POLICE U. L. REV. 317, 339 (2000); Yu-Hui Wang, *Lun gaolingzhe caichan guanli fazhi [Property Management for Elders]*, 9 CENT. POLICE U. L. REV. 203, 206–7 (2004).

perform legal acts[21] and had the power to commit the ward to a mental healthcare institution or confine the ward at home, under the recognition of the family council.[22] This system was an obvious infringement of human rights.[23] Due to these drawbacks, people were reluctant to enter guardianship. Table 5 indicates that the number of guardianships (Adjudication of Interdiction) were around 3,000 per year in Taiwan before the 2009 law reform.[24]

[21] Civil Code of the Republic of China, art. 1098 (1931). This is the rule for guardianship over minors but it also applies to adults according to paragraph 1 of Article 1113, which states "unless otherwise provided by the provisions of this Section, the provisions concerning the guardianship over minors shall apply mutatis mutandis to the guardianship over interdicted persons." *Id.* at art. 1113.

[22] *Id.* at art. 1112 (When the guardian is the parent or grandparent of the ward, Paragraph 2 of Article 1112 even allows guardians to make the decision without the permission of the family council.); Yu-Zu Tai, *Chutan deguo chengnian fuzhufa [A Brief Introduction of Guardianship over Adults in German and Taiwanese Laws]*, 167 TAIWAN L. REV. 137, 137–38 (2009).

[23] CHI-YEN CHEN ET AL., MINFA QINSHU XINLUN [THE NEW COMMENTARY ON FAMILY LAW OF CIVIL CODE], 484 (11th ed. 2013); Tai, *supra* note 22.

[24] Japan's population is 12.6 million, which is 5.4 times that of Taiwan, and there were 24,190 persons starting guardianship in 2008. Courts in Japan, *Statistics of Adult Guardianship*, COURTS IN JAPAN, http://www.courts.go.jp/vcms_lf/20512009.pdf (last visited Nov. 18, 2016). Compared to the guardianship numbers in Japan, Taiwan's numbers pale in comparison. But turning to Korea, which has only 804 guardianship cases in 2008, and two times the population of Taiwan, the numbers in Taiwan did not seem so extremely low. Inhwan Park, Korea's New Adult Guardianship System: Implementation and Challenges, East Asian Adult Guardianship Law Panel (May 27, 2014), at the Japan Adult Guardianship Law Association.

Table 5: Number of Cases Regarding Guardianship in Taiwan[25]

Year	Cases regarding guardianship (or Interdiction) solved by the court*牙α狠	Among α, the number of cases on commencement of guardianship (or Interdiction) **牙β狠	Among β, the number of guardianship (or Interdiction) cases approved by the court **	Among β, the number of assistance cases approved by the court **	Percentage of approval
2008	3,862	3,102	2,062	N/A	66.47%
2009	3,992	3,696	2,430	3	65.83%
2010	4,530	4,163	2,477	481	71.05%
2011	4,485	4,443	2,724	524	73.10%
2012	5,952	4,666	2,806	537	71.65%
2013	7,573	5,031	3,048	577	72.05%
2014	7,911	5,214	3,169	668	73.59%
2015	8,208	5,428	3,385	653	74.39%

*Judicial Statistics Yearbook (2008-2013)
**Data obtained during confidential interview with Judicial Yuan official

The 2009 law reform repeals the old adjudication of interdiction and establishes two types of protection: guardianship and assistance. More specifically, paragraph 1 of the new Article 14 provides,

> with respect to any person who is not able to make declaration of intention . . . or who lacks the ability to discern the outcome of the declaration of intention due to mental disability, the court may order the commencement of guardianship at the request of the person in question, his/her spouse, any relative within the fourth degree of kinship, a prosecutor, a competent authority or an organization of social welfare.[26]

[25] Judicial Yuan, *Judicial Statistics Yearbook (2008–2013)*, JUDICIAL YUAN, http://www.judicial.gov.tw/juds/goa/yearly.htm (last visited Nov. 22, 2016); Email interview with Si-Fan Chen, Judicial Yuan Judge, Taipei, Taiwan (Nov. 7, 2013 & Mar. 14, 2014).
[26] Civil Code of the Republic of China, art. 14 (2014).

Similarly, paragraph 1 of Article 15-1 stipulates that a person having "insufficient capacity to make" decisions can be declared "under assistance."[27] At the same time, legislators decided to maintain Article 15 for guardianship because people were accustomed to the declaration of incapacitation.[28] On the other hand, Article 15-2 recognizes a person under assistance still has the legal capacity to perform juristic acts. The person under assistance must obtain the consent of the assistant only if the person intends to perform the significant deals.[29]

Regardless of the creation of assistance, the entire deprivation of legal capacity by Article 15 is criticized as paternalistic without consideration for the ward's self-determination or autonomy.[30] In addition, the 2006 United Nations Convention on the Rights of Persons with Disabilities ("CRPD") proposed a new

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[27] *Id.* at art. 15-1. Article 15-1 provides

> (1) With respect to any person who has insufficient capacity to make declaration of intention, receive declaration of intention, or who lacks the ability to discern the outcome of the declaration of intention due to mental disability, the court may order the commencement of assistance at the request of the person in question, his/her spouse, any relative within the fourth degree of kinship, a prosecutor, a public agency or an organization of social welfare.(2) When the cause of assistance ceases to exist, the court must revoke the order of the commencement of guardianship at the request of the applicant set forth in previous paragraph.(3) If a person who is the subject to the order of commencement of assistance is in need of guardianship, the court, under paragraph 1 of Article 14, may change the order to the commencement of guardianship. *Id.* at art. 15-1

[28] Hsiu-Hsiung Lin, *Lun woguo xin xiuzheng zhi chengnian jianhu zhidu (The Amended System of Guardianship over Adults in Taiwan)*, 164 TAIWAN L. REV. 139, 142 (2009).

[29] According to paragraph 1 of Article 15-2, the significant deals include the following:

> (1) being a responsible person of a sole proprietorship, of a partnership company, or of a juristic person;
>
> (2) making loans for consumption, consumption deposit, a guaranty, a gift, or a trust; (3) taking any procedural action; . . .
>
> (4) agreeing to compromise, conciliation, adjustment, or signing arbitration contract; (5) performing any act with the purpose of obtaining or relinquishing any right regarding real estate, vessels, aircrafts, vehicles, or other valuable property; . . .
>
> (6) performing partition of the inheritance, legacy, waiving the right to inheritance, or any other related right;
>
> (7) performing any other act, at the request of the person or his/her assistant, appointed by the court under previous provision.

Civil Code of the Republic of China, art. 15 (2014).

[30] Lin, *supra* note 28, at 155.

paradigm and urged many countries to reform their guardianship law.[31] Given that "Taiwan is not a qualified signatory of UN conventions," constitutional court and commentators pay attention to international human rights movements by reflecting on judicial reviews and their research.[32] When evaluating the adult guardianship in Taiwan from the viewpoint of the CRPD, it has been noted that the current "two-type system" is not tailored to enable the person to exercise their "remaining capacities for decision-making."[33]

B. Who Can Be a Guardian or an Assistant?

Under the 1931 Civil Code, the guardian was "determined in the following order: (1) Spouse; (2) Parents; (3) Grandparents living in the same household with the interdicted person; (4) Head of the house; (5) Person designated by the will of the more recently deceased parent."[34] However, if the ward was elderly, it was likely that the "spouse, parents and grandparents" were also "at an advanced age," and it was unwise to burden them with the role of guardian.[35]

The 2009 amendment revoked the order of priority in Article 1111 and authorized the court to select "one or more guardians [or assistants] among [the] spouse, any relative within the fourth degree of kinship, [relatives with whom the ward has lived recently, the public agency], [the] organization of social welfare or other proper person[s]. . . ."[36] Since the public agency and the organization of social welfare are qualified to be the guardian and assistant,

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[31] To understand CRPD and its impact on guardianship, see Volker Lipp & Julian O. Winn, *Guardianship and Autonomy: Foes or Friends?*, 5 J. INT'L AGING L. & POL'Y 41, 43–45 (2011).
[32] Fort Fu-Te Liao, *Cong "yiliao", "fuli" dao quanli": shenxin zhangaizhe quanli baozhang zhi xin fazhan [From "Medicare" and "Welfare" to "Rights": New Development of Rights Protection of Persons with Disabilities]*, 2 ACADEMIA SINICA L.J. 167, 199 (2008).
[33] Sieh-Chuen Huang, *Adult Guardianship and Care in Taiwan: An Analysis on Decisions Relating to Compensation for Guardian*, *in* DAGMAE COESTER-WALTJEN, VOLKER LIPP & DONOVAN W.M. WATERS, LIBER AMICORUM MAKOTO ARAI 379 (Nomos 2015).
[34] Civil Code of the Republic of China, art. 1111 (1931).
[35] For the reason behind the revision, see Legislative Yuan Gazette 23(97), 2009.
[36] Civil Code of the Republic of China, art. 1111 (2014).

Subsection 4 of Article 1111-1 directly confirms that a juridical person (such as a corporation) can become a guardian or an assistant.[37] Nevertheless, to avoid a conflict of interest, Article 1111-2 prohibits anyone affiliated with a long-term care institution, at which the ward is receiving care, from being appointed as guardian.[38]

The guardian's duty is sometimes complicated; for example, if the ward has many assets, the property management must be handled by financial professionals. Sometimes, it may be necessary to have multiple guardians or assistants.[39] Pursuant to Articles 1112-1 and 1113-1 of the 2009 Civil Code, when selecting several people as guardians or assistants, the court may designate the guardians or the assistants to perform their duties jointly or separately.[40]

There are minimum qualifications to be a guardian and certain individuals cannot be guardians, including minors, other wards, a bankrupt individual, or an absent individual.[41] Article 1111-1 is the statutory standard the court uses to designate guardians or assistants.[42] According to Article 1111-1, when the court chooses a guardian, the court must focus on the ward's best interest, and consider the ward's opinion.[43] The court should also consider the following:

> (1) the ward's physical and spiritual health, [and] his [or]her life and finance[s];
> (2) relations between the ward and his [or]her spouse, children, and others living in the same household;

[37] *Id.* at art. 1111-1.
[38] *Id.* at art. 1111-2.
[39] Legislative Yuan Gazette, *supra* note 35, at 97–98.
[40] Civil Code of the Republic of China, art. 1112-1, art. 1113-1 (2014).
[41] *Id.* at art. 1096.
[42] *Id.* at art. 1111-1.
[43] *Id.*

> (3) [the ward's] occupation, experience, opinion of the guardian and relations between the guardian and the ward; and
> (4) when a juristic person is the guardian, the category and content of its business; and relations between the juristic person and its representative and the ward.[44]

Notwithstanding the fact that the guardian does not need to be a relative of the ward and could be a juridical person subject to the 2009 law reform, it is estimated that more than ninety percent of guardians in Taiwan are still family members of the ward.[45] A judge of Shilin District Court, one of the courts in Taipei City, stated in an interview held by the author that there were 180 cases on commencement of guardianship approved by the Shilin District Court in 2011. Among these, only twelve cases had non-family guardians selected.[46] Since all of the wards in those twelve cases resided in Yangming Home, a public institution that offers care and occupational training for those with intellectual disabilities, and lacking family networks, the court designated the Department of Social Welfare of Taipei City as the guardian.[47] In other words, the court gives priority to the family members if the person is not obviously inappropriate, which is not provided by the statutes.

The first reason for this family-inclined practice is that there are no trained legal professionals, such as lawyers and social workers, that the court can rely on to be guardians, due to the professional association's indifference to guardianship.[48] Secondly,

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[44] *Id.*
[45] Sieh-Chuen Huang & Ying Chieh Wu, *The Collaboration of Guardianship and Trusts*, NAT'L TAIWAN UNIV. CTR. FOR PUB. POL'Y & LAW, http://www.cppl.ntu.edu.tw/research/enresearch/summary/CPPL10306ensummary.pdf (last visited Nov.18, 2016).
[46] Chen Ziqiang (moderator), *Jianhu xuangao zhi shiwu u keti zuotanhui jilu [The Record of Forum on the Practice and Issues of Adult Guardianship] in* GAOLINGHUA SHEHUI FALU ZHI XIN TIAOZHAN: YI CAICAN GUANLI WEI ZHONGXIN [NEW LEGAL ISSUES IN AGING SOCIETY: FOCUSED ON FINANCIAL DECISION-MAKING] 392–93 (Sieh-Chuen Huang & Tzu-Chiang Chen eds. 2014).
[47] Ziqiang, *supra* note 46.
[48] Ziqiang, *supra* note 46, at 372. On the contrary, in Japan, among newly selected guardians in 2013, 42.2% are family guardians and 57.8% are third-party guardians. Meanwhile, among the third-

the only example of an organization of social welfare being designated as a guardian is the Hondao Senior Citizens Welfare Foundation.[49] Since there are few qualified individual professionals and juridical persons who are eligible and available to be the guardian, the remaining choice is "public agency."[50] Since the budget of public agencies comes from tax revenue, that is, the public, and guardianship is in some respects considered a private matter, public agencies and the court will not voluntarily appoint a public agency to be the guardian unless there is no other alternative.[51] As a result, although the 2009 law reform aims to release the burden of guardianship from the family to the social network by enhancing the qualification of the guardian, this has not followed through and the "socialization of guardianship"[52] is still insufficient.

C. Duty and Powers of Guardians and Assistants

Subject to Article 1098, a guardian of a minor is the statutory agent of the minor,[53] and this rule has been applied to adult guardianship.[54] Thus, the adult's guardian is plenary and has comprehensive power including decision-making matters related to property management and personal affairs for the ward.

As for the guardian's reasonable standard of care, Article 1112 provides that when making decisions regarding "the ward's life, treatment and financial management, the guardian shall respect the ward's intent."[55]

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party guardians, solicitors (shiho shoshi), lawyers, and social workers are at most in number. *See* Court in Japan, *Statistics of Adult Guardianship*, http://www.courts.go.jp/vcms_lf/20140526koukengaikyou_h25.pdf (last visited Nov. 18, 2016).

[49] Hondao Senior Welfare Foundation has provided guardians and assistants in twenty-four cases since 2002. Hondao Foundation, *Current Services*, http://www.hondao.org.tw/en/index.html (last visited Nov 18, 2014).

[50] Ziqiang, *supra* note 46, at 372.

[51] Ziqiang, *supra* note 46, at 387.

[52] Sieh-Chuen Huang, *supra* note 33, at 383.

[53] Civil Code of the Republic of China, art. 1098 (2014).

[54] *Id.* at art. 1113.

[55] *Id.* at art. 1112.

There are some detailed provisions regarding the duty of minors' guardians that are also applied *mutatis mutandis* to adult guardianship.[56] First, paragraph 1 of Article 1097 provides that except as otherwise stated, a guardian of a minor "shall, within the limits required for the protection and advancement of the ward's interests, exercise the rights and assume the duties of the parents in regard to a minor child."[57] This is similar to section 2-209 of the Uniform Guardianship and Protective Proceedings Act ("UGPPA") and section 5-309 of the Uniform Probate Code, under which the guardian of an incapacitated person was simply granted the powers of the guardian of a minor.[58] Based on Article 1097, it is widely admitted that the adult guardian is entitled to the power to consent to medical treatment and arrange a dwelling for the ward.[59] However, because some personal affairs implicate the incapacitated person's constitutional rights, the statutes granting such broad powers to the guardian without any safeguards, such as prior court order, is not encouraging.[60]

Secondly, Article 1103 allows the guardian to manage the ward's property.[61] As for the standard of property management, Article 1101 requires the guardian to act in the ward's best interest and "acquire permission from the court" when "purchasing or disposing [of] real property for the ward . . . renting out or providing others" use of the ward's residence, or "terminating [the] lease of the ward's [residence]."[62] The court's double-check on the disposition of real property is in light of the significant value of real property and its possible influence on the ward's assets, which will be further discussed in part III. And in the case of contract regarding

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[56] *Id.* at art. 1113.
[57] *Id.* at art. 1097.
[58] Also referred to as the "Parent-Child Model." *See* Lawrence A. Frolik, *Plenary Guardianship: An Analysis, a Critique and a Proposal for Reform*, 23 ARIZ. L. REV. 599, 606–11 (1981).
[59] Civil Code of the Republic of China, art. 1097; SHANG-KUAN SHIH, QINSHUFA LUN [FAMILY LAW] 596–600 (3d ed. 1974); YEN-HUI TAI, ZHONGGUO QINSHUFA LUN [FAMILY LAW)] 320 (rev. ed. 1959); Lin, *supra* note 28, at 145.
[60] *See generally* Sieh-Chuen Huang, *An Introduction to Taiwan's Adult Guardianship and Recent Development*, SEINEN KOKEN SEIDO [ADULT GUARDIANSHIP] 166 (2014).
[61] Civil Code of the Republic of China, art. 1103 (2014).
[62] *Id.* at art. 1101.

the ward's residence, it is because changing the ward's dwelling may have significant implications on the ward's mental condition.[63]

Finally, with regard to the duty and powers of the assistant, the "person under assistance" can make decisions by himself or herself except for important matters stipulated in Article 15-2.[64] The problem is that the provision is fixed and cannot be adjusted by the court's discretion.[65]

D. Monitoring of Guardianship

Under the 1931 Civil Code, it was the family council's duty to supervise guardianship.[66] However, the family council gradually lost its function in modern society and could no longer perform the duty, and so the law was amended to impose the duty upon the court. The court may, at any time, demand that a guardian submit a report on the affairs of guardianship or an inventory of the estate, and may investigate the affairs of guardianship or the situation of the property of the ward.[67]

Through the brief overview of Taiwan's statutes above, we can say that the old guardianship system placed guardianship inside the private family world, far from any public organizations. On the contrary, after 2009, any qualified person could be the guardian, and instead of the family council, the court became the only authority to oversee the guardian.[68] Despite the technical changes in the law, the law in practice is sometimes affected by other factors that will be discussed in part III.

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[63] It is a newly introduced rule referring to Article 859-3 of the Japan Civil Code. *See* CHEN ET AL., *supra* note 23, at 466.
[64] Civil Code of the Republic of China, art. 15-2 (2014).
[65] *Id.*
[66] *Id.* at art. 1099, 1101, 1103, 1106.
[67] *Id.* at art. 1103.
[68] *Id.* at art. 14, 15-1, 15-2, 1099, 1101, 1103, 1111.

III. STANDARDS FOR DISPOSITION OF REAL PROPERTY

A. Standard Created by Statutes

Unlike section 418(a) of the UGPPA, which clearly stipulates that a conservator is a fiduciary,[69] standards for guardian's financial decision making in Taiwan's Civil Code are obscure. According to paragraph 1 of Article 1101, the standard applied to a guardian's financial decision-making is the "best interest" rule.[70] On the other hand, Article 1112 provides that when undertaking affairs "relating to the ward's life, treatment, and financial management, the guardian shall respect the ward's intent."[71] This is similar to the "substituted judgment rule."[72] The situation is also similar to section 314(a) of the UGPPA, giving no preference for "best interest" or "substituted judgment" in its language.[73]

In order to determine the standards on guardian financial decision-making adopted by the guardian and the court, studying cases is a convenient and realistic approach. Nevertheless, since the powers of the guardian are plenary and the guardian does not go to the court for approval of decision-making, except those regarding real property, the following section will explore and analyze cases regarding disposition of real property.[74]

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[69] Robert B. Fleming & Rebecca C. Morgan, *Standards for Financial Decision-Making: Legal, Ethical, and Practical Issues*, 2012 UTAH L. REV. 1275, 1277 (2012) (arguing that acknowledging "the guardian as a fiduciary . . . sets a standard for appointment . . . as well as a standard for decision-making by the guardian").

[70] Civil Code of the Republic of China, art. 1101 (2014); Linda S. Whitton & Lawrence A. Frolik, *Surrogate Decision-Making Standards for Guardians*, 2012 UTAH L. REV. 1491, 1499–1500 (2012) (finding eighteen jurisdictions adopting this model and arguing that UGPPA Section 314 (a) has not dealt with the tension between "best interest" and "substituted judgment" yet).

[71] Civil Code of the Republic of China, art. 1112 (2014).

[72] Whitton & Frolik, *supra* note 70, at 1499–500.

[73] *Id.*

[74] In Taiwan, in 2000 all judicial cases were open and free to be searched except for cases regarding juvenile delinquency and sexual assault. *See* The Judicial Yuan of the Republic of China, *Latest Updates*, JUDICIAL YUAN OF THE REPUBLIC OF CHINA, http://jirs.judicial.gov.tw/eng/ (last visited Nov. 18, 2016).

B. The Significance of Disposition of Real Property in Practice

The number of dispositions of a ward's real property has gradually increased every year (see Table 6).[75] Among all petitions regarding adult guardianship, disposition of a ward's real property is the second largest matter to the commencement of guardianship and assistance dealt by the court. This is because the land office will refuse the applications for property registration if the guardian does not make a submission for court authorization pursuant to the Civil Code at subsection 1 of paragraph 2 of Article 1101,[76] and regulations of the Land Registration at paragraph 2 of Article 39.[77] The administrative process of land registration ensures the guardian's consultation with the court.[78]

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[75] *Id.*

[76] Civil Code of the Republic of China, art. 1101 (2014).

[77] Regulations of The Land Registration of the Republic of China, art. 39 (2014), provides as follows:

(1) parent's disposition of the land right on behalf of his/her minor child, requires said parent to sign and explicitly remark in the appropriate column of the application form, stating that such disposition is in the interest of such minor child when applying for land registration.

(2) A legal guardian of the minor under his/her guardianship, or a custodian of the person under his/her custody, shall be required to present proof of court approval in order to purchase or dispose of land on behalf of the said minor or person in custody.

(3) The registration of waiver of the right of inheritance requires no observance of the two conditions above if evidence of court approval for such waiver is presented with the application for the registration.

[78] Sieh-Chuen Huang, *Con xuke jianhuren daiwei budongchan chufen pingxi woguo chengnian jianhu zhidu zhi shiwu [Guardianship for Adults in Taiwan: from the Cases on Disposition of Ward's Real Property in Practice]*, 25 SOOCHOW L. REV. 75, 90 (2013).

Table 6: Number of Cases Regarding Disposition of Real Property[79]

Year	The Number of Cases of the Court's Authorization of Disposition of Ward's Real Property
2008	1
2009	39
2010	380
2011	435
2012	555

C. Four Types of Dispositions

Through observing and analyzing hundreds of Taiwan's court cases, one can conclude that dispositions can be categorized into four types: sale, participation in an urban renewal plan, division of estates, and gift.

1. Sale

Whether the court permits the sale of the real property depends on if it is necessary to obtain cash to care for the ward. For example, a guardian asserted that the ward could not afford to pay 40,000 New Taiwan Dollars ("NTD") (approximately $1,333 USD) every month for medical care and required the sale of four real estates.[80] The court only authorized the sale of two real estates since the expected receipts of 1.5 million NTD were sufficient to pay expenses for the next four years.[81] Generally speaking, if the ward's savings are enough to pay for his or her living expenses, even if the sale is profitable, most judges tend to refuse the request for selling real property.[82] The point is that the cash and bank savings are fluid

[79] The Judicial Yuan of the Republic of China, *supra* note 74.
[80] Shilin District Court 99 Jian No. 29 (2010).
[81] *Id.*
[82] For similar decisions, see cases such as Taipei District Court 98 Jia-Sheng No. 932 (2009); Shilin District Court 99 Jian No. 242 (2010); 100 Jian No. 186 (2011); 100 Jian No. 192 (2011); 100 Jian No. 206 (2011); Shinbei District Court 100 Jian No. 71 (2011); 100 Jian No. 559 (2011); 100 Jian No. 601 (2011).

and are more at risk of being misused by the guardian. However, there are different opinions in respects to this issue. In the case in which a ward was a tenant in common of land, in spite of sufficient bank savings, the court recognized the sale because it was difficult for the ward to use the land and obtaining money was advantageous.[83]

2. Participation in an Urban Renewal Plan

Sometimes, the ward's real property may be located in an urban renewal area. Entering into a renewal contract with the developer is considered as taking the old house for exchange of a new house; this is a type of disposition so court approval is necessary. In a case in which the ward's real estate was built more than thirty years prior, the court authorized the participation of renewal because the real estate had been too old to find a tenant without mentioning the financial needs of the ward.[84] Compared to the sale of real property, the court is relatively tolerant of petitions for renewal because of the external benefits to the society. In conclusion, the court is inclined to authorize petitions for renewal if participation has a profitable outcome.

3. Division of Estates

Generally, few people draft wills in Taiwan, meaning most decedents died intestate. In this case, an heir inherits based on statutory (intestate) share, with equal proportions to heirs when the decedent's children come to succeed the estates. If the estates of the decedent contain real property and the ward is one of the heirs, the division of the estates is considered a disposition of real property.

The majority of courts agree that the ward's acquisition from the distribution should not be less than his or her intestate share,

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[83] Kaohsiung District Court 100 Jian No. 381 (2011); Miaoli District Court 100 Jia-Sheng No. 43 (2011); Changhua District Court 100 Jian No. 203 (2011).
[84] Taipei District Court 99 Jia-Sheng No. 206 (2010); Miaoli District Court 100 Jia-Sheng No. 192 (2011).

because otherwise, the division would not be in the ward's best interests.[85] Meanwhile, even if the ward's acquisition does not achieve the amount of statutory share but only by a slight difference, the court might approve. For instance, in a division plan the ward received 4.91 million NTD (approximately $164,000 USD) from the estate, in which the value of intestate share was 4.93 million, the comparatively small 5% shortage was ignored and the distribution was authorized.[86]

While most decisions adopt the standard of statutory share as above, there are some exceptional cases that allow obviously "unfair" divisions, which can be divided into two types, as discussed below.

a. Providing the Ward with Maintenance

In Taipei District Court 100 Jian No. 252 (2011), the court approved the division plan in which the ward acquired nothing from the estate provided that all heirs promised to pay for the ward's medical expenses for life.[87] In other cases, the court will conclude that it is in the best interest of the ward to receive nothing from the estate; for example, when all heirs have decided that one of them will receive the entirety of the estate in exchange for taking care of the ward.[88] Nevertheless, if the division plan allowed one of the heirs to obtain all estates with an ambiguous duty such as "raising money for the ward's living and care" or "visiting the ward as usual and taking the responsibility," the division could not be authorized by the court.[89]

[85] Shilin District Court 100 Jian No. 209 (2011); Tainan District Court 99 Jian No. 221 (2010), 101 Jian No. 3 (2012); Changhua District Court 100 Jian No. 155 (2011); Taitung District Court 100 Jia-Kang No. 4 (2011); Pingtung District Court 99 Jia-Sheng No. 247 (2010).
[86] Changhua District Court 100 Jian No. 117 (2011).
[87] Taipei District Court 100 Jian No. 252 (2011).
[88] Yilan District Court 100 Jian No. 34 (2011), 100 Jian No. 92 (2011); Shinbei District Court 100 Jian No. 743 (2011).
[89] Taipei District Court 100 Jian No. 401 (2011); Hualien District Court 99 Jia-Sheng No. 46 (2010).

There is an interesting case, Taichung District Court 100 Jian No. 204 (2011), in which the guardian argued that the ward acquired nothing from the estates in exchange for immunity from supporting his elderly mother and sister with mental disability.[90] In this case, the value of the estates was three million NTD (approximately $100,000 USD).[91] There were five heirs, A, B, C, D, and E, each of whom had one-fifth statutory share.[92] C was the ward.[93] All heirs and C's guardian (C's wife) agreed that A and B would receive half of the estate individually. D (the sister of C) and E (the mother of C) would receive nothing but were to be supported by A and B. C, also obtaining nothing, was to be exempted from supporting C and D.[94] The court recognized the agreement of the division.[95]

b. Respecting the Decedent's Wishes

Another reason to justify a ward receiving little inheritance is the wishes of the decedent. For instance, in Tainan District Court 100 Jian No. 74, C was the ward and inherited estates with her siblings A, B, and D.[96] There were five pieces of real property, Z1, Z2, Z3, Z4, and Z5, contained in the estates.[97] C's guardian asserted that Z4 and Z5 were "family properties" that the decedent wished to be acquired by the sons, A and B.[98] Thus, in the division agreement, Z4 and Z5 belonged to A and B. Next, A, B, and C individually received one-sixth ownership of Z1, Z2, and Z3, and D received one-half ownership of Z1, Z2, and Z3.[99] In short, what the ward C obtained in the agreement was clearly less than her statutory share, which was one-fourth of the estates.[100] The court authorized the

[90] Taichung District Court 100 Jian No. 204 (2011).
[91] *Id.*
[92] *Id.*
[93] *Id.*
[94] *Id.*
[95] *Id.*
[96] Tainan District Court 100 Jian No. 74 (2011).
[97] *Id.*
[98] *Id.*
[99] *Id.*
[100] *Id.*

apparently "unfair" division because it was based on the desires of the decedent and all heirs were willing to comply.[101]

Provided that it is written in a will, the decedent's wish is legally meaningful and must be obeyed unless against legally reserved portions.[102] However, in the author's opinion, when there is no will to prove the decedent's intentions and the so-called "decedent's wish" is merely a statement made by the heirs and the guardian, the court should be more cautious about adopting this as the reason to reduce the ward's acquisition.

4. Gifts

Whether the gift of real property is to obtain support from the donee in return,[103] to allow the donee to raise funds for supporting the ward by mortgage loan,[104] to reduce the ward's assets in order to apply for Supplemental Security Income benefits,[105] or to accomplish the ward's wishes,[106] most courts refuse to authorize these dispositions.

It is difficult to say that a gift conforms with the interest of the ward since a gift is a voluntary transfer without full valuable consideration. However, in Shilin District Court 99 Jian No. 290 (2010), although the ward's estate was ample, including forty-seven real properties, and the ward had signed a contract to give one piece of land to the temple before the commencement of guardianship, the court refused the petition for gift.[107] If the wish or preference of the ward is clear, should it be more respected in decision-making?

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[101] *Id.*

[102] Legally reserved portion, also known as "legitime" (legitima portio), a forced share or legal right share, is the portion of the decedent's estate from which the decedent cannot disinherit his or her heirs. Hence it is considered a restriction on testamentary freedom. It is stipulated in Article 1223 of Taiwan's Civil Code. Civil Code of the Republic of China, art. 1223 (2014).

[103] Shinbei District Court 99 Jian No. 394 (2010); Keelung District Court 100 Jia-Sheng No. 194 (2011); Taichung District Court 101 Jian No. 105 (2012); 101 Jian No. 86 (2012); Changhua District Court 100 Jia-Kang No. 20 (2011).

[104] Taipei District Court 99 Jia-Kang No. 82 (2010); 99 Jian No. 193 (2010).

[105] Shilin District Court 99 Jian No. 64 (2010).

[106] Shilin District Court 99 Jian No. 290 (2010); Hualien District Court 101 Jia-Sheng No. 17 (2012).

[107] Shilin District Court 99 Jian No. 290.

IV. CONCLUSION

The court adopts different standards for dispositions of real property. In the sale of real property, the necessity of obtaining cash flow for living expenses is the key factor. Secondly, in participation in an urban renewal plan, the court tends to authorize if it is profitable to both the ward and the public. In the division of estates, whether the ward acquires the amount of intestate share is important in general, but sometimes the court compromises to the family's argument of maintenance for the ward or the decedent's wishes. Finally, making a gift of a ward's real property seems to face challenges in the petition for authorization even if it is what the ward desires.

As mentioned above, the 2009 law reform establishes two standards for financial decision-making: best interest (Article 1101) and substituted judgment (Article 1112).[108] Review of judicial cases demonstrates that the standards adopted by Taiwan's courts are relatively conservative, shifting towards the objective best interest rather than substituted judgment. Moreover, the best interest rule sometimes concedes to the family's intent especially in succession cases in which family members are substantially involved; a situation very different in the United States. Although UGPPA also sets forth two standards for the guardian, Section 411(c) requires that the court approve a conservator's exercise, considering if it is a decision that the protected person would have made.[109]

If looking at the powers of the guardian in financial decision-making, UGPPA section 411(a) lists actions for which a conservator needs to obtain prior court approval including making gifts and conveying interests in property, which is similar to the Taiwan Civil

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[108] Civil Code of the Republic of China, art. 1101, 1112.

[109] This is not only a standard for the court but also for the conservator. See comment of Section 411 (stating that "pursuant to subsection (c), decisions by the conservator under this section must be based primarily on the decision that the protected person would have made, if of full capacity"). *See generally* Unif. Guardianship & Protec. Proc. Act (1982).

Code Article 1101.[110] Nevertheless, in Taiwan's Code there is no exceptional rule such as Section 427(b) of the UGPPA that allows a conservator to make a gift without court order.[111] In addition, Taiwan's Civil Code Article 1101, paragraph 3 places restriction on the guardian's investment to extremely low-risk financial products.[112]

Compared to UGPPA, Taiwan's statutes (Article 1101) regarding guardian financial decision-making exercises strict control over the guardian and the standard adopted by the court to supervise the decision is the objective best interest.[113] In conclusion, this financial decision-making mechanism leaves the guardian with little discretion and the court with much dominance.

The strict practice of financial decision-making in Taiwan may be attributed to different factors. First, more than 90% of guardians in Taiwan are family members, who are not necessarily skilled at property management and familiar with professional ethics.[114] Second, in Taiwan, there is no system such as the supervisor of the guardian in Japan and Korea, to oversee or provide the guardian with suggestions on financial decision-making.[115] Therefore, the court has to take on the job of watching over every conveyance of the ward's real property.

Family members' participation in guardianship is not only limited to designation as a guardian, but also arises in cases such as

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[110] Unif. Guardianship & Protec. Proc. Act (1982); Civil Code of the Republic of China, art. 1101.
[111] Section 427(b) of the UGPPA provides "If an estate is ample to provide for the distributions authorized by subsection (a), a conservator for a protected person other than a minor may make gifts that the protected person might have been expected to make, in amounts that do not exceed in the aggregate for any calendar year 20 percent of the income of the estate in that year." Unif. Guardianship & Protec. Proc. Act (1982).
[112] Civil Code of the Republic of China, art. 1101.
[113] Unif. Guardianship & Protec. Proc. Act; Civil Code of the Republic of China, art. 1101.
[114] Sieh-Chuen Huang & Ying-Chieh Wu, *Guardianship and Trusts: The Duties and Supervision of Trustee*, CTR. PUB. POL'Y & THE LAW, NAT'L TAIWAN U., http://www.cppl.ntu.edu.tw/research/enresearch/2015summary/10404ensummary.pdf (last visited Nov. 18, 2016).
[115] *Id.*

estates succession to argue for a certain distribution plan. Advantages include that they can supervise the guardian's decision-making and offer information about the preferences or intentions of the ward. The risks are that they may conspire with the guardian to consume the ward's assets, or on the contrary, in order to inherit more on the ward's death, they may prevent the guardian from using the ward's assets even when the purpose is for receiving better medical treatment or care.

In conclusion, although the rationale behind the 2009 law reform is weakened family solidarity, the family's role in adult guardianship is indeed diminishing, but not vanishing. To make up for the deficit, the legislators involved the court and the court seeks to shoulder this responsibility. However, besides the court and the family, other parties such as legal professionals, public agencies, and social welfare organizations have limited participation in adult guardianship. It is easy to perceive the contrast between the active exercises undertaken by public agencies and organizations of social welfare in minor's guardianship and the indifference towards adult guardianship.[116] Because family still plays an important role in adult guardianship, the court needs to be careful about the distinction between family's arbitrariness and the ward's real wishes or interest. It is indeed a dilemma in a society where individual subjectivity and personal interest are not completely separate from his or her family such as in Taiwan and other areas influenced by Confucianism.

[116] Sieh-Chuen Huang, *Chutan wuoguo chengnian jianhu yu xintuo zhi bingyong* [*The Collaboration of Adult Guardianship and Trusts*], 153 FT. L. REV. 23, 25 (2014) (arguing that the Protection of Children and Youths Welfare and Rights Act allows the administration department to file a petition to the court for choosing a trustee for the minor. On the contrary, regarding adult guardianship, Senior Citizens Welfare Act provides unclear language on trusts and guardianship, and in practice the administration department does not offer any help with trusts).

TO BE, OR NOT TO BE: A GLOBAL PERSPECTIVE ON PHYSICIAN-ASSISTED SUICIDE

Jennifer Tindell*

> What I fear is a death that negates, as opposed to concludes, my life. I do not want to die slowly, piece by piece. I do not want to waste away unconscious in a hospital bed. I do not want to die wracked with pain.[1]

I. INTRODUCTION

The surging interest in physician-assisted suicide stems from society's movement from denying the inevitability of death to seeing death as an option.[2] Before modern medicine, death from a common cold was a far more certain outcome than it is presently.[3] Today people are able to forestall death and treat once fatal diseases.[4] This ability creates the notion that if someone can choose to prolong death, then they should have the right to choose the time and method of death when this treatment is no longer easing their pain and suffering.[5] As best summarized by U.S. Supreme Court

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[1] Carter v. Canada, 2015 SCC 5, [2015] 1 S.C.R. 331, para. 12 (S.C.C.) (quoting Gloria Taylor about the desire to obtain physician assisted suicide), *available at* https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/ index.do#_Toc410917608.

[2] Peter M. McGough, *Medical Concerns About Physician-Assisted Suicide*, 18 SEATTLE U. L. REV. 521, 522 (1994–1995) (discussing Daniel Callahan, THE TROUBLED DREAM OF LIFE: LIVING WITH MORTALITY 51 (1993)).

[3] *Id.*

[4] *Id.* (discussing CALLAHAN, *supra* note 2, at 92).

[5] *Id.*

Justice Antonin Scalia: "It would not make much sense to say that one may not kill oneself by walking into the sea, but may sit on the beach until submerged by the incoming tide . . . ."[6]

Physician-assisted suicide is a controversial topic across the globe. As of 2015, Montana,[7] Vermont,[8] Washington,[9] Oregon,[10] and California[11] are the only states in the United States that permit physician-assisted suicide, along with several countries, such as Canada, Switzerland, Belgium, and the Netherlands.[12] Many more countries will likely allow physician-assisted suicide in the coming years due to the increasing media presence of the topic[13] and the increase in data gathered from research on physician-assisted suicide participants in countries that allow this form of medicine.[14] Numerous worries originally expressed about physician-assisted suicide, including concerns that vulnerable populations of people would be more likely to be pressured to employ this method, have not developed in countries that permit physician-assisted suicide,

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[6] Cruzan by Cruzan v. Dir., Mo. Dept. of Health, 497 U.S. 261, 296 (1990) (involving the withdrawal of life support from a patient in a persistent vegetative state focusing on an argument founded in the Due Process Clause of the U.S. Constitution); Simon M. Canick, *Constitutional Aspects of Physician Assisted Suicide After* Lee v. Oregon, 23 AM. J.L. & MED. 69, 78 (1997).

[7] Baxter v. State, 224 P.3d 1211 (Mont. 2009) (ruling that physician-assisted suicide was not against public policy).

[8] Patient Choice and Control at End of Life Act, VT. STAT. TIT. 18, §§ 5281–5293 (2016).

[9] Death with Dignity Act, WASH. REV. CODE §§ 70.245.010–70.245.904 (2016).

[10] Death with Dignity Act, OR. REV. STAT. §§ 127.800–127.897 (2016).

[11] End of Life Option Act, CAL. HEALTH & SAFETY CODE §§ 443-444.12 (2015); Brakkton Booker, *California Governor Signs Physician-Assisted-Suicide Bill into Law*, NPR (Oct. 5, 2015), http://www.npr.org/sections/thetwo-way/2015/10/05/446115171/california-governor-signs-physician-assisted-suicide-bill-into-law.

[12] Dignitas, *Countries with End-of-life Help Laws and/or Regulations*, DIGNITAS, http://www.dignitas.ch/index.php?option=com_content&view=article&id=54&lang=en (last updated July 16, 2016).

[13] Irene Rubaum-Keller, *Dr. Kevorkian, aka Dr. Death's Art on Display*, HUFFINGTON POST, http://www.huffingtonpost.com/irene-rubaumkeller-/dr-kevorkian-aka-dr-death_b_5102089.html (Apr. 8, 2014); Cara Spoto, *Oregon-Based Doctor and Racine Native Gives Talk on State's Physician-Assisted Dying Law*, THE JOURNAL TIMES (Apr. 7, 2014), http://journaltimes.com/news/local/oregon-based-doctor-and-racine-native-gives-talk-on-state/article_42949584-be34-11e3-b5a5-0019bb2963f4.html; Rob Wright, *Why Death with Dignity in the U.S. Remains the Holy Grail*, LIFE SCIENCE LEADER (Apr. 9, 2014), http://www.lifescienceleader.com/doc/why-death-with-dignity-in-the-u-s-remains-the-holy-grail-0001.

[14] Elizabeth Trice Loggers et al., *Implementing a Death with Dignity Program at a Comprehensive Cancer Center*, 368 N. ENGL. J. MED. 1417, 1421 tbl.2 (2013); *see infra* pt. V.

thus other countries are more open to the idea now that such fears have been dispelled.[15]

Physician-assisted suicide is the safest and strongest when enacted through legislation.[16] But the forms of adopting legislation that allow for physician-assisted suicide can differ vastly. In this Article, the Author will discuss the terminology of physician-assisted suicide, the American laws that allow physician-assisted suicide, statistics and data on Americans who have opted for physician-assisted suicide, a sampling of other countries' laws governing physician-assisted suicide, and the importance of a patient's autonomy.

II. TERMINOLOGY

In order to convey any argument with clarity, terminology must be defined.[17] Physician-assisted suicide, the right to die, and euthanasia are not synonyms.[18] The distinction between many of these terms lies in the intent of the physician and the technical means by which the patient ceases living.

A. Euthanasia

The term "euthanasia" has Greek origins, and means "a gentle and easy death."[19] Euthanasia is mainly used in reference to

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[15] *See* Or. Health Auth., *Death with Dignity Act Annual Report* (2015), *available at* https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year17.pdf; Nicole Steck et al., *Suicide Assisted by Right-to-Die Associations: A Population Based Cohort Study*, INT'L J. OF EPIDEMIOLOGY (2014), *available at* http://ije.oxfordjournals.org/content/early/2014/02/17/ije.dyu010.full.pdf+html.

[16] David L. Sloss, *The Right to Choose How to Die a Constitutional Analysis of State Laws Prohibiting Physician Assisted Suicide*, 48 STAN. L. REV. 937, 973 (1995).

[17] Katherine Ann Wingfield & Carl S. Hacker, *Physician Assisted Suicide: An Assessment and Comparison of Statutory Approaches Among the States*, 32 SETON HALL LEGIS. J. 13, 15 (2007–2008).

[18] *Id.*

[19] *Id.* (citing JOHN KEOWN, EUTHANASIA, ETHICS, AND PUBLIC POLICY: AN ARGUMENT AGAINST LEGISLATION 10 (2002)).

a physician's decision to shorten the life of the patient, based on the belief that death would benefit the patient.[20] In this context, euthanasia would be better for the patient than continuing to live in his or her present state.[21]

Euthanasia has two subcategories that set apart the complexities of this simple definition. The first of these distinctions is passive euthanasia, which typically refers to a patient's natural death caused by disconnecting life-support or life-sustaining medical devices.[22] After the physician disconnects the life-support, the illness is allowed to run its course resulting in death of the patient.[23] This death could take days or months depending on the progression of the illness and the type of life-support that was removed. Passive euthanasia is also used when a physician refrains from administering life-supporting procedures.[24]

Next is active euthanasia, where a deliberate action is taken to end the patient's life.[25] The physician's role is instrumental in understanding the difference between passive and active euthanasia.[26] With active euthanasia, the death is intended by the physician's purposeful actions, whereas, with passive euthanasia, the death is merely a foreseeable result.[27] An example of active euthanasia would be a physician administering a lethal dose of drugs to a patient and thus deliberately taking a role in ending their life.[28] Passive euthanasia leads to a natural death that was only being forestalled by medical technology, whereas active euthanasia is a

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[20] *Id.*
[21] *Id.*
[22] *Id.* (citing JENNIFER M. SCHERER & RITA JAMES SIMON, EUTHANASIA AND THE RIGHT TO DIE: A COMPARATIVE VIEW 13 (1999)).
[23] McGough, *supra* note 2, at 521.
[24] Wingfield & Hacker, *supra* note 17 (citing RAPHAEL COHEN-ALMAGOR, THE RIGHT TO DIE WITH DIGNITY: AN ARGUMENT IN ETHICS, MEDICINE, AND LAW 81 (2001)).
[25] *Id.* at 16 (citing KEOWN, *supra* note 19).
[26] *Id.*
[27] *Id.* "Mercy killing" is also used synonymously with euthanasia, but only focuses on the motivation of the person doing the act that results in the individual's death. *Id.* at 17 (citing ARTHUR J. DYCK, LIFE'S WORTH: THE CASE AGAINST ASSISTED SUICIDE 32 (2002). Typically, the term "mercy killing" is used when discussing the compassionate aspects of wanting to end the person's suffering. *Id.*
[28] Wingfield & Hacker, *supra* note 17, at 16.

death that is a direct result of the physician's actions to end the patient's life.[29]

B. Physician-Assisted Suicide

Physician-assisted suicide, also referred to as "PAS," differs slightly from euthanasia in that the physician is helping the patient theoretically commit suicide.[30] Physician-assisted suicide is different from active euthanasia because the patient's action of taking the medication is what ends his or her life; however, in active euthanasia, the physician personally administers the lethal medication that kills the patient.[31] In both situations, the physician is unarguably involved, but the physician is only directly causing the patient's life to end in active euthanasia.[32]

There is also a movement to replace the word suicide when describing a patient's choice to end their life.[33] The terms "physician aided dying" or "self-deliverance" are used to replace the word suicide because the term suicide infers that the person is ending his or her life due to emotional or psychological trauma, whereas self-deliverance implicates that the person is ending his or her life based off of a careful and rational decision.[34] Advocate groups prefer the phrase "aid in dying" because it carries less of a social stigma and resonates the message that the patients are terminally ill and desire help to end their suffering, rather than healthy and wishing to take their own life.[35] In a Gallup poll conducted from 2013, the two

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[29] *Id.*
[30] *Id.* (citing KEOWN, *supra* note 19 at 20) "Assisted suicide" is also used, but generally means that someone other than a physician helped the person commit suicide. *Id.* (citing SCHERER & SIMON, supra note 22, at 13).
[31] *Id.*
[32] *Id.* at 16, 17 (citing SCHERER & SIMON, *supra* note 22, at 13).
[33] *Id.*
[34] *Id.*
[35] Erik Eckholm, *'Aid in Dying' Movement Takes Hold in Some States*, N.Y. TIMES, Feb. 7, 2014, *available at* http://www.nytimes.com/2014/02/08/us/easing-terminal-patients-path-to-death-legally.html.

phrases were presented to U.S. residents ages 18 and older in a Values and Beliefs survey, and the term suicide is far less popular:

> In the same month that Vermont became the fourth state to legalize physician-assisted suicide, a May 2–7 Gallup survey finds 70% of Americans in favor of allowing doctors to hasten a terminally ill patient's death when the matter is described as allowing doctors to "end the patient's life by some painless means." At the same time, far fewer—51%—support it when the process is described as doctors helping a patient "commit suicide."[36]

The poll results also show that only 16% of those polled find suicide morally acceptable.[37] The key variable in public opinion on physician-assisted suicide seems to revolve around how it is described to the participants in the poll.[38] When presenting the topic using the word "suicide," there is no mention of family member involvement or that it will be as a result of "painless means," thus gaining less support than alternative phrases.[39]

C. Right to Die

The phrase "right to die" is more malleable than the previous terms. In general, it concerns the constitutional right to die by refusing medical treatment that would otherwise keep patients

[36] Lydia Saad, *U.S. Support for Euthanasia Hinges on How It's Described*, GALLUP, http://www.gallup.com/poll/162815/support-euthanasia-hinges-described.aspx (May 29, 2013).
[37] *Id.*
[38] *Id.*
[39] *Id.*

alive.[40] This constitutional right applies only to refusing action, not the right to take action to end one's life.[41]

III. PHYSICIAN-ASSISTED SUICIDE IN THE UNITED STATES

For patients who refuse life-sustaining medical treatment, the Natural Death Act outlines their rights of medical decision-making.[42] This act has a statutory approach where it provides a set of definitions, procedures for executing and revoking a living will, and immunity for health care providers.[43] However, this act only applies to the refusing of medical treatment and does not offer any options for physician-assisted suicide or other end of life options for terminally ill patients.[44]

A. States That Allow Physician-Assisted Suicide

Both Oregon and Washington have enacted similar Death With Dignity Acts ("DWDA") to permit physician-assisted suicide in their states.[45] The Death With Dignity Act began in Oregon as a "voter initiative drafted by Elvin Sinnard, who helped his terminally ill wife die."[46]

In 1994, Oregon was the first state to enact legislation allowing physician-assisted suicide on a very regulated basis:

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[40] *Id.* at 16 (referencing Cruzan by Cruzan v. Dir., Mo. Dept. of Health, 497 U.S. 261, 277 (1990)).
[41] *Id.* at 16–17 (referencing *Cruzan*, 497 U.S. at 278 (1990)).
[42] Natural Death Act, WASH. REV. CODE §§ 70.122.010–70.122.925 (2016); McGough, *supra* note 2, at 523.
[43] WASH. REV. CODE §§ 70.122.010–70.122.925; Peggy L. Collins, *The Foundations of the Right to Die*, 90 W. VA. L. REV. 235, 244–258 (1987).
[44] WASH. REV. CODE §§ 70.122.010–70.122.925; Collins, *supra* note 43, at 252–53.
[45] Death with Dignity Act, WASH. REV. CODE §§ 70.245.010–70.245.904 (2016); Death with Dignity Act, OR. REV. STAT. §§ 127.800–127.897 (2016).
[46] Stephanie Hendricks, *Pain Relief, Death with Dignity, and Commerce: The Constitutionality of Congressional Attempts to Regulate Physician-Assisted Suicide in Oregon via the Commerce Clause After Lopez and Morrison*, 37 WILLAMETTE L. REV. 691 (2001).

> An adult who is capable, is a resident of Oregon, and has been determined by the attending physician and consulting physician to be suffering from a terminal disease, and who has voluntarily expressed his or her wish to die, may make a written request for medication for the purpose of ending his or her life in a humane and dignified manner….[47]

The Death with Dignity Act has six sections: "General Provisions; Written Request for Medication to End One's Life in a Humane and Dignified Manner; Safeguards; Immunities and Liabilities; Severability; and Form of the Request."[48] The first section sets out the general definitions of words and phrases used in the Act.[49] The patient must be an adult and have a terminal disease, which is defined as "an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months."[50] The patient cannot be incapacitated; rather, the patient must be "capable," which is defined as a patient who "has the ability to make and communicate health care decisions to health care providers."[51] The statute "requires that the patient make an oral and written request to his or her physician and then reiterate this oral request no less than fifteen days after the original request."[52] This written request "must be signed and dated by at least two individuals who, in the presence of the patient, attest that to the best of their knowledge and belief the

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[47] OR. REV. STAT. ANN. § 127.805; Diani Hassel, *Sex and Death: Lawrence's Liberty and Physician-Assisted Suicide*, 9 U. PA. J. CONST. L. 1003, 1021 (2007); Chelsea A. Cerutti, *Donation After Cardiac Death: Respecting Patient Autonomy and Guaranteeing Donation With Guidance From Oregon's Death with Dignity Act*, 75 ALB. L. REV. 2199, 2220 (2011–2012).
[48] OR. REV. STAT. ANN. §§ 127.800–127.897 (2016); Steven B. Datlof, *Beyond Washington v. Glucksberg Oregon's Death with Dignity Act Analyzed from Medical and Constitutional Perspectives*, 14 J. L. & HEALTH 23, 26 (1999–2000).
[49] OR. REV. STAT. ANN. § 127.800; Datlof, *supra* note 48.
[50] OR. REV. STAT. ANN. § 127.800(12); Datlof, *supra* note 48; Wingfield & Hacker, *supra* note 17, at 47.
[51] OR. REV. STAT. ANN. § 127.800(3).
[52] OR. REV. STAT. ANN. § 127.840; Cerutti, *supra* note 47, at 2220.

patient is capable, acting voluntarily, and is not being coerced to sign the request ."[53]

Additionally, the Safeguards section requires that a physician "counsel the patient and ensure that the patient is making an informed decision," and the physician must diagnose the patient "as suffering from a terminal illness."[54] The consulting physician must then confirm the first physician's diagnosis.[55] If either physician believes the patient is "suffering from a psychiatric or psychological disorder or depression causing impaired judgment" the physician must refer the patient for counseling.[56] Not every patient receives counseling such as this, however, if they do, the "mental health professional must determine that the patient is free from any mental illness that would cause impaired judgment before the patient receives medication for the purpose of suicide."[57]

Further, the patient may rescind his or her request at any time.[58] "In order to minimize impulsive behavior, the Death with Dignity Act specifies that a patient must make three requests, two oral and one written."[59] The second oral request has to be within fifteen days of the first oral request and the written request.[60] The written request must be made in the presence of two witnesses, and one witness must not be a relative, have any interest in the patient's estate, or be associated with the medical care facility.[61] The physician must wait at least fifteen days after the initial oral request before he or she writes the prescription.[62] After the written request is made, "there is a forty-eight hour waiting period before a

[53] OR. REV. STAT. ANN. § 127.810(1), Cerutti, *supra* note 47, at 2220; Datlof, *supra* note 48, at 26.
[54] OR. REV. STAT. ANN. § 127.820; Cerutti, *supra* note 47, at 2220–21; Datlof, *supra* note 48, at 25.
[55] OR. REV. STAT. ANN. § 127.820; Cerutti, *supra* note 47, at 2220; Datlof, *supra* note 48, at 26.
[56] OR. REV. STAT. ANN. § 127.825; Datlof, *supra* note 48, at 26.
[57] OR. REV. STAT. ANN. § 127.825; Datlof, *supra* note 48, at 26–27.
[58] OR. REV. STAT. ANN. § 127.845; Datlof, *supra* note 48, at 27.
[59] OR. REV. STAT. ANN. § 127.840.
[60] *Id.*
[61] OR. REV. STAT. ANN. § 127.810(1)–(2).
[62] OR. REV. STAT. ANN. § 127.850.

prescription may be written."[63] Before writing the prescription the physician "must verify that the patient is making an informed decision."[64]

The doctors prescribing the medication are also protected from civil or criminal liability, and from professional disciplinary action.[65] The doctors are not allowed to actively participate or help the patient commit suicide, such as by suffocating the patient.[66] Finally, the Oregon Department of Human Services collects "information about the patients and physicians who participate . . . to monitor compliance with laws and regulations, and to publish annual statistical reports."[67]

Although physicians are protected when in compliance with this Act, they are still subject to charges if found to have aided a patient in bad faith or in a manner that breaches the statutory procedures.[68] Oregon statutes also provide that any form of assisted suicide that does not meet the Act's standards is manslaughter in the second degree, which is a Class B felony,[69] and sanctioned with a "maximum potential prison term of 10 years and/or a maximum potential fine of $250,000."[70] Additionally, Washington enacted a mirrored Death with Dignity Act in 2009.[71] This Act also explicitly prohibits active euthanasia, and considers such a Class C Felony,

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[63] OR. REV. STAT. ANN. § 127.850; Datlof, *supra* note 48, at 27.
[64] OR. REV. STAT. ANN. § 127.830; Datlof, *supra* note 48, at 27.
[65] OR. REV. STAT. ANN. § 127.887; Cerutti, *supra* note 47, at 2222; Datlof, *supra* note 48, at 27.
[66] OR. REV. STAT. ANN. § 127.880; Kathy T. Graham, Last Rights: Oregon's New Death With Dignity Act, 31 WILLIAMETTE L. REV. 601, 602 (1995) (discussing Measure 16 of the initial ballot proposal Death with Dignity Act, where active euthanasia was originally proposed, but later modified to only include physician-assisted suicide).
[67] OR. REV. STAT. ANN. § 127.865; Wingfield & Hacker, *supra* note 17, at 48.
[68] OR. REV. STAT. ANN. § 127.880; Datlof, *supra* note 48, at 27; Wingfield & Hacker, *supra* note 17, at 48.
[69] OR. REV. STAT. ANN. § 163.125; Wingfield & Hacker, *supra* note 17, at 48.
[70] OR. REV. STAT. ANN. § 161.605, 161.625; Evelien Delbeke, *The Way Assisted Suicide is Legalized: Balancing a Medical Framework Against a Demedicalised Model*, 18 EUR. J. HEALTH L. 149, 150 (2011).
[71] Death with Dignity Act, WASH. REV. CODE §§ 70.245.010-70.245.904 (2016).

which is punishable by a maximum prison sentence of "five years and a fine up to $10,000."[72]

In October of 2015, California passed the End of Life Option Act[73] that was modeled after Oregon's Death with Dignity Act, which now allows physician-assisted suicide to more than 1 in 10 Americans.[74] In an interview with the *Los Angeles Times*, Governor Jerry Brown[75] discusses that his decision to sign the bill stemmed from considering his own circumstances, and how he would feel if he had a terminal illness:

> In the end, I was left to reflect on what I would want in the face of my own death . . . I do not know what I would do if I were dying in prolonged and excruciating pain. I am certain, however, that it would be a comfort to be able to consider the options afforded by this bill. And I wouldn't deny that right to others.[76]

The bill gained media attention due to the advocacy for physician-assisted suicide from a 29-year-old named Brittany Maynard, who was dying of brain cancer and had to move from California to Oregon in order to have this option.[77] Maynard partnered with

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[72] WASH. REV. CODE § 70.245.180; The Washington statute prohibits a person from promoting the suicide of another considering this crime a Class C Felony. WASH. REV. CODE § 9A.36.060, 9A.20.021.

[73] CAL. HEALTH & SAFETY CODE §§ 443–444.12 (2016).

[74] Patrick McGreevy, *After Struggling, Jerry Brown Makes Assisted Suicide Legal in California*, L.A. TIMES, Oct. 5, 2015, *available at* http://www.latimes.com/local/political/la-me-pc-gov-brown-end-of-life-bill-20151005-story.html.

[75] *About Jerry Brown*, JERRY BROWN, http://www.jerrybrown.org/about (last visited Oct. 26, 2016).

[76] McGreevy, *supra* note 74 (quoting Letter from Edmund G. Brown, Jr., Governor of California, to the Members of the California State Assembly, *California End of Life Option Bill AB-15*, (Oct. 5, 2015), *available at* https://www.gov.ca.gov/docs/ABX2_15_Signing_Message.pdf).

[77] Brittany Maynard, *My Right to Death with Dignity at 29*, CNN, http://www.cnn.com/2014/10/07/opinion/maynard-assisted-suicide-cancer-dignity/ (Nov. 2, 2014).

Compassion & Choices using her illness to shed light on the options for the terminally ill and her own personal process of deciding that physician-assisted suicide was the best option for her.[78] California's intent to pursue legislation to allow physician-assisted suicide was announced only two months after her death, and now more than fifteen states have introduced aid-in-dying bills.[79]

On May 20, 2013, Vermont's legislature enacted a physician-assisted suicide act called Patient Choice and Control at End of Life.[80] This Act is less detailed than the Death with Dignity Act,[81] and the End of Life Options Act,[82] but has the same main requirements. In Vermont, the patient must be at least eighteen years old and be dying of a terminal illness, which generally means the patient has six months to live.[83] There is a clause expressing that physicians participating in this form of treatment are not civilly or criminally liable, or subject to professional discipline, if the physician documents in the patient's record that all statutory safeguards were followed.[84] Also, Vermont requires two oral requests and one written request for physician-assisted suicide, and the lethal prescription must be written over 48 hours after the final request.[85] The written request must be signed by at least two witnesses, who are not "interested persons," and the patient must be free from "duress or undue influence."[86] Vermont requires that two physicians review the patient and that the patient be referred for psychiatric evaluation if he or she shows any sign of impaired judgment.[87]

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[78] Jessica Firger, *Family Releases Final Brittany Maynard Video as Calif. Debates Right to Die*, CBS NEWS (March 25, 2015), http://www.cbsnews.com/news/brittany-maynard-video-california-debates-right-to-die-law/.
[79] *Id.*
[80] VT. STAT. TIT. 18, §§ 5281–5293 (2016); *Patient Choice and Control at End of Life*, VERMONT DEPT. OF HEALTH, http://healthvermont.gov/family/end_of_life_care/patient_choice.aspx#forms (last visited Oct 26, 2016).
[81] OR. REV. STAT. § 127.860; WASH. REV. CODE § 70.245.130.
[82] CAL. HEALTH & SAFETY CODE §§ 443–444.12.
[83] VT. STAT. TIT. 18, § 5283 (a)(4)–(5).
[84] *Id.* at § 5283(a).
[85] *Id.* at § 5283(a)(1)–(4).
[86] *Id.* at § 5283(a)(4).
[87] *Id.* at § 5283(a)(7)–(8).

Unlike Oregon, Washington, and California's [88] specified residency requirements, Vermont's residency requirement is determined by the patient's physician.[89] Proving residency may include any of the following: having a Vermont driver's license, being registered to vote in Vermont, showing that he or she leases or owns property in Vermont, or proof of filing a Vermont tax return for the most recent tax year.[90] Why Vermont did not include specific ways to prove residency is unclear, but the statute may be amended in the future to include such.

Unlike Washington, Oregon, Vermont and California, Montana's physician-assisted suicide laws originated from the judiciary rather than the legislature.[91] In *Baxter v. State*,[92] the Supreme Court of Montana ruled that "physician aid in dying provided to a terminally ill, mentally competent adult patient was not against public policy."[93] This 2009 ruling was decided "despite the fact that in Montana, assisted suicide is punishable by a prison term of a maximum of ten years and a maximum fine of $50,000."[94]

The plaintiff, Robert Baxter, was a retired truck driver who suffered from a terminal illness called lymphocytic leukemia with diffuse lymphadenopathy.[95] Chemotherapy was no longer working

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[88] CAL. HEALTH & SAFETY CODE § 443.2(a); OR. REV. STAT. § 127.860; WASH. REV. CODE § 70.245.130. Residency is a concern due to residents of border states utilizing this service. Since Physician-assisted suicide is only allowable per the state's statutes, it is a feature only available to that state's residents.

[89] VT. STAT. TIT. 18, § 5283(5)(E).

[90] *Patient Control and Choice at End of Life—Frequently Asked Questions*, VERMONT DEPT. OF HEALTH, http://healthvermont.gov/family/end_of_life_care/documents/Act39_faq.pdf (last visited June 3, 2016).

[91] Baxter v. State, 224 P.3d 1211 (Mont. 2009).

[92] 224 P.3d 1211 (Mont. 2009).

[93] *Id.* at 1215; Delbeke, *supra* note 70, at 151.

[94] *Baxter*, 224 P.3d at 1234; Delbeke, *supra* note 70, at 151.

[95] *Baxter*, 224 P.3d at 1214. Lymphocytic leukemia with diffuse lymphadenopathy is a type of "cancer in which the bone marrow makes too many lymphocytes (a type of white blood cells)" and is the second most common type of leukemia in adults. *General Information About Chronic Lymphocytic Leukemia*, NATIONAL CANCER INSTITUTE, http://www.cancer.gov/cancertopics/pdq/treatment/CLL/Patient/page1 (last visited Oct. 26, 2016).

for Mr. Baxter's condition.[96] He was suffering a plethora of symptoms associated with his illness, so he requested the option of physician-assisted suicide.[97] Mr. Baxter, four physicians, and Compassion & Choices[98] filed the case challenging "the constitutionality of the application of Montana homicide statutes to physicians who provide aid in dying to mentally competent, terminally ill patients."[99] The Supreme Court of Montana held that under Article II, sections 4 and 10 of the Montana Constitution

> [i]ndividuals who are mentally competent and incurably ill and face death within a relatively short period of time have the right to self-administer, at a time and place of their choosing, a life-ending substance prescribed by their physician. The physician simply makes the medication available to the patient who requests it and the patient ultimately chooses whether to cause her own death by self-administering the medicine.[100]

This permission of physician-assisted suicide also protected physicians from Montana's homicide statute.[101] The Court further

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[96] *Baxter*, 224 P.3d at 1214.

[97] *Id.* The additional symptoms involved "infections, chronic fatigue and weakness, anemia, night sweats, nausea, massively swollen glands, significant ongoing digestive problems and generalized pain and discomfort." *Id.*

[98] "Compassion & Choices is the leading nonprofit organization committed to helping everyone have the best death possible." *About*, COMPASSION AND CHOICES, https://www.compassionandchoices.org/who-we-are/about/ (last visited Oct. 26, 2016)

[99] *Baxter*, 224 P.3d at 1214.

[100] *Id.* at 1233. The Montana Constitution defines "Individual Dignity" as "the dignity of the human being is inviolable. No person shall be denied the equal protection of the laws. Neither the state nor any person, firm, corporation, or institution shall discriminate against any person in the exercise of his civil or political rights on account of race, color, sex, culture, social origin or condition, or political or religious ideas." MONT. CONST. art. II, § 4. The Montana Constitution defines the "Right to Privacy" as "the right of individual privacy is essential to the well-being of a free society and shall not be infringed without the showing of a compelling state interest." MONT. CONST. art. II, § 10.

[101] *Baxter*, 224 P.3d at 1221; Nickolas C. Murnion & Rita L. Marker, *Brief Amicus Curiae in Robert*

stated that physician-assisted suicide "quintessentially involves the inviolable right to human dignity—our most fragile fundamental right." [102] In a passionate concurrence, Justice James C. Nelson stated:

> Society does not have the right to strip a mentally competent, incurably ill individual of her inviolable human dignity when she seeks aid in dying from her physician. Dignity is a fundamental component of humanness; it is intrinsic to our species; it must be respected throughout life; and it must be honored when one's inevitable destiny is death from an incurable illness.[103]

The Court resolved the issue of physician-assisted suicide by describing how Montana's current state policy "does not permit a person or entity to force an agonizing, dehumanizing, demeaning, and often protracted death upon a mentally competent, incurably ill individual for the sake of political ideology, religious belief, or a paternalistic sense of ethics."[104]

Since the Court, rather than the legislature, ruled to allow physician-assisted suicide, there has been heavy criticism about the vagueness of the process in permitting physician-assisted suicide.[105] Instead of applying the Montana Constitution, the Montana

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Baxter Versus State of Montana, 25 ISSUES L. & MED. 33 (2009–2010).

[102] *Baxter*, 224 P.3d at 1233.

[103] *Id.*

[104] *Id.*

[105] Betsy Griffing, *The Rise and Fall of the New Judicial Federalism Under the Montana Constitution*, 71 MON. L. REV. 383, 392 (2010); William L. Saunders, *The Montana Supreme Court Legalizes Assisted Suicide*, 11 ENGAGE: J. FEDERALIST SOC'Y PRAC. GROUPS 114 (2010), *available at* http://www.fed-soc.org/aboutus/ DownloadLibrary?id=4452.

Supreme Court "analyzed the consent defense to homicide and stated that it was not a violation of public policy for physicians to use that defense if they prescribed medication to terminally ill, competent patients."[106] This reasoning is based off of the difference between active and passive suicide: "the patient—not the physician—commits the final death-causing act by self-administering a lethal dose of medicine."[107] In previous Montana court cases on this subject, the courts would determine whether or not the physician had violated a patient's fundamental right. However, the Court in *Baxter* simply avoided the constitutional issue altogether and left it open for another court or for the state legislature to interpret.[108]

Allowing for physician-assisted suicide, while not amending the state constitution or statutes, leaves a dangerously gray area in the law. The Death with Dignity Act not only decriminalized physician-assisted suicide, but it also set out specific rules to regulate the process.[109] By the court "restricting its holding to the judicial realm, the court has chosen to leave the future of the state's aid-in-dying laws up to the legislative process."[110] In Montana, a future case could find that physician-assisted suicide is not a fundamental right and make it against public policy.[111]

IV. PHYSICIAN-ASSISTED SUICIDE DEMOGRAPHICS AND STATISTICS

Since the enactment of the Death with Dignity Act in Oregon in 1997, a total of 1,327 patients have had Death with Dignity Act prescriptions written and 859 of those patients chose to take the prescriptions.[112] Some patients chose not to take the lethal drug but

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[106] Griffing, *supra* note 105, at 392.
[107] Kristina Ebbott, *A "Good Death" Defined by Law: Comparing the Legality of Aid-in-Dying Around the World*, 37 WM. MITCHELL L. REV. 170, 196 (2010–2011).
[108] *Baxter*, 224 P.3d at 1221; Griffing, *supra* note 105, at 392; Saunders, *supra* note 105, at 117.
[109] OR. REV. STAT. §§ 127.800–127.897; WASH. REV. CODE §§ 70.245.010–70.245.904.
[110] Ebbott, *supra* note 107, at 196; Saunders, *supra* note 105, at 117.
[111] Saunders, *supra* note 105, at 117.
[112] Or. Health Auth., *supra* note 15, at 2.

ultimately died later due to other causes.[113] From 1998 to 2014, of the 752 patients, 72.1% were college educated, of which 45.7% obtained a Baccalaureate degree or higher, and only 6.0% of the patients had less than a high school education.[114] In 2014, there were 105 Death with Dignity Act deaths, 67.6% were 65 years or older.[115] The median age of those people was 72, with 29 being the youngest and 96 being the oldest.[116] From the years 1988 to 2013, the median age remained 71, with the youngest being 25 years old and the oldest being 96 years old.[117]

The majority of patients who have received Death with Dignity Act prescriptions were patients with cancer or chronic lower respiratory disease.[118] Of the 2014 Death with Dignity Act patients, 89.5% died at home, and 93% were enrolled with Hospice care either at the time the prescription was written or at the time of death.[119] Similar to the previous studies, in 2014, the "three most frequently mentioned end-of-life concerns were: loss of autonomy (91.4%), decreasing ability to participate in activities that made life enjoyable (86.7%), and loss of dignity (71.4%)."[120] Further, in 2013, "no referrals were made to the Oregon Medical Board for failure to comply with DWDA requirements."[121] According the last 17 years of reports, there has been no case of a patient calling in to panic or change his or her mind after ingesting the medication.[122]

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[113] *Id.* Thirty-seven of the 155 patients who were provided written prescriptions chose not to take the prescriptions and eventually died from other causes. *Id.*

[114] *Id.* at 4 tbl.1. In 2014, the numbers were similar: 72.4% of the patients had some college education or a degree, with only 5.7% having less than a high school education. *Id.*

[115] *Id.*

[116] *Id.*

[117] *Id.*

[118] *Id.* at 5 tbl.1. The overall percentage for those patients with cancer dropped from 79.4% to 68.6%, while those with amyotrophic lateral sclerosis (ALS) increased from 7.2% to 16.2%. *Id.* at 2.

[119] *Id.* at 6 tbl.1. In 100% of the known cases, the patient had some form of health insurance, private or Medicare/Medicaid. *Id.* at 2.

[120] *Id.*

[121] *Id.* at 3 tbl.1.

[122] All reports can be found at https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx.

In Washington, as of December 2014, only 725 patients had requested and taken lethal prescriptions from physicians participating in the Death with Dignity Act.[123] Along with Oregon's data, this helps ease public fears and misconceptions of a sudden flooding of terminally ill patients wishing to commit suicide.[124] Oregon's 859 deaths from physician-assisted suicide since 1997 average to 48 people each year over the past 18 years.[125] In 2014, the age range of participants in Washington was 21 to 101, with 55% being ages 65-84 and 17% being 85 or older.[126] Further, 95% of Washington participants had a high school level or higher degree of education.[127]

A concern from opponents of the Death with Dignity Act is that it might disproportionately affect populations, such as minorities and lower-income populations, who feel pressured to choose physician-assisted suicide in order to avoid medical debt.[128] However the findings from the Oregon and Washington studies do not support this apprehension.[129] While motivation to avoid debt is a factor in screening patients for physician-assisted suicide, thus far there is no evidence in either Oregon or Washington that this impulse will manifest into a reality.[130]

A 2014 study from Switzerland shows similar results to the U.S. regarding patients who chose physician-assisted suicide.[131]

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[123] Wash. Dept. of Health, *Death With Dignity Act Report* 4 fig. 2 (2014), *available at* http://www.doh.wa.gov/portals/1/Documents/Pubs/422-109-DeathWithDignityAct2014.pdf; Serena Gordon, *Physician-Assisted Suicide Program Rarely Used, Study Finds*, U.S. NEWS (Apr. 10, 2013), http://health.usnews.com/health-news/news/articles/2013/04/10/physician-assisted-suicide-program-rarely-used-study-finds.

[124] Loggers et al., *supra* note 14, at 1421 tbl.2; Gordon, *supra* note 123.

[125] Or. Health Auth., *supra* note 15, at 2.

[126] Wash. Dept. of Health, *supra* note 123, at 5 tbl.1; Loggers et al., *supra* note 14, at 1421 tbl.2.

[127] Wash. Dept. of Health, *supra* note 123, at 5 tbl.1.

[128] Loggers et al., *supra* note 14, at 1423; Murnion & Marker, *supra* note 101, at 43.

[129] Or. Health Auth., *supra* note 15; Wash. Dept. of Health, *supra* note 123.

[130] Or. Health Auth., *supra* note 15; Wash. Dept. of Health, *supra* note 123; Margaret P. Miller, *Boot-Strapping Down a Slippery Slope in the Second and Ninth Circuits: Compassion in Dying Is Neither Compassionate nor Constitutional*, 30 CREIGHTON L. REV. 833, 856–57 (1997) (discussing the concerns of the court in Compassion in Dying v. State of Wash., 79 F.3d 790, 826 (1997), about a person who may want to die to avoid becoming an economic burden for loved ones).

[131] Steck et al., *supra* note 15.

This study reviewed the demographics of individuals choosing this option and voiced the same concern as most of the U.S. indicating "vulnerable or disadvantaged groups"[132] are more likely to opt for physician-assisted suicide.[133] The study was conducted using statistics from the 2003–2008 census and the analysis was based on 5,004,403 Swiss residents and 1,301 assisted-suicides.[134] Of the 1,301 assisted-suicides, 439 were in the age range of 25–64 years old, and 862 were in the age range of 65–94 years old.[135] Like studies in the United States, the "rate was also higher in more educated people, in urban compared with rural areas and in neighborhoods [sic] of higher socio-economic position."[136]

During the end stages of many illnesses, such as Alzheimer's disease,[137] patients may be prohibited from making life-ending decisions because they lack the requisite mental capacity.[138] Physician-assisted suicide is only an option for terminally ill patients who are still mentally capable.[139] The primary illness of persons who requested physician-assisted suicide was cancer.[140] The American Cancer Society estimates that in 2016 there will be 1,685,210 new diagnoses of cancer in the United States.[141] Further, the American Cancer Society estimates that there will be 595,690

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[132] *Id.* at 1.
[133] *Id.* at 2.
[134] *Id.* at 2–3.
[135] *Id.* at 4.
[136] *Id.*
[137] Alzheimer's is a type of dementia that causes problems with memory, thinking and behavior. Symptoms usually develop slowly and get worse over time, becoming severe enough to interfere with daily tasks. *See What is Alzheimer's,* ALZHEIMER'S ASSOCIATION, http://www.alz.org/alzheimers_disease_what_is_alzheimers.asp (last visited Oct. 26, 2016)
[138] OR. REV. STAT. ANN. § 127.800(3) (1999). *See generally* Norman L. Cantor, *Twenty-five Years After* Quinlan*: A Review of the Jurisprudence of Death and Dying,* 29 J.L. MED. & ETHICS 182 (2001).
[139] Cantor, *supra* note 138.
[140] In 2014, 68.6% of patients in Oregon had cancer. Or. Health Auth., *supra* note 15, at 2; In 2014, 73% of patients in Washington had cancer. Wash. Dept. of Health, *supra* note 123, at 1; Loggers et al., *supra* note 14, at 1421 tbl.2.
[141] *Cancer Facts & Figures 2016,* AMERICAN CANCER SOCIETY 4 tbl.1 (2015), *available at* http://www.cancer.org /acs/groups/content/@research/documents/document/acspc-047079.pdf.

deaths in 2016 caused by cancer.[142] In 2010, the U.S. National Vital Statistics Report showed that 574,743 deaths were from some form of cancer, and the American Cancer Society had estimated that the total number of cancer related deaths that year would be 569,490.[143] In 2011, the estimated number of cancer related deaths was 571,950 and the actual number was 575,313.[144] While the American Cancer Society figures are only estimates, they are rather close to the actual yearly American deaths from cancer.[145] These statistics show that cancer does affect a fair size of the population.

V. PHYSICIAN-ASSISTED SUICIDE ACROSS THE GLOBE

Outside of the U.S., several other countries permit physician-assisted suicide, either through enacted laws or through the lack of laws regulating the procedure. Some physicians find this process permissible simply because there are no laws regulating this issue. Countries such as the Canada, Switzerland, Belgium, and the Netherlands allow physician-assisted suicide by various methods permitted by law.[146]

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[142] *Id.* at 3 tbl.1.

[143] *Cancer Facts & Figures 2010,* AMERICAN CANCER SOCIETY 4 tbl.1 (2010), *available at* http://www.cancer.org/acs/groups/content/@epidemiologysurveilance/documents/document/acspc-026238.pdf; Melonie Heron, *Deaths: Leading Causes for 2010*, 62 NAT'L. VITAL STATISTICS REP. 1, 17 tbl.1. (2015), *available at* http://www.cdc.gov/nchs/data/nvsr/nvsr62/nvsr62_06.pdf.

[144] *Cancer Facts & Figures 2011,* AMERICAN CANCER SOCIETY 4 tbl.1 (2011), *available at* http://www.cancer.org/acs/groups/content/@epidemiologysurveilance/documents/document/acspc-029771.pdf; Donna L. Hoyert & Jaiquan Xu, *Deaths: Preliminary Data for 2011*, 61 NAT'L. VITAL STATISTICS REP. 1, 4 tbl.B (2012), *available at* http://www.cdc.gov/nchs/data/nvsr/nvsr61/nvsr61_06.pdf.

[145] *See supra* nn.140–43 (discussing statistics on the number of deaths from cancer in the United States).

[146] *Euthanasia and Assisted Suicide Laws Around the World*, THE GUARDIAN (July 17, 2014), http://www.theguardian.com /society/2014/jul/17/euthanasia-assisted-suicide-laws-world. Please note that this is not an exhaustive list of countries. Other countries that permit PAS are Germany, Denmark, Luxembourg. *See World Laws on Assisted Suicide*, EUTHANASIA RESEARCH & GUIDANCE ORG. http://finalexit.org/assisted_suicide_world_laws_page2.html (last updated August 28, 2010).

A. Canada

One of the newest countries to debate physician-assisted suicide is Canada. In February 2015, the Supreme Court of Canada unanimously overturned the 1993 ban on physician-assisted suicide, in *Carter v. Canada*.[147] The government has a year to rewrite its law on physician-assisted suicide and determine whether it wants to follow suit with countries like Belgium or the Netherlands, or create its own distinct set of rules.[148] In *Carter*, Gloria Taylor suffered from amyotrophic lateral sclerosis ("ALS").[149] Ms. Taylor described the reason for wanting physician-assisted suicide was because she "did not want to 'live in a bedridden state, stripped of dignity and independence,' she said; nor did she want an 'ugly death.'"[150] Ms. Taylor was joined in the case by Lee Carter and Hollis Johnson, "who had assisted Ms. Carter's mother, Kathleen Carter, in achieving her goal of dying with dignity by taking her to Switzerland to use the services of Dignatas,[151] an assisted suicide clinic."[152] Ms. Carter suffered from spinal stenosis and required assistance with almost all of her daily activities.[153] She made the decision to seek physician-assisted suicide in Switzerland by reasoning "she did not wish to live out her life as an 'ironing board,' laying flat in bed."[154]

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[147] *Canada to Allow Doctor-Assisted Suicide*, BBC NEWS (Feb. 6, 2015), http://www.bbc.com/news/world-us-canada-31170569; *see also* Miranda Barbuzzi, *Who Owns the Right to Die? An Argument about the Legal Status of Euthanasia and Assisted Suicide in Canada*, 10 PENN BIOETHICS J. 16 (2014).

[148] Carter v. Canada, 2015 SCC 5, [2015] 1 S.C.R. 331, 147 (S.C.C.) (ruling that the law forbidding physicians assisted suicide was unconstitutional but that the Court's decision was suspended for 12 months); *Canada to Allow Doctor-Assisted Suicide*, *supra* note 147.

[149] *Carter*, 2015 SCC at 11; Laura Peyton, *Supreme Court Says Yes to Doctor-Assisted Suicide in Specific Areas*, CBC NEWS, http://www.cbc.ca/news/politics/supreme-court-says-yes-to-doctor-assisted-suicide-in-specific-cases-1.2947487 (last updated Feb 06, 2015, 5:48 PM ET).

[150] *Carter*, 2015 SCC at 12.

[151] Dignitas is an organization in Switzerland whose objective is to ensure "a life and death with dignity." *Who is Dignitas*, DIGNITAS, http://www.dignitas.ch/index.php?option=com_content&view=article&id=4&Itemid= 44&lang=en (last visited Oct. 26, 2016).

[152] *Carter*, 2015 SCC 5 at 11.

[153] *Id.* at 17.

[154] *Id.*

B. Switzerland

Standing apart from other countries, Switzerland allows for assisted suicide without requiring that a physician supervise or conduct the act.[155] Switzerland allows non-residents and even those who are not suffering from a terminal illness to receive assistance in ending their lives.[156] While this approach is more extreme than laws in other countries, in most circumstances, a physician is considered a "necessary safeguard in assisted suicide and euthanasia."[157] "Switzerland seems to be the only country in which the law limits the circumstances in which assisted suicide is a crime, thereby decriminalizing [sic] it in other cases, without requiring the involvement of a physician."[158] This stems from the 1918 Swiss law stating that committing suicide or aiding someone in committing suicide is not a crime, unless the person aiding someone commit suicide was motivated by "selfish reasons."[159] Interestingly, this allowance of suicide was not focused on ending the suffering of the terminally ill, but rather, it was "motivated by honour and romance, which were considered to be valid motives."[160] Thus, these kinds of motives did not require a physician to be involved in the suicide, which is why physicians were left out of these law.[161]

C. Belgium

Belgium is considered to have one of the most liberal approaches to physician-assisted suicide due to the recent

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[155] Samia A Hurst & Alex Mauron, *Assisted Suicide and Euthanasia in Switzerland: Allowing a Role for Non-Physicians*, 326 BRIT. MED. J. 271, 272 (2003), *available at* https://www.ncbi.nlm.nih.gov/pmc/articles /PMC1125125/.

[156] *Where to Go to Die*, THE ECONOMIST, July 19, 2014, http://www.economist.com/news/international/21607888-small-group-countries-helping-someone-die-not-crime-where-go-die.

[157] Hurst & Mauron, *supra* note 155, at 271.

[158] Ebbott, *supra* note 107, at 198; Hurst & Mauron, *supra* note 155, at 271.

[159] Hurst & Mauron, *supra* note 155, at 271.

[160] *Id.*

[161] *Id.* at 272. It is the position of the Swiss Academy of Medical Sciences that assisted suicide is not a part of a physician's activity. *Id.* This statement has been construed to mean that assisted suicide does not fall into the purview of the medical profession and therefore allows physicians to act as any other citizen and altruistically assist suicide. *Id.*

amendment to the Belgian Act on Euthanasia, which removed the age requirement and now affords minors the same right as adults.[162] The original act was adopted in 2002 and applies to patients suffering physically or mentally from a disease.[163] This act requires that the patient be in a "medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident."[164] Belgium also allows legally competent adults or emancipated minors to instruct their physician to perform physician-assisted suicide in an advance directive.[165]

As for allowing children to elect physician-assisted suicide, the child must meet the same terminal requirements as an adult. They must show that they fully understand the choice they are making.[166] Furthermore, the final decision must be approved by the parents of the terminally ill child as well.[167] As stated by Scott Martelle of the LA Times:

> It's not an easy conclusion to reach. But if we believe that it is humane to give terminally ill adults the right to end their lives with medical help, how can we not extend that ability to terminally ill minors? Because of

[162] *The Right to Die in Belgium: An Inside Look at the World's Most Liberal Euthanasia Law*, PBS NEWS HOUR (Jan. 17, 2015, 11:30 AM EDT), http://www.pbs.org/newshour/bb/right-die-belgium-inside-worlds-liberal-euthanasia-laws-2/; Charlotte McDonald-Gibson, *Belgium Extends Euthanasia Law to Kids*, TIME (Feb. 13, 2014), http://time.com/7565/belgium-euthanasia-law-children-assisted-suicide/; Prior to these amendments the patient had to be an adult or emancipated minor. Ebbott, *supra* note 107, at 190.

[163] *The Belgian Act on Euthanasia of May 28th, 2002*, 9 ETHICAL PERSP. 182 (Dale Kidd trans., 2002), *available at* http:// www.kuleuven.be/cbmer/viewpic.php?LAN=E&TABLE=DOCS&ID=23 [hereinafter *The Belgian Act*]; Ebbott, *supra* note 107, at 189.

[164] Ebbott, *supra* note 107, at 189; *The Belgian Act on Euthanasia*, *supra* note 163.

[165] *The Belgian Act*, *supra* note 163, at 183–85.

[166] McDonald-Gibson, *supra* note 162.

[167] *Id.*

> their age, they should be forced to suffer more than an adult?[168]

The legislation to widen this law came from the Belgium Senator Philippe Mahoux,[169] who called for this expansion because this practice was already being done illegally in the country.[170]

D. Netherlands

The first country to legalize physician-assisted suicide was the Netherlands in 2002, through the Termination of Life on Request and Assisted Suicide Act.[171] This act requires that the "request by the patient [be] voluntary and well-considered"[172] and that his or her suffering is "lasting and unbearable."[173] Similar to Oregon's Death with Dignity Act, the physician is required to consult with another physician who can certify that the patient meets the requirements previously outlined.[174] If the physician thinks the patient may lack capacity, then a psychiatrist must be consulted.[175]

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[168] Scott Martelle, *Extend Assisted Suicide to Children? Belgium Says Yes; So Should We*, LOS ANGELES TIMES (Feb 14. 2014), http://articles.latimes.com/2014/feb/14/news/la-ol-assisted-suicide-children-belgium-says-yes-20140214.

[169] Philippe Mahoux is a senator in Belgium and holds a Doctor of medicine, surgery and obstetrics. *Philippe Mahoux: Portrait*, PHILIPPE-MAHOUX, http://www.philippe-mahoux.be/010_portrait.php (last visited Aug. 13, 2016). He has been involved in politics since 1988. *Id.*

[170] *Belgium Approves Assisted Suicide for Minors*, DEUTSCHE WELLE (Feb. 13, 2014), http://www.dw.de/belgium-approves-assisted-suicide-for-minors/a-17429423.

[171] Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding [The Termination of Life on Request and Assisted Suicide (Review Procedures) Act of 2001] Staatsblad van het Koninkrijk der Nederlanden (STB) 2001, 194, *available at* http://www.eutanasia.ws/documentos/Leyes/Internacional/Holanda%20Ley%202002.pdf [hereinafter The Termination of Life on Request and Assisted Suicide Act]; Marlise Simons, *Dutch Becoming First Nation to Legalize Assisted Suicide*, NY TIMES (Nov 29, 2000), http://www.nytimes.com/2000/11/29/world/dutch-becoming-first-nation-to-legalize-assisted-suicide.html; Penney Lewis & Isra Black, *Adherence to the Request Criterion in Jurisdictions Where Assisted Dying Is Lawful? A Review of the Criteria and Evidence in the Netherlands, Belgium, Oregon, and Switzerland*, 41 J. L. MED. & ETHICS 885 (2013); Barbuzzi, *supra* note 147, at 18.

[172] Termination of Life on Request and Assisted Suicide Act, ch. II art. 2 § 1(a).

[173] *Id.* at § 1(b).

[174] *Id.* at § 1(e).

[175] Termination of Life on Request and Assisted Suicide Act, ch. II art. 2 § 2; Barbuzzi, *supra* note 147, at 18–19; Lewis & Black, *supra* note 171 at 885.

Minors ages twelve to sixteen years old may request physician-assisted suicide if they meet the same requirements set forth for adults and their guardians or parents agree to the request.[176] Patients who are sixteen to eighteen years old, can make a request for physician-assisted suicide, and are only required to have their guardians or parents "involved in the decision process."[177] The requirement that the guardians or parents be involved is ambiguous because "[it] is unclear from the Act at which stage parental or guardian involvement must occur—that is, whether the minor may make the request for assistance to die independent of their involvement."[178]

VI. AUTONOMY IN PATIENT'S CHOICES

Regardless of where this issue is being discussed, autonomy is a key component to the debate on allowing physician-assisted suicide.[179] Autonomy centers on the ability of patients to determine their fates regarding private matters that involve their own welfare.[180] The focus on autonomy regarding medical decisions in the U.S. began with the 1990 Patient Self-Determination Act,[181] when institutions reimbursed by Medicare were required to inform patients of their right to actively participate in medical decisions and the right to complete advance directives.[182] Advance directives are

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[176] Termination of Life on Request and Assisted Suicide Act, ch. II art. 2 § 4; Lewis & Black, *supra* note 171, at 886.
[177] Termination of Life on Request and Assisted Suicide Act, ch. II art. 2 § 3; Lewis & Black, *supra* note 171, at 886.
[178] Lewis & Black, *supra* note 171, at 886.
[179] Anne Marie Su, *Physician Assisted Suicide: Debunking The Myths Surrounding the Elderly, Poor, and Disabled*, 10 HASTINGS RACE POVERTY L.J. 145, 146, 171 (2013); *see also* BARRY ROSENFELD, ASSISTED SUICIDE AND THE RIGHT TO DIE: THE INTERFACE OF SOCIAL SCIENCE, PUBLIC POLICY, AND MEDICAL ETHICS 9, 44 (2004).
[180] Thomas Preston et al., *The Role of Autonomy in Choosing Physician Aid in Dying*, in PHYSICIAN-ASSISTED DYING: THE CASE FOR PALLIATIVE CARE AND PATIENT CHOICE, 39 (2004); *see also*, RONALD DWORKIN, LIFE'S DOMINION: AN ARGUMENT ABOUT ABORTION, EUTHANASIA, AND INDIVIDUAL FREEDOM 190 (1993); Dan W. Brock, *Voluntary Active Euthanasia*, in LIFE AND DEATH: PHILOSOPHICAL ESSAYS IN BIOMEDICAL ETHICS 202, 205–06 (1993).
[181] 42 U.S.C. §§ 1395cc(f), 1396a(w) (2012).
[182] ROSENFIELD, *supra* note 179, at 44.

designed to allow a patient autonomy in end of life decision-making, but they are only implicated when a patient no longer has the capacity to make choices about his or her own health care.[183] A terminally ill patient with capacity cannot rely on a health care surrogate or living will to take effect because advance directives are triggered when incapacity is determined.[184] Surrogate decision making in advance directives is based on a best-interest standard.[185] An appointed surrogate makes the decision of what is in the best interest of the patient once the patient is no longer able to make his or her own medical decisions.[186] Yet patients are able to make an informed choice of what is in the best interest of their care but they are not allowed to choose to end their suffering on their own terms.[187]

The top three most frequently mentioned end-of-life concerns to patients participating in physician-assisted suicide are loss of autonomy, decreasing ability to participate in activities that made life enjoyable, and loss of dignity.[188] Although medication and technology allow terminally ill patients to maintain their autonomy longer, they do not have the same quality of life near the end of their lives.[189] Terminally ill patients who choose to hasten their death are "logical when faced with the fact that certain diseases are incurable and certain suffering is irresolvable."[190] Their choice is not a choice between life and death; it is a choice between "a slow, agonizing

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[183] *Id.* at 42.
[184] *See Living Wills, Health Care Proxies, and Advance Health Care Directives*, ABA, http://www.americanbar.org/groups/real_property_trust_estate/resources/estate_planning/living_wills_health_care_proxies_advance_health_care_directives.html (last visited Oct. 26, 2016) (explaining health care surrogates and living wills and explaining that they are tools to be used when a person does not have capacity).
[185] ROSENFIELD, *supra* note 179, at 56.
[186] *Id.*
[187] KEOWN, *supra* note 19, at 66–68.
[188] Or. Health Auth., *supra* note 15, at 2; Loggers et al., *supra* note 14, at 1422 tbl. 3.
[189] ROSENFELD, *supra* note 179, at 23; Su, *supra* note 179, at 147; *see also* Robert Pear, *Researchers Find Huge Variations in End of Life Treatment*, N.Y. TIMES, Apr. 7, 2008, http://www.nytimes.com/2008/04/07/health/policy/07care.html.
[190] ROSENFELD, *supra* note 179, at 9; Su, *supra* note 179, at 147.

death and a quick, merciful one."[191] The unfortunate reality of palliative care is that it can only do so much for the patient, but often times is not able to offer complete pain relief.[192] Many terminally ill patients are justified in fearing pain and worrying that their pain will not be adequately managed.[193]

Criticism to the autonomy argument asserts that no terminally ill patient can have true autonomy.[194] Those against physician-assisted suicide argue that patients are subject to influences from family, friends, and caregivers.[195] However, all patients making major health care decisions are subject to these same influences, whether it be emergency surgery, hospice care, do not resuscitate orders, or the withdrawal of life support.[196]

The idea of autonomy in physician-assisted suicide should be set at the same reasonable standard that is required for "informed consent by patients who refuse life-sustaining medical treatment or ask that such treatment is withdrawn."[197] Most patients consult their spouse, children, friends or trusted advisors before making any major decisions or completing advance directives.[198] This consultation of loved ones does not mean that patients have lost their autonomy; it means that they have discussed their choices with family members and explained their stance on the issue.[199] Asking that the patient make a decision based on "perfect understanding of all possible details" or one "completely free from all potentially

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[191] Marcia Angell, *The Quality of Mercy*, in PHYSICIAN-ASSISTED DYING: THE CASE FOR PALLIATIVE CARE AND PATIENT CHOICE 15, 21 (2004).
[192] Su, *supra* note 179, at 169; *see also* Dan W. Brock, *Physician Suicide as a Last-Resort Option at the End of Life*, in PHYSICIAN-ASSISTED DYING: THE CASE FOR PALLIATIVE CARE AND PATIENT CHOICE 130 (2004).
[193] ROSENFELD, *supra* note 179, at 95–96; Su, *supra* note 179, at 147.
[194] Preston et al., *supra* note 180, at 42; *see* Barbara Secker, *The Appearance of Kant's Deontology in Contemporary Kantianism: Concepts of Patient Autonomy in Bioethics*, 24 J. MED & PHIL. 43, 49–51 (1999).
[195] Preston et al., *supra* note 180, at 42.
[196] *Id.*
[197] *Id.* at 43.
[198] *Id.*
[199] *Id.*

coercive influences" is unrealistic as no human choice is completely free of outside influence.[200] However, requiring that the patient be free from mental illness or coercion that would undermine his or her ability to make a sound choice is a reasonable standard to impose.[201]

VII. CONCLUSION

Stated simply, physician-assisted suicide is a multifaceted issue with equally passionate supporters and protestors. It all boils down to the ability for a terminally ill individual, who still has capacity to make health care decisions, to make a choice. This choice is founded on autonomy, which for many patients with a terminal illness, is one of the few traits they have left from the self they once were. Rather than making the patient waste away in a hospital bed, another option is available. An option that would conclude the person's life in a dignified manor rather than allow a disease to completely take everything the person was during his or her lifetime. Physician-assisted suicide is not the only option for a terminally ill patient, but it is an option that the patient should have the opportunity to consider.

[200] *Id.*
[201] *Id.*

HOARDING AND THE ELDERLY: THE DANGER HIDDEN BEHIND CLOSED DOORS

Hannah M. Tyson*

I. INTRODUCTION

Janet is an elderly mother of nine who lives alone in Michigan. Most people only see Janet at church because hardly anyone comes to her home.[1] Many of Janet's children have not visited her in years, so they are unaware of the condition that their mother, or her home are in. Janet only agreed to a cleanup of her home because her one of her daughters, who visits the home most regularly, threatened to call Adult Protective Services if Janet did not begin cleaning up the mountains of garbage consuming the home.

Janet's home has not had heat or working plumbing for two years. Living in Michigan without heat, Janet often uses as many as seven blankets to keep warm. Janet sleeps in a recliner, but when you walk into her home you can barely see her nestled in the chair because it is nearly engulfed by belongings that cover every inch of the floor. To get into this "bed," Janet must use her cane to ascend the mountain of possessions she has spent decades accumulating. And what makes up this so-called hoard? Half-eaten food,

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[1] *Hoarders: Phyllis/Janet* (A&E television broadcast June 20, 2011), *available at* http://www.amazon.com/gp/product/B00AVAYO5Q/ref=atv_terms_dp.

documents dating back to the nineties, soiled diapers, countless jars full of urine, and even plastic bags filled with bowel movements. In some places of Janet's home, the piles of rotting food, human excrement, and trash are so high that if a person stands on one, he or she will be taller than the ceiling fan. Since Janet does not have working plumbing, she normally goes to the bathroom outside by the side of her house, but there are times she cannot make it outside because of having to climb through the hoard.

Janet is literally living in her own filth. To make matters worse, Janet has congenital heart failure and living in this environment makes her medical condition even more severe. Due to the unsanitary conditions during the cleanup, the workers all wore masks and protective gloves in order to be able to work in the home. Throughout the cleanup process, Janet often became angry when told she had to throw away certain items because she "never felt good about wasting things."[2]

A cleanup expert estimated that the dump trucks filled with the hoarded possessions cleaned out of Janet's home weighed between 7,500 and 10,000 pounds. Nearly everything was thrown away during the cleanup because barely anything was salvageable as it had either expired or was unsanitary due to the exposure to feces. A lifetime of memories and countless dollars were hauled away in those dump trucks, and if Janet fails to control her hoarding, one day the disorder could take her life.[3]

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[2] *Id.*

[3] The narrative about Janet is largely based on the hoarding situation of Janet featured in Season 4, Episode 1 of A&E's *Hoarders. Id.* Although the hoarding scenario of Janet depicts what many hoarders' homes may look like, just like every person is different, so are cases of hoarding. *See, e.g.*, Karen Longwell, *"Hoarding Situation" Complicated 2011 Baltimore Fire*, NORTHUMBERLAND NEWS (Apr. 3, 2014), http://www.northumberlandnews.com/news-story/4444193--hoarding-situation-complicated-2011-baltimore-fire/ (a hoarding situation in an apartment in Baltimore, Maryland complicated firefighters' ability to fight the blaze and prevent it from spreading to the apartment unit next-door); Andrea Lucia, *67-Year-Old Hoarder Dead; Dog Rescued*, CBS DFW (Mar. 27, 2014), http://dfw.cbslocal.com/2014/03/27/67-year-old-hoarder-dead-dog-rescued/ (reported missing by friends, a 67-year-old man was found dead in his Dallas, Texas home when officials were forced to cut a hole through the roof to access the home to search for him after unsuccessful attempts by firefighters to push their way through a ten foot wall of trash); David McCormack, *Wealthy Hoarder Who Filled His Manhattan Apartment with*

Janet is not alone in her struggle with hoarding; an estimated six to fifteen million people in America hoard, however, the elderly are more likely to hoard than younger age groups.[4] Additionally, studies have shown hoarding is much more prevalent in the population than OCD, with a 5% occurrence (weighted for population, the community sample was nearly 4%).[5] Further results indicate that hoarding is more than twice as prevalent in older age groups (55–94) than younger age groups (34–44, 45–54).[6] The statistic of 6.2% prevalence in age group 55–94 was nearly three times as high as the youngest age group; therefore, this study supports the conclusion that hoarding is of particular concern to the

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So Much Junk He Has to Climb Through the Fire Escape to Get In Is Told to Clean Up or Get Out, DAILY MAIL, http://www.dailymail.co.uk/news/article-2578384/Hoarding-trust-fund-son-famed-Hollywood-couple-told-clean-Manhattan-apartment.html (last updated Mar. 11, 2014) (the son of Hollywood Walk of Fame stars living on a trust fund from his parents' estate, who was even featured in an October 2011 episode of *Hoarders*, once again faces eviction from his Manhattan Upper East Side apartment); Associated Press, *Man Who Hoarded Snakes in Orange County Home Charged*, THE MERCURY NEWS (Mar. 14, 2014), http://www.mercurynews.com/california/ci_25346472/man-who-hoarded-snakes-orange-county-home-charged (a California teacher arrested on January 29, 2014, for hoarding more than 400 snakes, of which 240 were dead, in his Orange County, California home was charged with felony animal abuse); Sadie Whitelocks, '*The Stench is Amazing': Three Hoarder Brothers Live Among Mice, Rats and Hundreds of Cockroaches After Two Decades of Compulsive Hoarding*, DAILY MAIL (Mar. 26, 2014), http://www.dailymail.co.uk/femail/article-2589838/The-stench-amazing-Three-hoarder-brothers-live-mice-rats-hundreds-cockroaches-two-decades-compulsive-collecting.html (three senior brothers were featured on *Hoarding: Buried Alive*, in which even the exterminators called the 1,100 square foot home one of the worst hoarding situations they have ever seen and that they "felt physically ill just being in there").

[4] Jack F. Samuels et al., *Prevalence and Correlates of Hoarding Behavior in A Community-Based Sample*, 46 BEHAV. RES. & THERAPY 836, 839–42 (2008). Statistics found regarding the prevalence of hoarding in different age groups were based on 742 participants in the Hopkins Epidemiology of Personality Disorder Study conducted between 1997 and 1999. *Id.* at 837. At the time of the study, hoarding was still considered part of Obsessive-Compulsive Disorder (OCD), as specified in DSM-IV. *Id.* at 838. Interviewers ask participants questions such as "Do you find it almost impossible to throw out worn-out or worthless things? If so, is that true even when they don't have any sentimental value? Give me some examples. Is this a problem for you or for others? If so, tell me about it." *Id.* It was also encouraged for interviews to "cross-examine" the participants in order to determine the presence of the behavior. Prior to this study, prevalence of hoarding was estimated at only 0.4% based on the known population prevalence of OCD and the proportion of OCD cases with hoarding. *Id.* at 841–42.

[5] *Id.*

[6] *Id.*at 839–40.

elderly.[7] Nationally[8], and even internationally,[9] news reports of hoarding occur daily, but if this many are being reported, how many hoarding situations go unreported? Moreover, is there anything that can be done to address this disorder that becomes more prevalent each year?

Headlines about hoarding can make a person cringe and wonder, "how can someone live like that?" Is the entertainment aspect of hoarding part of the problem instead of the solution? Hoarding has become part of mainstream media through shows such as *Hoarders*[10] and *Hoarding: Buried Alive,*[11] but what about the hoarders? Instead of merely depicting a hoarder's life on television, is there more that can be done to help a hoarder who often does not realize he or she has a problem?[12] Just as other disorders or medical

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[7] *Id.*

[8] The following headlines are just a small sample of reports of hoarding provided through Google Alerts from March 2014. *See, e.g.*, Bruce Jancin, *Hoarding: Not Just a Symptom of OCD*, CLINICAL PSYCHIATRY NEWS DIGITAL NETWORK (Mar. 24, 2014), http://www.clinicalpsychiatrynews.com/specialty-focus/bipolar-disorder/single-article-page/hoarding-not-just-a-symptom-of-ocd/36f736e41301cff373449d5b906b4964.html; Kenneth Hart, *Participants Needed for Study*, THE DAILY INDEPENDENT (Mar. 22, 2014), http://www.dailyindependent.com/local/x787228080/Participants-needed-for-study (a clinical psychology doctoral candidate seeking participants for his dissertation study on compulsive hoarding).

[9] For instance, in Bondi, Australia, an infamous hoarding family, the Bobolas, were ordered by the Land and Environment Court to have workers begin the 5-day cleanup process on April 11, 2014. Leigh Van Den Broeke, *Hoarders' Yard Clear-Out Will Take Five Days As Council Set to Send in Contractors on Friday*, THE DAILY TELEGRAPH (Apr. 8, 2014, 3:52 PM), http://www.dailytelegraph.com.au/news/hoarders-yard-clearout-will-take-five-days-as-council-set-to-send-in-contractors-on-friday/story-fni0cx4q-1226877974078. It is estimated that the forced cleanups, of which the next will be the fourteenth, have cost ratepayers more than $350,000 and the amount of rubbish is estimated to be large enough to fill an Olympic sized swimming pool. *Id.* In the Greater Victoria area of Victoria, British Columbia, it is estimated that there are about 11,000 homes with hoarding problems. Victoria Island Health Authority, *Hoarding*, VICTORIA ISLAND HEALTH AUTHORITY, http://www.viha.ca/health_info/hoarding.htm (last visited June 25, 2016). In 2012, Hoarding Education & Action Team (HEAT) was founded to help hoarders in Greater Victoria. *Id.*

[10] *Hoarders* (A&E television series 2009–2013).

[11] *Hoarding: Buried Alive* (TLC television series 2010–2014).

[12] *See, e.g.*, Andy Heger, *The Rise of Compulsive Hoarding*, HEALTH LEADER, http://www.uthealthleader.org/index/article.htm?id=7296b67d-7f16-4f39-b1bf-defde8d8ff96 (last updated Sept. 12, 2012) (discussing comments from Erica Bruce, LCSW, a senior clinical social worker in the Department of Psychiatry & Behavioral Services at the University of Texas Health Medical School: "Most people realize they have a problem, but some heavily defend their actions. Sometimes it takes family members, protective services or some other agency's involvement to prompt the intervention. . . . It may even require confronting the person who hoards, since their behavior is similar to someone with an addiction issue who remains in denial."); Samuels et al.,

conditions can affect different people in different ways, so can hoarding. Of particular concern is hoarding by elders because of the dangerous and sometimes deadly combination of the over-accumulation of items and common characteristics of aging, such as decreased mobility,[13] memory loss,[14] and compromised immune systems.[15]

Hoarding should be an international concern because of the ever-increasing population of elders, which includes the first wave of the baby boomer generation turning 65 in 2011.[16] This Article suggests that with the constantly growing population of elders, the increased prevalence of hoarding by elders, and the increased dangers hoarding poses to elders, international legislatures should amend their adult protective statutory definitions of elder abuse and neglect to specifically enumerate hoarding as a form of self-neglect

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supra note 4 (Johns Hopkins study showing hoarding behavior is more prevalent among older adults and existence of hoarding is far greater than the previously estimated prevalence of 0.4% based on the presence of hoarding in people diagnosed with OCD).

[13] Admin. on Aging, *A Profile of Older Americans: 2012*, DEP'T OF HEALTH & HUMAN SERVS. (Apr. 10, 2013), http://www.aoa.gov/Aging_Statistics/Profile/2012/docs/2012profile.pdf. "Some type of disability (i.e., difficulty in hearing, vision, cognition, ambulation, self-care, or independent living) was reported by thirty-five percent of men and thirty-eight percent of women age 65+ in 2011. Some of these disabilities may be relatively minor but others cause people to require assistance to meet important personal needs." *Id.*

[14] Elizabeth Andersen et al., *Reasons to Accumulate Excess: Older Adults Who Hoard Possessions*, 27 HOME HEALTH CARE SERVICES QUARTERLY 187, 189 (2008) (citing J. P. Hwang et al., *Hoarding Behavior in Dementia: A Preliminary Report*, 6 AM. J. GERIATRIC PSYCHIATRY 285, 285–89 (1998), which found 22.6% of dementia patients showed hoarding behaviors). Compulsive hoarding is a recognized feature of dementia. Approximately twenty percent of people with dementia exhibit hoarding behavior. Henriette Kellum, *Hoarding Behavior in the Elderly*, 27 AGE IN ACTION, Summer 2012 at 1, 2 (citing J. P. Hwang et al., *Hoarding Behavior in Dementia: A Preliminary Report*, 6 AM. J. GERIATRIC PSYCHIATRY 285, 285–89 (1998), which found 22.6% of dementia patients showed hoarding behaviors).

[15] Kathy Turner et al., *Treating Elders with Compulsive Hoarding*, 17 COGNITIVE & BEHAV. PRAC. 449, 449 (2010) (discussing Randy O. Frost et al., *Hoarding: A Community Health Problem*, 8 HEALTH & SOCIAL CARE IN THE COMMUNITY 229, 229 (2000)). "Severe hoarding can be especially dangerous for elders at risk for falling and those with chronic health conditions like emphysema because of dust and other allergens, as well as insect and rodent infestation." Turner et al., *supra* note 15.

[16] *See generally* Sandra Colby & Jennifer Ortman, *The Baby Boom Cohort in the United States: 2012 to 2060*, UNITED STATES CENSUS BUREAU (May 2014), https://www.census.gov/prod/2014pubs/p25-1141.pdf; *The Canadian Population in 2011: Age and Sex*, STATISTICS CANADA 5 (May 2012), http://www12.statcan.gc.ca/census-recensement/2011/as-sa/98-311-x/98-311-x2011001-eng.pdf.

that is mandatory to report. In amending their statutory definitions of elder neglect,[17] other legislatures should follow Illinois's statute, which specifically includes hoarding as a form of self-neglect[18] and as a result triggers the provision of services to those in need.[19]

To demonstrate the need for legislatures around the world to address the issue of hoarding by elders, Part II will discuss what hoarding is, who hoarders are, what can be hoarded, and the dangerous effects of hoarding. Part III will provide information regarding the history of the elderly population, statutory regulations of elder abuse, and statistics regarding elder abuse in the United States, Canada, South Africa, Australia, New Zealand, and the United Kingdom. Part IV will provide other international examples of hoarding reported in the news and additional self-neglect and hoarding statistics regarding elders. It will also discuss Illinois's Adult Protective Services statute, and explain in-depth why international legislatures should follow Illinois's guidance and amend their Adult Protective Services[20] statutes to specifically enumerate hoarding as a form of self-neglect. Part V will provide a conclusion and reinforce the importance of legislatures updating their Adult Protective Services statutes to require hoarding as a form of self-neglect that is mandatory to report, similar to abuse, neglect, and exploitation.

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[17] FLA. STAT. § 415.102 (16).

[18] *See* 320 ILL. COMP. STAT. 20/2 (i-5); *infra* note 189 and accompanying text (providing Illinois's definition of self-neglect and explaining change from previous version of statute).

[19] *See* 320 ILL. COMP. STAT. 20/2 (i-5). Although the provision of services can infringe upon a person's autonomy, this Article does not focus on such implications. Instead, the focus of this Article is that there is proof that hoarding by the elderly is a significant concern as it occurs worldwide, yet legislatures are behind in updating statutory definitions of neglect/self-neglect to include compulsive hoarding as a form of self-neglect that in certain circumstances should trigger the provision of assistive services.

[20] Not all countries categorize their statute and provision of services for adults in need as Adult Protective Services, but the term is being used to provide consistency and also because in the U.S. Adult Protective Services is a term of common knowledge.

II. WHY DOES HOARDING MATTER?

Unlike other mental disorders such as Obsessive-Compulsive Disorder (OCD),[21] hoarding has only recently been studied and recognized as a distinct mental disorder.[22] Although the American public knew the story of the Collyer brothers in 1947,[23] hoarding became a common term largely due to shows such as *Hoarders*[24] and *Hoarding: Buried Alive*.[25] Although hoarding is now a well-known term, the first systemic study of hoarding was published just two decades ago in 1993.[26] Studies on the prevalence of hoarding are limited.[27] This is mostly because hoarding is considered a "hidden" disease where many cases go unreported due to the hoarders living alone or only socializing outside of the home.[28]

Hoarding can also pose health risks,[29] especially depending on what constitutes the hoard. For instance, is the hoarder living in his or her own filth, surrounded by soiled diapers, decaying animals, and rotted food? Sadly, in some hoarding situations, that is the case,

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[21] *About OCD*, STANFORD SCHOOL OF MEDICINE, http://ocd.stanford.edu/about/ (last visited June 25, 2016). "Obsessive-compulsive disorder (OCD) was described as early as the seventeenth century . . . Modern concepts of OCD began to evolve in France and Germany in the nineteenth century. In the late twentieth century we have begun to understand the biology of this mental disorder" as both knowledge and technology have improved. *Id.*; *see also infra* notes 63–65 and accompanying text regarding the Collyer brothers.

[22] *See infra* notes 35–39 (hoarding disorder is included in DSM-V, which was published in 2013).

[23] RANDY O. FROST & GAIL STEKETEE, STUFF: COMPULSIVE HOARDING AND THE MEANING OF THINGS 1–9 (2011).

[24] *Hoarders*, *supra* note 10.

[25] *Hoarding: Buried Alive*, *supra* note 11.

[26] Randy O. Frost & Rachel C. Gross, *The Hoarding of Possessions*, 31 BEHAV. RES. & THERAPY 367 (1993).

[27] Randy O. Frost et al., *Hoarding: A Community Health Problem*, 8 HEALTH & SOCIAL CARE IN THE COMMUNITY 229, 229–234 (2000).

[28] Interview with Amanda Medley Raines, Assistant Dir. of Anxiety and Behavioral Health Clinic at Florida State Univ., in Tallahassee, Florida (Feb. 26, 2014) (notes on file with Author); FROST & STEKETEE, *supra* note 23, at 11.

[29] For instance, see *infra* notes 82–83 and accompanying text; Jenny Yuen, *Dirty Secret: Toronto Hoarders Comes Clean*, SAULT STAR, (Aug. 2, 2014), http://www.saultstar.com/2014/08/02/dirty-secret-toronto-hoarder-comes-clean (explaining that "[i]nfestations of vermin and mold are common in hoarding cases and it quickly becomes a health and safety issue").

and the hoarder fails to realize the severity of the condition or the serious threat it poses to his or her life.[30] What about the hoarder who already has a compromised immune system due to other health conditions such as COPD? And how safe can a hoarder be when living in a house with an ammonia smell from cat urine that is so strong to put the animals' lives at risk?[31]

To truly understand why hoarding should be included in Adult Protective Services[32] statutes as a form of self-neglect,[33] not only should the prevalence of hoarding be addressed, but the dangers posed by the disease must also be considered. But what exactly is hoarding? Does spending all your money on fancy clothes and expensive jewelry constitute hoarding? Collecting thousands of beer cans, dolls, or other trinkets? Having twenty cats, or wait, is it twenty-one? Many people say they are "collectors"[34] but when does

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[30] *See infra* note 167 and accompanying text.

[31] *Hoarders: Terry/Adelle* (A&E television broadcast Dec. 3, 2012) (describing "Terry's fridge is packed with dead cats, and she has another fifty live ones. Her son thinks her problems stem from the time her father died of a heart attack right in front of her she was just a small child."); Rich Juzwiak, *The Most Disgusting Episode of* Hoarders, *or Any Show Ever, Probably, Aired Last Night*, GAWKER (Dec. 4, 2012), http://gawker.com/5965617/the-most-disgusting-episode-of-hoarders-or-any-show-ever-probably-aired-last-night (reacting to the episode, the columnist called Terry "the cat lady to end all cat ladies," and pointed out that only eighteen of the forty-nine cats living with Terry were healthy enough to be saved, that the "house had enough ammonia smell to make a kitten's eyes pop out" and that Terry kept dozens of dead animal carcasses in her fridge in hopes of getting them stuffed one day). A partially liquefied cat stored in a freezer bag in her closet was also found. *Id.* Terry estimated the number of frozen and refrigerated cats to be between seventy-five and hundred, and throughout the cleanup process Terry broke down several times and seemed to realize the severity of her hoarding problem. Ree Hines, *'Hoarders' Horror: Woman Has Nearly 100 Dead Cats in Refrigerator*, TODAY (Dec. 4, 2012), http://www.today.com/entertainment/hoarders-horror-woman-has-nearly-100-dead-cats-refrigerator-1C7421024. Terry even said, "I can't even say anymore that I love animals 'cause I treated them so horrible." *Id.*

[32] It should be noted that other countries do not necessarily use the same term "Adult Protective Services," but the general idea of providing protection for elder abuse and neglect is the same.

[33] *See infra* notes 120–134 and accompanying text (explaining that state statutes vary, and although the term self-neglect is neither used nor defined within the definitions section of Florida's Adult Protective Services statute, the concept of self-neglect is incorporated within the provided definition of neglect).

[34] Collecting many possessions does not automatically equate to hoarding. Int'l OCD Foundation, *What Is Hoarding, and How Does It Differ from Collecting?* INTERNATIONAL OCD FOUNDATION, http://208.88.128.33/hoarding/about.aspx (last visited July 9, 2016). Hoarding is typically characterized by difficulty discarding possessions no longer needed as well as acquiring too many possessions. *Id.* Once a "collection" leads to so much disorganization and clutter that it affects a person's health or safety, or leads to distress, then it is considered a hoarding disorder. *Id.* Collectors are usually well organized, proudly displays the collection, and items typically differ to create an

the hobby of collecting knickknacks cross the line to be categorized as the mental disease of hoarding? Due to the severe consequences hoarding can have on the elderly and the lack of recognition as to the severity, international communities must amend their Adult Protective Services statutes to include hoarding as a form of self-neglect.

A. What Is Hoarding?

Even though the cause of and treatment for hoarding is not clear-cut, the latest edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*[35] includes "hoarding disorder" as a distinct disorder.[36] Researchers and hoarding treatment professionals involved with hoarding are hopeful that the inclusion of hoarding as a disorder in *DSM-5* will provide better access to treatment for those affected by hoarding since certain therapies may now be covered by insurance, and more research will be done on the disorder.[37] As described in *DSM-5*:

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interesting, and sometimes valuable collection. *Id.* On the other hand, major features of hoarding include blocked exits, difficulty moving around the home, and rooms can no longer be used. *Id.*

[35] AM. PSYCHIATRIC ASS'N, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS (DMS-V), (5th ed., American Psychiatric Publishing). "*Diagnostic and Statistical Manual of Mental Disorders (DSM)* is the standard classification of mental disorders used by mental health professionals in the United States and contains a listing of diagnostic criteria for every psychiatric disorder recognized by the U.S. healthcare system." *Id.* The *DSM* has been used by a wide array of professionals, including psychiatrists, physicians, social workers, nurses, psychologists, and occupational and rehabilitation therapists. *Id.* In 2009, the initial DSM-5 Research Planning Conference convened, and the final approved *DSM-5* was released in May 2013. American Psychiatric Association, *DSM-5 Overview: The Future Manual*, DSM5, http://www.dsm5.org/about/Pages/DSMVOverview.aspx (last visited June 25, 2016).

[36] Am. Psychiatric Publ'g, *Obsessive Compulsive and Related Disorders*, AM. PSYCHIATRIC ASS'N DSM-5 DEV., http://www.dsm5.org/Documents/Obsessive%20Compulsive%20Disorders%20Fact%20Sheet.pdf (last visited June 25, 2016). Prior to *DSM-5*, individuals displaying hoarding behaviors were often diagnosed with "obsessive-compulsive disorder (OCD), obsessive-compulsive personality disorder, anxiety disorder not otherwise specified or no diagnosis at all, since many severe cases of hoarding are not accompanied by obsessive or compulsive behavior." *Id.*

[37] *See, e.g.*, Interview with Amanda Medley Raines, *supra* note 28; Interview with Charles P. Golbert, Deputy Public Guardian, Office of the Cook County Public Guardian (Mar. 10, 2014); Christine Roberts, *Hoarding to Receive New Clinical Definition by the Psychiatric Association 'Bible'*, NY DAILY NEWS (Dec. 12, 2014), http://www.nydailynews.com/life-style/health/hoarding-receive-new-clinical-definition-psychiatric-association-bible-article-1.1216495 (discussing quotes

> Hoarding disorder is characterized by the persistent difficulty discarding or parting with possessions, regardless of the value others may attribute to these possessions. The behavior usually has harmful effects—emotional, physical, social, financial, and even legal—for the person suffering from the disorder and family members. For individuals who hoard, the quantity of their collected items sets them apart from people with normal collecting behaviors. They accumulate a large number of possessions that often fill up or clutter active living areas of the home or workplace to the extent that their intended use is no longer possible.[38]

Although definitions of hoarding may vary slightly, they generally focus on the difficulty of discarding possessions, the attachment of value to possessions, and the harmful effects keeping the possessions has on a person.[39] For hoarders, the problem is not just the attachment of value to objects; the problem is that the over-accumulation of objects begins to negatively affect their lives.[40]

Hoarders often have a fear of waste, and instead of throwing items away they accumulate items that are not necessary.[41] When does a collector cross the line and become a hoarder? There are a few key differences between hoarders and collectors, one being that hoarders rarely seek to display their possessions, while collectors

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from Randy O. Frost, "We don't know yet whether there are medications that might be useful for this. . . . But that's one of the things that will happen now that it's in the DSM. There will be an interest in researching this.").

[38] *See, e.g.*, Am. Psychiatric Publ'g, *supra* note 36.

[39] For instance, hoarding has also been defined as "(a) the acquisition of, and failure to discard, a large number of possession; (b) living spaces sufficiently cluttered as to preclude activities for which those spaces are designed; and (c) significant distress or impairment in functioning caused by hoarding." Randy O. Frost, *Special Series: Hoarding, Introduction*, 17 COGNITIVE & BEHAV. PRAC. 401, 401 (2010). The Mayo Clinic maintains the same main principles, but uses a shorter definition for hoarding: "persistent difficulty discarding or parting with possessions because of a perceived need to save them." Mayo Clinic, *Hoarding-Definition*, MAYO CLINIC, http://www.mayoclinic.org/diseases-conditions/hoarding-disorder/basics/definition/con-20031337?reDate=11062016 (last visited June 25, 2016).

[40] FROST & STEKETEE, *supra* note 23, at 11–15.

[41] *Id.*

proudly display their collections.[42] Hoarders also typically do not organize their possessions, while collectors keep their collections well organized.[43] A person who starts as a collector may one day become a hoarder because of the negative impact the collection begins to have on his or her life. For instance, one man was not a hoarder when he first began collecting beer cans, but when his "collection" reached nearly fifty thousand cans, a specific garage had to be built to store some of the cans, and his ability to move around his home became limited due to the massive amount of cans throughout it, he was then considered a hoarder.[44] However, hoarding does not only affect a person's mobility within the home, it can also affect a person's financial stability. The beer can collector who became a hoarder spent nearly half a million dollars amassing his collection over the years; he is on the verge of bankruptcy, struggling with the reality that he must sell his collection in order to live.[45] Further, although it is clear that hoarding poses dangers,[46] research has not determined a definitive cause of hoarding.[47] Due to the difficulty of determining the cause of hoarding, establishing the best course of treatment has also been a challenge, although cognitive behavioral therapy and similar treatments for OCD have been employed with some success.[48]

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[42] Int'l OCD Found., *Hoarding Fact Sheet*, INT'L OCD FOUND., https://iocdf.org/wp-content/uploads/
2014/10/Hoarding-Fact-Sheet.pdf (last visited June 25, 2016).
[43] *Id.;* FROST & STEKETEE, *supra* note 23, at 11.
[44] *Hoarders: Bob/Richard* (A&E television broadcast Dec. 22, 2009), *available at* http://www.aetv.com/hoarders/video/bob-richard (in this episode, Richard collected so many beer cans and other items that he was on the verge of bankruptcy).
[45] *Id.* Richard's family was also concerned about Richard's health and whether he would be able to afford medication. *Id.* Family said that Richard was always willing to help others, but now it was time for him to help himself. *Id.*
[46] *See supra* notes 1–3; *infra* notes 79–94 and accompanying text.
[47] Andersen et al., *supra* note 14 (hoarding occurs in twenty to thirty percent of people with OCD, and is also observed in people with anorexia nervosa, psychotic disorders, depression, and organic mental disorders). As much as eighty percent of people who hoard grew up with a family member who also hoards. Kellum, *supra* note 14, at 2. Research has also shown a positive correlation between a unique chromosome 14 pattern and hoarding behavior. *Id.*
[48] John E. Calamari, et al., *Obsessive-Compulsive Disorder in Late Life*, 19 COGNITIVE & BEHAV. PRAC. 136, 138–47 (2012); Turner et al., *supra* note 15, at 449.

B. Who Are Hoarders?

Hoarding is estimated to affect anywhere from two to five percent of the U.S. population,[49] meaning that between six million and fifteen million Americans suffer from the disorder.[50] Hoarding was once only considered a small subset of OCD.[51] with estimates that OCD affects one percent of the U.S. population[52] or 3.16 million Americans,[53] which would mean hoarding affects even less than 1% of the U.S. population. However, recent studies show that hoarding is far more prevalent than OCD.[54]

Hoarding is also prevalent in other countries, although research indicates the majority of studies on hoarding have been conducted in the United States. For instance, it is estimated that one

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[49] *See, e.g.*, Am. Psychiatric Publ'g, *supra* note 36; Interview with Amanda Medley Raines, *supra* note 28; American Psychiatric Association, *Hoarding Disorder,* AM. PSYCHIATRIC ASS'N, http://www.psychiatry.org/hoarding-disorder (last visited June 25, 2016); Roberts, *supra* note 37 (discussing comments from Randy Frost, a Smith College professor of psychology and one of the first to research hoarding, that as many as 15 million people may suffer from hoarding disorder); Christopher Frank & Brian Misiaszek, *Approach to Hoarding in Family Medicine*, 58 CAN. FAM. PHYSICIAN 1087, 1088 (Oct. 2012) (citing David F. Tolin, *Understanding and Treating Hoarding: A Biophyschosocial Perspective*, 67 J. CLINICAL PSYCHOLOGY 517–26 (2011)).

[50] These estimates were calculated using the United States Census Bureau's 2013 population figures. U.S. Census Bureau, *State & Country QuickFacts—USA*, U.S. CENSUS BUREAU, http://quickfacts.census.gov/qfd/states/00000.html (last updated Mar. 27, 2014) The U.S. Census Bureau estimates the 2013 United States population at 316,128,839, which equates to approximately six million to fifteen million people in the United States being affected by hoarding. *See also* Roberts, *supra* note 37 (citing hoarding expert Randy Frost estimated number of hoarders being as high as fifteen million people).

[51] *See, e.g.*, Samuels et al., *supra* note 4; Int'l OCD Found., *supra* note 34 (an estimated "1 in 5 people with hoarding problems report significant OCD symptoms like checking or cleaning rituals).

[52] *See, e.g.*, Int'l OCD Found., *Who Gets OCD?*, https://iocdf.org/about-ocd/who-gets-ocd/ (last visited Nov. 11, 2016); National Institute of Mental Health, *Obsessive Compulsive Disorder Among Adults*, NAT'L INST. OF MENTAL HEALTH, http://www.nimh.nih.gov/statistics/1ocd_adult.shtml (last visited Nov. 11, 2016); Anxiety and Depression Ass'n of Am., *Facts & Statistics*, ANXIETY & DEPRESSION ASS'N OF AM., http://www.adaa.org/about-adaa/press-room/facts-statistics (last visited Nov. 11, 2016).

[53] U.S. Census Bureau, *supra* note 50. Based on the estimated 2013 U.S. population of 316,128,839, extrapolating the statistic that one percent of the population is affected by OCD, Andersen et al., *supra* note 14, means approximately 3.16 million people in the United States have OCD.

[54] *Compare supra* notes 52 (explaining OCD affects approximately 1% of the population) *with infra* notes 55–59 (indicating hoarding disorder exists in up to five percent of national populations) and accompanying text.

to two percent of the populations in South Africa[55] and Australia suffer from hoarding disease.[56] However, because hoarding is often a hidden disorder only reported by family members or friends when forced to do so, therefore, the actual statistics may be much higher.[57] In the United Kingdom, similar to the United States, it is estimated that between two and five percent of the adult population have hoarding disorder symptoms.[58] An estimated 1.75 million Canadians, five percent of the Canadian population, are affected by hoarding disorder.[59]

Unlike other diseases and disorders that may be more common in certain types of people,[60] hoarding does not discriminate based on a person's unique characteristics.[61] Whether rich or poor,

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[55] Helen Grange, *Digging Deeper into Hoarders,* INDEPENDENT ONLINE (Dec. 29, 2011, 4:00 PM), http://www.iol.co.za/lifestyle/home-garden/home/digging-deeper-into-hoarders-1.1205829?ot=inmsa.ArticlePrintPageLayout.ot.

[56] Jeremy Story Carter, *Hoarding Is a 'National Disorder' and Affects 400,000 Australians,* ABC AUSTRALIA (Feb. 11, 2015), http://www.abc.net.au/radionational/programs/rnafternoons/hoarding-a-national-disorder/6086108.

[57] Grange, *supra* note 55.

[58] Nat'l Health Serv., *Hoarding Disorder,* NAT'L HEALTH SERV. (June 19, 2015), http://www.nhs.uk/conditions/hoarding/Pages/Introduction.aspx.

[59] B.C. Ctr. for Elder Advocacy & Support, *Compulsive Hoarding*, BRITISH COLUMBIA CTR. FOR ELDER ADVOCACY & SUPPORT, http://bcceas.ca/getting-help/elder-abuse-and-neglect/compulsive-hoarding/ (last visited June 25, 2016).

[60] *Compare* American Cancer Soc'y, *What Are the Key Statistics About Breast Cancer in Men?,* AM. CANCER SOC'Y, http://www.cancer.org/cancer/breastcancerinmen/detailedguide/breast-cancer-in-men-key-statistics (last updated Jan. 6, 2016) (stating men are about 100 times less like to get breast cancer than women), *with e.g.* Sandra G. Boodman, *The Hoarders Among Us*, AARP (Feb. 4, 2011), http://www.aarp.org/health/conditions-treatments/info-02-2011/the_hoarders_among_us.2.html (citing a Maryland psychologist who heads a hoarding program and is a consultant for a hoarding task force that "[b]oth sexes are equally affected, but women seek more treatment"); Jan Hoffman, *Understanding Hoarding*, N.Y. TIMES (May 26, 2013), http://www.nytimes.com/2013/05/28/health/understanding-hoarding.html ("Men and women suffer in equal numbers.").

[61] As Dr. Robin Barnett, a psychotherapist in New Jersey who has treated more than twenty hoarders over the past twenty years explains, "'Hoarding can affect anyone. . . . It crosses all socioeconomic lines." Cecilia Vega, *Teams Learn to Handle Hoarders with Care as They Clean, Get Them Help,* ABC NEWS (Apr. 1, 2014), http://abcnews.go.com/blogs/lifestyle/2014/04/teams-learn-to-handle-hoarders-with-care-as-they-clean-and-get-them-help/ (Dr. Barnett was quoted in this news story that featured the hoarding home of a retired psychiatrist, showing even the highly educated can be affected by hoarding disorder).

highly educated or uneducated, old or young, anyone can hoard.[62] Take the Collyer brothers for example: the sons of a doctor and an opera singer, both men went onto higher education and studied at Columbia University.[63] Homer Collyer received several law degrees and became an admiralty lawyer, while Langley Collyer studied engineering.[64] In 1947, authorities found both brothers dead in their family home, a brownstone in Manhattan, New York.[65] Their plight became one of the first hoarding stories to make news headlines.[66] A recent episode of *Hoarding: Buried Alive*, featured the home of a retired orthopedic surgeon from Philadelphia, whose cockroach infestation was so serious that the city threated to condemn the home.[67] Exterminators found roaches crawling throughout the entire home, in the bedroom, on the bed, and they even found as many as 200 dead cockroaches in one pot.[68] A study from Johns Hopkins[69]

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[62] One illustrative example is Kevin McCrary, a 64-year-old son of early radio personalities Tex McCrary and Jinx Falkenburg faces eviction from his Upper East Side Manhattan, rent-controlled apartment. McCormack, *supra* note 3. Although unemployed, McCrary lives off the trust fund left from his parents' estate and he pays just $1,400.00 a month for rent. *Id.* McCrary considers himself a collector, not a hoarder, but he appeared on an episode of A&E's *Hoarders* in October 2011. *Id.* During the episode, a team of cleaners packed up eight truckloads of possessions from the apartment he has lived in for twenty years. *Id.* McCrary's collection of possession grew so large that he had to enter his apartment using the fire escape and his belongings even extended to his Ford E250 van. *Id.*; *see also* Carter, *supra* note 56.

[63] FROST & STEKETEE, *supra* note 23, at 5–6.

[64] *Id.*

[65] *Id.* at 1–9. Homer was found dead as a result of starvation, while Langley was crushed to death by the hoard. *Id.* Police and workers removed one hundred and thirty tons of garbage from the Collyer brownstone in the several weeks it took to clean the home. *Id.* Amongst the hoard were fourteen pianos, two organs, violins, banjos, more than twenty-five thousand books, human organs pickled in jars, eight live cats, the chassis of an old Model T, guns, old food, the folding top of a horse-drawn carriage, decades old newspapers and magazines, and the list goes on and on. *Id.* Although the Collyer brothers were educated and wealthy compared to what many think of hoarders to be, they were still affected by the hoarder disorder, and collected more expensive possessions instead of just commons items such as newspapers.

[66] *Id.*

[67] Tracy Miller, *See It: Thousands of Cockroaches Swarm Philadelphia Home on 'Hoarding: Buried* Alive', N.Y. DAILY NEWS, http://www.nydailynews.com/life-style/health/thousands-cockroaches-swarm-new-jersey-home-article-1.1727005 (last updated Mar. 19, 2014) (showing that hoarding can affect any person, even those whose careers involve cleanliness and sanitation, such as surgeons).

[68] Nat'l Health Serv., *supra* note 58 (The owner of the exterminating company even said in all his "years of doing this type of work, nothing freaks me out, but seeing the type of filth that I just witnessed makes my skin crawl.").

[69] Samuels et al., *supra* note 4 (study showing prevalence of hoarding in the elderly as 6.2% compared to less than 3% for younger age groups).

and a study of complaints to the Massachusetts Health Department[70] show hoarding is more prevalent in the elderly population. Specific dangers associated with hoarding by the elderly will be addressed later in this Article.

C. What Can Be Hoarded?

Absolutely anything can be hoarded because hoarders can attach meaning to any item: animals (living or dead), trash, newspapers, soiled diapers, and even rotten food. The list of items that can be hoarded is endless. In a 2001 study, researchers found that elderly hoarders "most frequently collected newspapers, containers, and other paper trash, which were predominantly found in the living room, dining room, kitchen, and bathroom." [71] Bathrooms were found cluttered in three-quarters of elderly hoarding cases, and in more than half of the elderly hoarding cases the bathrooms were difficult to get into.[72]

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[70] Frost et al., *supra* note 27. In the study, a two-part questionnaire was mailed to 325 Board of Health Offices in Massachusetts. *Id.* at 230. Only eighty-eight health officers responded, which represented 1.79 million residents. *Id.* Although only twenty-eight percent of health offices responded, the findings are likely to be representative of typical hoarding. *Id.* The first part of the questionnaire "asked for information about the population served by the agency and posed three additional questions: (1) the number of hoarding complaints lodged in each year from 1992 through to the middle of 1997, (2) the number of new hoarding cases in each of these years, and (3) the number of repeat offender cases during each of these years." *Id.* The second part asked for information regarding recent hoarding cases, such as type of residence, who made the initial complaint, what rooms were most affected, and the circumstances alleged. *Id.* Sixty-four percent of health officials reported at least one hoarding case during the targeted time-period. *Id.* at 231. Neighbors most often made complaints and circumstances surrounding the complaint included the following: fire hazard (67%), unsanitary conditions and accumulation of junk (88%), odor (53%), and odd behavior (38%). *Id.* Inside the home, items were most often located in the living room (90%), kitchen (79%), and bedroom (79%). *Id.* at 232. The following statistics were reported regarding the effect of the accumulation of possessions: inhibited normal movement within the home (86%), inhibited access to furniture such as a bed or sofa (92%), inhibited access to foot preparation and storage (80%), and interfered with basic hygiene (88%). *Id.* Although statistics about the impact of hoarding on activity was high, only fifty percent of hoarders acknowledged the lack of sanitation due to hoarding. *Id.* In three cases, hording directly contributed to the death of the hoarder in a house fire. *Id.* at 233. Even though no information was collected regarding age of the alleged hoarders, nearly half of the cases involved the department of aging, which suggested that more attention needs to be given to the problem of hoarding with the elderly. *Id.*

[71] Gail Steketee, et al., *Hoarding by Elderly People*, 23 HEALTH & SOC. WORK 176, 183 (2001).

[72] *Id.*

Animal hoarding is a specific type of hoarding where large numbers of animals are kept without proper care, and the hoarders are often unaware of the harm caused to the animals.[73] In seventy-eight percent of animal hoarding cases, the homes are heavily littered with garbage;[74] nearly seventy percent of the cases include homes covered in animal feces and urine; and in eighty percent of animal hoarding cases dead or dying animals are discovered.[75] Animal hoarding is typically considered animal cruelty and is regulated under such statutes, which require owners to properly care for their animals or face animal cruelty charges that can be punished with jail time, animal forfeiture, or fines.[76] The term "cat lady" seems to have some merit, as the Animal Legal Defense Fund reports that seventy-two percent of animal hoarders are women; and cats, followed by dogs, are the most common victims of animal hoarding.[77] An estimated 250 thousand animals suffer from hoarding each year in the U.S., and although hoarders can face criminal charges for animal abuse or neglect, studies find that

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[73] Int'l OCD Foundation, *supra* note 42.

[74] *Id.*

[75] Phillip Snyder, *Animal Hoarding, Everyone Suffers,* SUNCOAST HUMANE SOC'Y (Feb. 24, 2013), http://humane.org/index.php/press/55-animal-hoarding-everyone-suffers.

[76] Victoria Hayes, Note, *Detailed Discussion of Animal Hoarding*, ANIMAL LEGAL & HISTORICAL CENTER, 2010, *available at* http://www.animallaw.info/articles/ddushoarding.htm#. Effective January 1, 2002, Illinois's Humane Care of Animals Act enables the court to require counseling for those convicted of animal cruelty who meet the definition of "companion animal hoarder." 510 ILL. COMP. STAT. 70/2.10 (defining companion animal hoarder as "a person who (i) possesses a large number of companion animals; (ii) fails to or is unable to provide what he or she is required to provide under Section 3 of this Act; (iii) keeps the companion animals in a severely overcrowded environment; and (iv) displays an inability to recognize or understand the nature of or has a reckless disregard for the conditions under which the companion animals are living and the deleterious impact they have on the companion animals' and owner's health and well-being."). Animal hoarding is a misdemeanor in Hawaii and is defined as:

> (1) A person commits the offense of animal hoarding if the person intentionally, knowingly, or recklessly: (a) Possesses more than fifteen dogs, cats, or a combination of dogs and cats; (b) Fails to provide necessary sustenance for each dog or cat; and (c) Fails to correct the conditions under which the dogs or cats are living, where conditions injurious to the dogs', cats', or owner's health and well-being result from the person's failure to provide necessary sustenance.

HAW. REV. STAT. § 711-1109.6 (2014)

[77] Animal Legal Defense Fund, *Animal Hoarding Facts*, ANIMAL LEGAL DEFENSE FUND, http://aldf.org/resources/when-you-witness-animal-cruelty/animal-hoarding-facts/ (last visited June 25, 2016).

between sixty and hundred percent of animal hoarders indicate they would hoard animals again if given the opportunity.[78]

D. Why Is Hoarding Especially Dangerous to the Elderly?

Although research on hoarding is somewhat scant, information about the dangers of hoarding has been gathered. Severe hoarding can pose a threat to any hoarder, but also to the community in which they live.[79] Hoarding creates fire hazards by blocking exits and making fires more difficult to control due to the volume of the hoard, and the location of flammable items such as magazines and newspapers near heat sources like stoves or furnaces can increase the risk of fire.[80] Hoarding not only causes fires, but also makes fires more dangerous, often requiring a greater allocation of resources to fight the blaze than the average residential fire.[81] As recently as April 2014, there have been reports of hoarding associated fires causing the death of the hoarder.[82] Not only can hoarding pose a risk

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[78] *Id.* As recently as February 2014, a Manatee County Florida animal shelter, Napier Family Farm and Animal Rescue, had 300 dogs, cats, horses, goats, chickens, hogs, and geese removed from the premises by law enforcement. Bradenton Herald Editorial, *Spotlight Now on Manatee's Animal Services After Shelter Raid*, BRADENTON HERALD (Feb. 13, 2014), http://www.bradenton.com/2014/02/13/4988327/spotlight-now-on-manatees-animal.html. Attorneys for the couple, Alan and Sheree Napier, who owned the facility admitted the two were "sloppy and hoarded" but states that did not equate to animal abuse. *Id.* It was reported that many of the animals suffered from diseases and infections, were malnourished, and filthy, but animal rescue organization and veterinarians stepped in to help the animals recover. *Id.* It is still unclear whether prosecutors will pursue charges against the couple. *Id.*

[79] *See generally* Randy O. Frost, Gail Steketee & Lauren Williams, *Hoarding: A Community Health Problem*, 8 HEALTH AND SOCIAL CARE IN THE COMMUNITY 229 (2000).

[80] *Infra* notes 166–169 and accompanying text evidencing fires in hoarding homes.

[81] Emily Colpas et al., *An Analysis of Hoarding Fire Incidents and MFB Organisational Response*, WORCHESTER POLYTECHNIC INST. (May 2, 2012), https://web.wpi.edu/Pubs/E-project/Available/E-project-050112-083627/unrestricted/An_Analysis_of_Hoarding_Fire_Incidents_and_MFB_Organisational_Response.pdf. *See* David Mittleman, *Three Fires in Lansing Area Linked to Hoarding*, THE LEGAL EXAMINER (March 28, 2014), http://lansing.legalexaminer.com/uncategorized/three-fires-in-lansing-area-linked-to-hoarding/ (Lansing, Michigan firefighters responded to a third house fire in one month involving hoarding).

[82] Katelyn Smith, *UPDATE: 1 Person Killed in Mountville Fire*, WGAL NEWS 8 (Apr. 1, 2014, 1:44 PM EDT), http://www.wgal.com/ news/susquehanna-valley/lancaster/home-burns-overnight-in-mountville/

to the hoarders and their community, but it can also harm emergency personnel who provide assistance with cleaning up hoarding homes or fires at hoarding homes.[83]

Elders often face more health problems than younger generations, and this explains why hoarding by the elderly can have such severe results. The elderly population already experience limited mobility, memory loss, and ever-increasing health issues, therefore hoarding by the elderly should be of particular concern since it can pose additional dangers, like unsanitary conditions and impeded walking paths, to this already vulnerable group.

Due to the excessive clutter associated with hoarding, the fact that many elderly have some type of disability,[84] and that walking is the most limited daily activity for elders,[85] hoarding

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25261526. Although there has not been a report about the cause of the fire that killed Kenneth Murry, 75, in Mountville, Pennsylvania on April 1, 2014, emergency officials stated Murry had a hoarding problem. *Id.* Due to the amount of clutter in the home it was unsafe for firefighters to go inside. *Id.* One of Murry's friends said it was difficult to even get in the home and hard to even walk inside the home, and as a result firefighters were forces to fight the flames from outside. *Id.*

[83] Molly Born, *Hoarders Cause Piles of Trouble at Fires*, PITTSBURGH POST-GAZETTE (Mar. 30, 2014), http://www.post-gazette.com/local/region/2014/03/31/Hoarders-cause-piles-of-trouble-at-fires/stories/201403310041. The Pittsburgh Post-Gazette reported in March 2014 that firefighters had to crawl over piles of books, newspapers, and boxes to extinguish a fire in a vacant home in Homestead, Pennsylvania. *Id.* Chief of Emergency Services for Allegheny County, Pennsylvania explained that hoarding "has always been an issue . . . . It remains a concern for the individual living in that condition ... but also for public safety personnel." *Id.* The piles of possessions can simultaneously fuel a fire and inhibit, or in some cases even hurt, firefighters trying to fight the flames. *Id.* For example, a firefighter injured by an electrical shock while extending a hose to the second floor would not have been at as great of a risk if the stairwell had been accessible. *Id.*

[84] Admin. on Aging, *supra* note 13 (showing statistics that thirty-five percent of men and thirty-eight percent of women over the age of 65 have some type of disability). Limitations in activities of daily living were the most severe in people 85 years and over; however, even people ages 65 to 74 experienced limitations in daily activities. *Id.* The most limited activities of daily living based on the average of percentage limitations for the three age categories (65–74, 75–84, and 85 and over) are: walking (30.33%), getting in/out of bed/chairs (14%), bathing/showering (13.67%), dressing (9%), using toilet (9%), and eating (3.66%). *Id.*

[85] Admin. on Aging, *supra* note 13 (limitations in walking were seventeen percent for 65-year-olds to 74-year-olds, twenty-eight percent for 75-year-olds to 84-year-olds, and forty-six percent for 85 years and over); Statistics S. Afr., *Profile of Older Americans in South Africa*, STATISTICS S. AFR. p. iv, http://www.statssa.gov.za/publications/
Report-03-01-60/Report-03-01-602011.pdf (last visited June 25, 2016) ("Old age is often characterised by poor health due to frailty, morbidities and disabilities. This culminates into an inability to perform certain functions such as walking, hearing, seeing, remembering and concentrating as well as self-care.").

increases the risk of falling.[86] "For more than 80 percent of [hoarding] clients, the clutter also represent[s] a serious physical threat, including fire hazard, fall, and unsanitary conditions."[87] A 2010 study found that hoarding caused various injuries to older adults including insect bites, falls, health problems like asthma, interference with wound healing, other skin issues, and in one case, a snake bite.[88] The 2010 study also found that over one-third "of the hoarding cases [they reviewed] involved additional health hazards related to pests, rotting food, human [and] animal waste, or nonworking utilities; and acting agencies reported 16 cases (thirty-one percent) with an unmanageably large number of companion animals (i.e., animal hoarding)."[89] As the severity of hoarding increases, so does the risk of physical threat.[90] Despite the many health and safety hazards hoarding can pose to elders, only fifteen percent of the elders who had serious problems with hoarding actually recognized that their behavior was problematic.[91]

Elderly hoarders also face an increased risk of homelessness when living conditions are unsafe and their landlords seek

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[86] *See, e.g.*, Kellum, *supra* note 14; Margit Novak, *Rooms of Shame: Senior Move Manager's Perspective on Hoarding*, 20 J. GERIATRIC CARE MANAGEMENT Fall 2010, at 21, 22.
[87] Steketee et al., *supra* note 71.
[88] Rosemary Kennedy Chapin, *Hoarding Cases Involving Older Adults: The Transition from a Private Matter to the Public Sector*, 53 J. GERONTOLOGICAL SOC. WORK 723, 733 (2010).
[89] *Id.* at 732. Combining the injuries such as insect bites and interference with wound healing with the health hazards relating to rotting food, waste, and pets, is unsettling due to the likely increase in risk of infection due to the often unsanitary conditions in hoarding homes.
[90] Steketee et al., *supra* note 71.
[91] Frost, Steketee & Williams, *supra* note 79. Although statistics show the great majority of elderly hoarders do not recognize their hoarding behavior is a problem, *id.*, in some cases individuals do realize they need help, such as a Cape Coral, Florida woman who admits she knew she needed help but did not know where to turn. Joelle Parks, *Cape Coral Woman Speaks Out About Hoarding Situation*, NBC2 (Mar. 05, 2014 6:49 PM EST), http://www.nbc-2.com/story/24897802/ cape-coral-woman-speaks-out-about-hoarding-situation#.U0SOeVfy2dw. The woman, who remained anonymous, voluntarily gave up the animals and accepted help, although she maintains she is not a hoarder. *Id.* A total of twenty-two animals were taken from her home after the county animal services received an anonymous call about urine and feces odor coming from the residence. *Id.* Florida's Lee County Domestic Animal Services currently monitors about fifty cases for hoarding and attributes the recent increase in reports to media coverage. *Id.*

eviction.[92] Since hoarding typically presents itself at childhood or adolescence and increases gradually with age, treating elderly hoarders can pose a distinct challenge because "elder hoarders are likely to have ingrained behavior patterns and substantial clutter."[93] Since hoarding "tends to be a lifelong problem that [worsens] with age,"[94] the United States, and in fact the entire world, can no longer fail to address this disorder, specifically with regard to elders.

III. HISTORY OF ELDER ABUSE

In large part due to the baby boomers' generation aging, the elderly population continues to grow worldwide. With the growing elderly population, the amount of elder abuse also continues to increase; however, laws regarding elder abuse have failed to keep up with the aging population. A common theme both nationally and internationally, is the lack of easy to understand and uniform definitions of elder abuse, which only adds to confusion as to whether hoarding is a form of self-neglect and further supports the argument for hoarding to be specifically enumerated in Adult Protective Services statutes as a form of self-neglect.

A. Population of Elders: Past, Present, and Future

In 2013, persons 65 years of age and older represented 14.1% of the U.S. population, equating to roughly one in every seven Americans.[95] The elderly population is anticipated to grow

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[92] *See, e.g.*, Christopher C. Ligatti, *Cluttered Apartments and Complicated Tenancies: A Collaborative Intervention Approach to Tenant "Hoarding" Under the Fair Housing Act*, 46 SUFFOLK U. L. REV. 79, 84 (2013) (citing David F. Tolin et al., *The Economic and Social Burden of Compulsive Hoarding*, 160 PSYCHIATRY RES. 200, 209 (2008) for the statistic that as many as one in eight hoarders are either evicted or threatened with eviction); Turner et al., *supra* note 15, at 449.

[93] Chapin, *supra* note 88. The program also noted that physical sorting and moving objects was more difficult for this older client group, especially for sustained periods of time. *Id.*

[94] Boodman, *supra* note 60 (quoting Maryland psychologist Elspeth N. Bell, who heads the Behavior Therapy Center's hoarding program and is a consultant to the Montgomery County Hoarding Task Force in Maryland).

[95] Admin. on Aging, Admin. for Community Living & U.S. Dep't of Health and Human Services, *A Profile of Older Americans: 2014*, ADMIN. FOR COMMUNITY LIVING 2, http://www.aoa.acl.gov/aging_statistics/profile/2014/docs/2014-profile.pdf.

significantly, especially now that the eldest members of the baby boomer generation have turned 65 years old.[96] In fact, the 65 and over population in the United States increased from 35.9 million in 2003 to 44.7 million in 2013, constituting a 24.7% increase in a decade.[97] In 2013, people over 65 years of age constituted 14.1% of the United States' population, but by 2040 that percentage is expected to grow to 21.7%.[98] The population of Americans over the age of 65 is projected to reach 82.3 million by 2040, and ninety-eight million by 2060.[99]

The 2011 Canadian Census reported there were 4.9 million Canadians aged 65 years and older, which had increased 14.1% between 2006 and 2011.[100] In 2013, the Canadian senior population (65 years and older) had once again increased to 5.4 million, and the projection for Canadian seniors in 2063 is between 11.1 million and 15.1 million people.[101] In 2013, the senior population comprised 15.3% of Canada's population and is expected to increase to between 23.8% and 27.8% by 2063.[102] Similarly, the senior population in South Africa has increased in recent years. The population of people aged 60 years and older has increased from 2.8 million in 1996 to 4.1 million in 2011, which is an increase from 7.1% of the South African population to 8%.[103] By July 2014, South Africa's total population had grown to an estimated 54 million

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[96] *Id.* at 3.
[97] *Id.*
[98] *Id.*
[99] *Id.*
[100] Laurent Martel et al., *The Canadian Population in 2011: Age and Sex*, STATISTICS CANADA 4, https://www12.statcan.gc.ca/census-recensement/2011/as-sa/98-311-x/98-311-x2011001-eng.cfm (last updated December 21, 2015) (the 65+ population growth rate was more than double the 5.9% growth rate for Canada's population overall).
[101] Statistics Canada, *Section 2—Results at the Canada level, 2013 to 2063*, STATISTICS CANADA, http://www.statcan.gc.ca/pub/91-520-x/2014001/section02-eng.htm#a5 (last updated Nov. 30, 2015).
[102] *Id.*
[103] Statistics S. Afr., *supra* note 85.

people and comprised of 8.4% (4.54 million) of persons aged 60 years or older.[104]

Between 1994 and 2014, the population aged 65 years and older in Australia increased from 11.8% to 14.7%.[105] Australia's elderly population is expected to reach roughly 5.8 million in 2031, between 9 million and 11.1 million in 2061, and between 11.5 and 18.1 million by 2101; all of which are significant increases from the 3.2 million Australians aged 65 years and older in 2012.[106]

In New Zealand, the population aged 65 years and over is projected to double by 2041 to approximately 1.28-1.37 million, which will comprise almost a quarter of the country's population.[107] By 2025, New Zealand is expected to have more people aged 65 and over than children 14 years and younger, and by 2064, it is projected that twenty-seven percent of the country's population will be aged 65 years and older.[108]

The United Kingdom's population of persons aged 65 years and older increased from fifteen percent of the overall population in 1985 to seventeen percent in 2010.[109] The population aged 65 years and older is projected to account for twenty-three percent of United Kingdom's total population by 2035.[110] In 2010, Wales had the

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[104] Statistics S. Afr., *Mid-Year Population Estimates 2014*, STATISTICS SOUTH AFRICA 2, http://www.statssa.gov.za/?p=2990 (last visited July 10 2016).
[105] Austl. Bureau of Statistics, *3101.0 - Australian Demographic Statistics, Jun 2014*, AUSTRALIAN BUREAU OF STATISTICS (Dec. 18, 2014, 11:30 AM), http://www.abs.gov.au/AUSSTATS/abs@.nsf/allprimarymainfeatures/54A5E977BB10644CCA257E1300775B9B?opendocument .
[106] Austl. Bureau of Statistics, *3222.0—Population Projections, Australia, 2012 (base) to 2101*, AUSTRALIAN BUREAU OF STATISTICS (Nov. 26, 2013, 11:30 AM), http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/3222.0main+features52012%20(base)%20to%202101.
[107] Statistics New Zealand, *National Population Projections: 2014(base)–2068*, STATISTICS NEW ZEALAND, http://www.stats.govt.nz/browse_for_stats/population/estimates_and_projections/NationalPopulationProjections_HOTP2014.aspx (last visited Nov. 11, 2016).
[108] Office for Senior Citizens, *2014 Report on the Positive Ageing Strategy*, Ministry of Social Development (Apr. 2015) https://www.msd.govt.nz/documents/what-we-can-do/seniorcitizens/positive-ageing/msd-17470-2014-ageing-strategy-report-final.pdf.
[109] Office for Nat'l Statistics, *Population Ageing in the United Kingdom, its Constituent Countries and the European Union*, THE NAT'L ARCHIVES 3 (Mar. 2, 2012), http://www.ons.gov.uk/ons/dcp171776_258607.pdf.
[110] *Id.*

highest population aged 65 years and older at nineteen percent, Scotland at seventeen percent, England at sixteen percent, and Northern Ireland had the lowest with fourteen percent.[111] Because the elderly population worldwide is anticipated to increase for decades to come, it is particularly important for international legislatures to address issues that seriously affect the elderly, including hoarding disorder.

B. History of Elder Abuse Regulation

Despite a significant portion of the world being categorized as elderly, the issue of elder abuse and neglect is still relatively new to the legal world. In fact, before 1977, "no state had a statute specifically aimed at protecting the aged" in the United States.[112] In 1978, the Select Committee on Aging of the House of Representatives issued a report entitled *Elder Abuse: The Hidden Problem*, and in 1981, all states were encouraged to draft and pass laws protecting the elderly.[113] Unfortunately, in its subsequent report nearly a decade later, the Committee found the hidden problem of elder abuse and neglect had not only worsened, but it had actually increased by fifty percent in a decade.[114]

Although the exact number of elders who suffer mistreatment such as abuse or neglect is still unclear, the reporting

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[111] *Id.* at 7.

[112] Seymour Moskowitz, *Saving Granny from the Wolf: Elder Abuse and Neglect-the Legal Framework*, 31 CONN. L. REV. 77, 85 (1998).

[113] Ryan C. Hall et al., *Exploitation of the Elderly: Undue Influence as a Form of Elder Abuse*, 13 CLINICAL J. AM. GERIATRICS SOC'Y, Feb. 2005, at 28, *available at* http://www.clinicalgeriatrics.com/articles/Exploitation-Elderly-Undue-Influence-Form-Elder-Abuse. The 1981 congressional report specifically encouraged laws which would protect the elderly from physical, emotional, and financial exploitation. *Id.* Since the 1981 report, all fifty states have enacted elder abuse statutes, but the laws are inconsistent from state to state. *Id.*

[114] SUBCOMM. ON HEALTH AND LONG-TERM CARE OF THE SELECT COMMITTEE ON AGING HOUSE OF REPRESENTATIVES, *Elder Abuse: A Decade of Shame and Inaction*, COMM. PUB. NO. 101-752, at 2 (1990).

of elder mistreatment has increased,[115] however, it is still estimated that the majority of elder abuse is never reported to authorities.[116] Just like the topic of elder abuse, which only began making headlines in the past several decades, the dangerous and sometimes deadly disorder of hoarding has only recently become more widely discussed.[117] While shows such as *Hoarders* and *Hoarding: Buried Alive* have publically exposed the dangers of hoarding and the challenges of educating and rehabilitating people afflicted with the disease, more must be done to provide assistance to those in need, especially elders.

C. Statutory Regulation of Elder Abuse and Neglect

The statutory regulation of elder abuse and neglect varies by country and in many cases also by state or territory. This segmented approach to the regulation of elder abuse and neglect can contribute to inconsistent reporting and insufficient assistance for elders in need.

1. United States

In the United States, there are both federal and state regulations for elder abuse and neglect. The Older Americans Act provides for the federal regulation of services for the elderly, resulting from concern over a lack of "community social services for older persons."[118] The 2006 Amendment of the Older Americans

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[115] Nat'l Center on Elder Abuse, Admin. on Aging, *Statistics/Data*, NAT'L CENTER ON ELDER ABUSE, ADMIN ON AGING, http://www.ncea.aoa.gov/Library/Data/index.aspx#problem (last visited June 25, 2016). The most recent major studies reported that 7.6% to 10% of study participants experienced abuse in the prior year, but one in ten adults experienced abuse not including financial abuse. *Id.*

[116] Interview with Amanda Medley Raines, *supra* note 28; FROST & STEKETEE, *supra* note 23, at 11. Estimates for unreported elder abuse vary; some say only one in fourteen cases coming to the attention to authorities, however some say for every case of abuse know by agencies, there are twenty-four unknown cases. FROST & STEKETEE, *supra* note 23, at 11.

[117] Frost & Gross, *supra* note 26 (the first systemic study of hoarding was completed in 1993); *Hoarders*, *supra* note 10 (first episode aired in 2009); *Hoarding: Buried Alive*, *supra* note 11 (first episode aired in 2010).

[118] U.S. Dep't of Health & Human Serv., *Administration on Aging (AoA), Older Americans Act*, ADMIN. FOR COMMUNITY LIVING, http://www.aoa.gov/AoA_programs/OAA/ (last visited July 10, 2016). On July 16, 2015, the Older Americans Reauthorization Act of 2015 passed the Senate

Act amended the definition of neglect to include self-neglect, and defined it as:

> [A] n adult's inability, due to physical or mental impairment or diminished capacity, to perform essential self-care tasks including -
> (A) obtaining essential food, clothing, shelter, and medical care;
> (B) obtaining goods and services necessary to maintain physical health, mental health, or general safety; or
> (C) managing one's own financial affairs.[119]

The United States also regulates elder abuse and neglect on the state level in both criminal and Adult Protective Services contexts. Currently, all fifty states and the District of Columbia have statutes that protect the aged.[120] Although all states have statutes protecting elders, the statutes and the levels of protection they offer vary greatly from one state to another.[121] Generally, the statutory definition of abuse may be physical abuse, sexual abuse, neglect, exploitation, emotional abuse, abandonment, self-neglect, or some combination of the like.[122] Some statutes separately define the term

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without Amendment and is being considered by the House. Govtrack.us, S. 192: Older Americans Act Reauthorization Act of 2015, https://www.govtrack.us/congress/bills/114/s192 (last accessed Nov. 11, 2016). On April 19, 2016, the bill was signed by the President and enacted and became law. *Id.*

[119] *Id.*

[120] D.C. CODE §§ 7-1901–7-1913 (2016); Admin. on Aging, *What Is Elder Abuse?*, ADMIN. ON AGING, http://www.aoa.gov/aoa_programs/elder_rights/ea_prevention/whatisea.aspx (last visited July 10, 2016) (stating legislatures in all fifty states have passed elder abuse prevention laws);.

[121] D.C. CODE §§ 7-1901–7-1913; Admin. on Aging, *supra* note 120; *see infra* notes 123–126 (providing examples of Adult Protective Services statutes from different states).

[122] Admin. on Aging, *supra* note 120. The Administration on Aging specifically defines the following terms, although every state does not use this exact terminology with their individual statutes:

> Physical Abuse—inflicting physical pain or injury on a senior, e.g. slapping, bruising, or restraining by physical or chemical means. Sexual Abuse—non-consensual sexual contact of any kind. Neglect—the failure by those responsible to provide food, shelter, health care, or protection for a vulnerable elder. Exploitation—the illegal taking, misuse, or concealment of funds, property, or assets of a senior for someone else's benefit. Emotional Abuse—

"self-neglect," while others incorporate self-neglect within the definition of neglect.[123] Approximately one-third of states separately define self-neglect within the definition section of their Adult Protective Services or similarly titled statute.[124] Although Adult Protective Services statutes vary greatly among states,[125] they serve the same general purpose—to protect adults who are no longer able to protect themselves.[126]

> inflicting mental pain, anguish, or distress on an elder person through verbal or nonverbal acts, e.g. humiliating, intimidating, or threatening. Abandonment—desertion of a vulnerable elder by anyone who has assumed the responsibility for care or custody of that person. Self-neglect—characterized as the failure of a person to perform essential, self-care tasks and that such failure threatens his/her own health or safety. *Id.*

[123] *See, e.g.*, ALASKA STAT. § 47.24.900 (2015) (separately defining self-neglect); ARK. CODE ANN. § 12-12-1703 (West, Westlaw Next current through the end of the 2016 Second Extraordinary, 2016 Fiscal, and 2016 Third Extraordinary Sessions of the 90th Arkansas General Assembly, and include changes made by the Arkansas Code Revision Commission received through May 1, 2016.) (including the term self-neglect within the definition of neglect); FLA. STAT. § 415.102(16) (2016) (incorporating the concept of self-neglect within the definition of neglect, without using the actual term self-neglect).

[124] *See, e.g.*, COL. REV. STAT. ANN. § 26-3.1-101 (West, Westlaw Next current through laws effective April 22, 2016 of the Second Regular Session of the 70th General Assembly (2016)) (defining self-neglect as "an act or failure to act whereby an at-risk adult substantially endangers his or her health, safety, welfare, or life by not seeking or obtaining services necessary to meet his or her essential human needs. Choice of lifestyle or living arrangements shall not, by itself, be evidence of self-neglect. Refusal of medical treatment, medications, devices, or procedures by an adult or on behalf of an adult by a duly authorized surrogate medical decision maker or in accordance with a valid medical directive or order, or as described in a palliative plan of care, shall not be deemed self-neglect. Refusal of food and water in the context of a life-limiting illness shall not, by itself, be evidence of self-neglect . . ."); LA. STAT. ANN. art. 15:1503 (2016) (defining self-neglect as the failure, either by the adult's action or inaction, to provide the proper or necessary support or medical, surgical, or any other care necessary for his own well-being. No adult who is being provided treatment in accordance with a recognized religious method of healing in lieu of medical treatment shall for that reason alone be considered to be self-neglected); N.Y. SOC. SERV. LAW § 473 (2016) (using the following definition of self-neglect: "an adult's inability, due to physical and/or mental impairments to perform tasks essential to caring for oneself, including but not limited to, providing essential food, clothing, shelter and medical care; obtaining goods and services necessary to maintain physical health, mental health, emotional well-being and general safety; or managing financial affairs").

[125] *See, e.g.*, *supra* notes 123–126 and accompanying text.

[126] *See, e.g.*, FLA. STAT. § 415.101 (explaining that "[t]he Legislature recognizes that there are many persons in this state who, because of age or disability, are in need of protective services. Such services should allow such an individual the same rights as other citizens and, at the same time, protect the individual from abuse, neglect, and exploitation. It is the intent of the Legislature to provide for the detection and correction of abuse, neglect, and exploitation through social services and criminal investigations and to establish a program of protective services for all vulnerable adults in need of them. It is intended that the mandatory reporting of such cases will cause the protective services of the state to be brought to bear in an effort to prevent further abuse, neglect, and exploitation of vulnerable adults. In taking this action, the Legislature intends to place the fewest possible restrictions on personal liberty and the exercise of constitutional rights, consistent with due

a. Florida's Adult Protective Services Statute

As an example of state regulation in the United States, the State of Florida has various statutes aimed at protecting elders and even prescribes harsher punishments for crimes committed against elders.[127] Florida even requires that "*any person*… who knows, or has reasonable cause to suspect, that a vulnerable adult has been or is being abused, neglected, or exploited *shall immediately report* such knowledge or suspicion to the central abuse hotline."[128] Although Florida's Adult Protective Services statute may seem progressive since it requires the mandatory reporting of abuse, neglect, or exploitation of vulnerable adults, there are still gaps of protection that result in elders not receiving needed assistance, specifically when concerning neglect. Florida defines neglect under the Adult Protective Services chapter as:

> [T]he failure or omission on the part of the caregiver or vulnerable adult to provide the care, supervision, and services necessary to maintain the physical and mental health of the vulnerable adult, including, but not limited to, food, clothing, medicine, shelter, supervision, and medical services, which a prudent

process and protection from abuse, neglect, and exploitation. Further, the Legislature intends to encourage the constructive involvement of families in the care and protection of vulnerable adults."); MD. FAM. LAW CODE ANN. § 14-102 (West, Westlaw Next current through all legislation from the 2016 Regular Session of the General Assembly in effect through July 1, 2016) (explaining "it is the policy of the State that adults who lack the physical or mental capacity to care for their basic daily living needs shall have access to and be provided with needed professional services sufficient to protect their health, safety, and welfare"); OKLA. STAT. ANN. TIT. 43A, § 10-102 (2016) (stating "A. The Legislature recognizes that many citizens of this state, because of the infirmities of aging, incapacity, or other disability are unable to manage their own affairs or to protect themselves from exploitation, abuse, or neglect and are in need of protective services. B. Services provided pursuant to the provisions of the Protective Services for Vulnerable Adults Act shall guarantee, to the maximum degree of feasibility, the individual the same rights as other citizens, and at the same time protect the individual from exploitation, abuse, or neglect. C. The Protective Services for Vulnerable Adults Act is designed to establish a program of protective services for vulnerable adults in need of those services.").

[127] FLA. STAT. §§ 415, 430, 825.

[128] FLA. STAT. § 415.1034(1)(1) (emphasis added).

> person would consider essential for the well-being of a vulnerable adult. The term "neglect" also means the failure of a caregiver or vulnerable adult to make a reasonable effort to protect a vulnerable adult from abuse, neglect, or exploitation by others. "Neglect" is repeated conduct or a single incident of carelessness which produces or could reasonably be expected to result in serious physical or psychological injury or a substantial risk of death.[129]

However, Florida, unlike many states, does not use the term self-neglect at all within the definitions portion of the Adult Protective Services statute.[130] In fact, as recently as 2004, Florida's Adult Protective Services statutory definition of neglect required the neglect to have occurred at the hands of a caregiver and, therefore, self-neglect was not a legal form of neglect.[131] In 2006, Florida amended the Adult Protective Services statute definitions to include "the failure or omission on the part of the caregiver *or vulnerable adult*…" as neglect.[132] The amended language from 2006 is still in effect today.[133] Although Florida's definition of neglect technically includes the concept of self-neglect, it could be clearer and consequently more effective, if it followed the majority of states and included the term "self-neglect" within the neglect definition.[134]

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[129] FLA. STAT. § 415.102(16) (defining neglect but never using the term "self-neglect" nor providing examples of what can constitute self-neglect, such as hoarding).
[130] *Id*. For examples of different states' use of the term self-neglect within Adult Protective Services or similarly titled statute review, see s*upra* notes 123–126 and accompanying text.
[131] Fla. Dep't of Children & Fam. Servs. v. McKim, 869 So. 2d 760, 761 (Fla. 1st Dist. App. 2004).
[132] FLA. STAT. § 415.102(15) (2006) (emphasis added). When revised in 2006 by House Bill 329, "neglect" was defined in section 415.102(15) of the Florida Statutes. 2006 FLA. LAWS. ch. 2006–131 (H.B. 329). House Bill 329 was approved by the Governor on June 9, 2006 and immediately took effect. *Id.* Neglect is currently defined in section 415.102(16) of the Florida Statutes.
[133] *Supra* note 132 (comparing the wording in the 2006 House Bill 329, which was approved, to the language currently used in the definitions section of Florida's Adult Protective Services statute).
[134] For examples of different terminology used in Adult Protective Services statutes, see *supra* notes 123–126 and accompanying text. Although it is perplexing as to why the term self-neglect is not used in Florida's Adult Protective Services statute since the majority of states include the term within their comparable statutes, this Article does not delve into the reasoning behind the absence of the term or the impact this may have since the concept of self-neglect is encompassed within the definition of neglect. FLA. STAT. § 415.102(16).

Florida's neglect statute, as well as many other national and international statutes, would also be more effective if they included examples of self-neglect, such as hoarding, within the statute. Due to the lack of examples and guidance in the statutes, many citizens are unclear on what constitutes self-neglect, and what exactly must be reported to authorities in their jurisdictions.

2. Canada

Similar to the United States, Canada's adult protection is mainly addressed at a more local level.[135] It is important to note that in Canada, "none of the [adult protection] laws contain a broad definition of elder abuse and neglect per se."[136] However, some territorial and provincial legislation addresses the abuse and neglect of adults.[137] For example, the Yukon definition of neglect, which includes self-neglect, states "Neglect means any failure to provide necessary care, assistance, guidance, or attention to an adult that causes, or is reasonably likely to cause, within a short period of time, the adult serious physical, mental or emotional harm, or substantial financial damage or loss to the adult, and includes self-neglect."[138]

Additionally, Newfoundland and Labrador's *Neglected Adults Welfare Act* includes the lack of properly caring for oneself when defining a neglected adult:

Neglected adult means an adult:

1. who is incapable of caring properly for himself or herself because of physical or mental infirmity,

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[135] Dep't of Justice, Canada, *Legal Definitions of Elder Abuse and Neglect*, GOV'T OF CANADA, DEP'T. OF JUSTICE, http://www.justice.gc.ca/eng/rp-pr/cj-jp/fv-vf/elder-aines/def/p211.html#s21 (last updated Mar. 24, 2015).
[136] *Id.*
[137] *Id.*
[138] The Adult Protection and Decision Making Act being Schedule A to the Decision-Making Support and Protection to Adults Act, c. 21 R.S.Y. 2003 § 58.

2. who is not suitable to be in a treatment facility under the Mental Health Care and Treatment Act,
3. who is not receiving proper care and attention, and
4. who refuses, delays or is unable to make provision for proper care and attention for himself or herself.[139]

3. South Africa

South Africa's Aged Persons Amendment Act, 1998, focuses on protecting older persons in residential care from abuse, and defines "abuse" as the maltreatment of an aged person or any other infliction of physical, mental, or financial power on an aged person, which adversely affects that person.[140] However, it is anticipated that the Aged Persons Act will be repealed when the Older Persons Act, 2006[141] comes into force.[142] The Older Persons Act narrows the definition of elder abuse to relationships based on trust and defines an older person as a male 65 years of age or older, or a female 60 years of age or older.[143] The Older Persons Act defines an older person in need of care and protection as one who "has been neglected or abandoned without any visible means of support"[144] or "is in a state of physical, mental or social neglect,"[145] however, self-neglect is not included in the statute.

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[139] Neglected Adults Welfare Act, c. N-3 R.S.N.L. 1990 § 2 (replaced by Adult Protection Act, c A-4.01 S.N.L. 2011).
[140] Aged Persons Amendment Act 100 of 1998 § 1 (S. Afr.), *available at* http://www.gov.za/sites/www.gov.za/files/a100-98.pdf.
[141] Older Persons Act 13 of 2006 (S. Afr.), *available at* http://www.justice.gov.za/legislation/acts/2006-013_olderpersons.pdf.
[142] Dep't of Justice, Canada, *Legal Definitions of Elder Abuse and Neglect: 6.0 South Africa, 6.1 Legislation*, GOV'T OF CANADA, DEP'T. OF JUSTICE, http://www.justice.gc.ca/eng/rp-pr/cj-jp/fv-vf/elder-aines/def/p6.html#s61 (last updated Mar. 24, 2015).
[143] Older Persons Act 13 of 2006 §§ 1, 30(2) (S. Afr.), *available at* http://www.justice.gov.za/legislation/acts/2006-013_olderpersons.pdf.
[144] *Id.* at § 25(5)(c).
[145] *Id.* at § 25(5)(h).

4. Australia

Although the Australian national government enacted the Aged Care Act 1997,[146] which addresses residential care facilities, the country does not have national legislation that deals with elder abuse or adult guardianship.[147] Instead, Australia's state and territorial governments have enacted adult guardianship and protection legislation, however, such statutes fail to define elder abuse or neglect.[148] Since the terms elder abuse and neglect are not defined by law, policy organization definitions are typically followed.[149] One such policy organization is the Australian Network for the Prevention of Elder Abuse (ANPEA), which defines elder abuse as "any act occurring within a relationship where there is an implication of trust, which results in harm to an older person. Abuse may be physical, sexual, financial, psychological, social, and/or neglect."[150] It is important to note that Australian definitions regarding elder abuse and neglect focus on relationships involving trust and do not include self-neglect.[151]

5. New Zealand

New Zealand's national legislative structure applies the same laws nationwide, however, the national legislature has yet to enact laws that are specifically aimed at preventing elder neglect and abuse.[152] The Protection of Personal and Property Rights Act 1988 (amended in 2007) does provide protection to older persons by way

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[146] *Aged Care Act 1997* (Cth) (Austl.), *available at* https://www.comlaw.gov.au/Details/C2013C00389.

[147] Dep't of Justice, Canada, *Legal Definitions of Elder Abuse and Neglect: 4.0 Australia, 4.1 Legislation*, GOV'T OF CANADA, DEP'T. OF JUSTICE, http://www.justice.gc.ca/eng/rp-pr/cj-jp/fv-vf/elder-aines/def/p4.html#s41 (last updated Mar. 24, 2015).

[148] *Id.*

[149] *Id.* at *4.2 Policy, 4.2.1 Emphasis on Relationships of Trust* (emphasis on relationships of trust).

[150] *Id.*

[151] *Id.*

[152] Dep't of Justice, Canada, *Legal Definitions of Elder Abuse and Neglect: 5.0 New Zealand, 5.1 Legislation*, GOV'T OF CANADA, DEP'T. OF JUSTICE, http://www.justice.gc.ca/eng/rp-pr/cj-jp/fv-vf/elder-aines/def/p5.html#s51 (last updated Mar. 24, 2015).

of enduring powers of attorney, but the Act defines neither abuse nor neglect.[153] The Mental Health (Compulsory Assessment and Treatment) Act 1992 provides for compulsory assessment and treatment in certain circumstances, and in the least restrictive manner, ensuring both the vulnerable person and the public are protected from harm.[154] Although the neglect or ill treatment of patients or proposed patients is addressed in the Act,[155] self-neglect is not.

6. United Kingdom

Legislation specifically defining elder abuse has not been enacted by Parliament; however, definitions of neglect, harm, and ill treatment do exist in statutes.[156] England and Wales enacted the Mental Capacity Act 2005, which made the willful neglect or ill treatment of a person who lacks relevant mental capacity a criminal offence.[157] Additionally, the Mental Capacity Act Code of Practice, which provides guidance to those dealing with adults who may lack capacity, defines abuse to include neglect.[158]

In Scotland, the Adult Support and Protection Act 2007[159] provides protection for adults who may be at risk of harm, are unable to safeguard themselves, their property, or their rights, and are affected by a mental disorder, disability, physical or mental

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[153] *Id.*
[154] N.Z. Ministry of Health, *Guidelines to the Mental Health (Compulsory Assessment and Treatment) Act 1992*, NEW ZEALAND MINISTRY OF HEALTH 1 (Nov. 2012), *available at* https://www.health.govt.nz/system/files/documents/publications/guide-to-mental-health-act.pdf.
[155] Mental Health (Compulsory Assessment and Treatment) Act 1992 (N.Z.), *available at* www.legislation.govt.nz/act/public/1992/0046/latest/DLM262176.html.
[156] Dep't of Justice, Canada, *Legal Definitions of Elder Abuse and Neglect: 3.0 United Kingdom, 3.1 Legislation*, GOV'T OF CANADA, DEP'T. OF JUSTICE, http://www.justice.gc.ca/eng/rp-pr/cj-jp/fv-vf/elder-aines/def/p3.html#s31 (last updated Mar. 24, 2015).
[157] Mental Capacity Act, 2005, c. 9, § 44 (Eng.).
[158] Dep't of Constitutional Aff., *Mental Capacity Act 2005 Code of Practice*, GOV.UK 244 (Apr. 2007), https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf.
[159] Adult Support and Protection (Scot.) Act, 2007, asp 10, *available at* http://www.opsi.gov.uk/legislation/scotland/s-acts2007a.

infirmity or illness.[160] Further, to be considered an adult at risk, the Adult Support and Protection (Scotland) Act defines adult to mean a person 16 years or older and has a broad definition for what constitutes harm, including self-harm.[161]

As will be discussed below, hoarding occurs in every country and research indicates the prevalence of hoarding is increasing. However, no national statutes and almost no state, territorial, or provincial statutes include hoarding as a form of self-neglect. This is problematic because the family, friends, and neighbors of those with hoarding disorder may not realize that there are resources available to provide help for this form of self-neglect.

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[160] *Id.* at § 3 defining "Adults as risk" as

1. "Adults at risk" are adults who—
    1. are unable to safeguard their own well-being, property, rights or other interests,
    2. are at risk of harm, and
    3. because they are affected by disability, mental disorder, illness or physical or mental infirmity, are more vulnerable to being harmed than adults who are not so affected.
2. An adult is at risk of harm for the purposes of subsection (1) if—
    1. another person's conduct is causing (or is likely to cause) the adult to be harmed, or
    2. the adult is engaging (or is likely to engage) in conduct which causes (or is likely to cause) self-harm.

[161] *Id.* at § 53, which provides the following interpretation for who is considered an adult at risk:

In this Part—

"adult" means an individual aged 16 or over,

"harm" includes all harmful conduct and, in particular, includes—

1. conduct which causes physical harm,
2. conduct which causes psychological harm (for example: by causing fear, alarm or distress),
3. unlawful conduct which appropriates or adversely affects property, rights or interests (for example: theft, fraud, embezzlement or extortion),
4. conduct which causes self-harm.

IV. HOARDING IN TODAY'S SOCIETY AND NECESSARY LEGISLATIVE CHANGES TO COMBAT THE DANGERS ASSOCIATED WITH HOARDING

Through television shows and news stories, the exposure of hoarding has become more prevalent, however laws regarding the dangers associated with hoarding have failed to keep up with the serious disorder. While it is clear by the stories reported that hoarding can have serious and often life-threatening effects on both humans and animals, little has been done to require protective services to be provided for people with hoarding disorder.

A. Hoarding in the Media

Even though hoarding is not included in the great majority of Adult Protective Services statutes as a form of self-neglect, a quick internet search about hoarding and the elderly returns countless results in various countries.[162] Some of the most shocking and horrifying hoarding stories, which include the discovery of

[162] *See, e.g.*, Diane C. Lade, *Hoarding Is About Mental Illness Not Clutter*, SUN SENTINEL (July 7, 2012), http://articles.sun-sentinel.com/2012-07-07/features/fl-elderly-hoarders-20120706_1_gail-steketee-hoarders-mental-illness (providing general information about hoarding); *See generally* Nancy D. Henry & E. J. Ernst, *Hoarding by Elderly Long-Term Care Residents*, 21 ANNALS LONG-TERM CARE: CLINICAL CARE & AGING 22 (2013), *available at* http://www.annalsoflongtermcare.com/article/hoarding-elderly-long-term-care-residents#sthash.eDy3g97W.dpuf (hoarding by elderly long-term care residents); Andres Jauregui, *72 Cats Rescued from Florida Hoarder's Home*, HUFFINGTON POST (Mar. 19, 2014, 9:33 AM ET), http://www.huffingtonpost.com/2014/03/19/72-cats-hoarder-florida_n_4991852.html (last updated Mar. 20, 2014) (officials were forced to wear hazmat suits during the seven-hour cleanup at a Florida cat hoarding home).

animal[163] and even human remains[164] within a hoarding home, show just how dangerous this disorder can be, especially to the elderly.[165]

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[163] In 2010, a Progress Energy worker stumbled upon an extreme animal hoarding case, including hundreds of dead and neglected animals, in Marion County, Florida. Wesh 2 News, *More Than 400 Dead Animals Found in Marion County*, YOUTUBE (Apr. 17, 2010), http://www.youtube.com/watch?v=zYsXwCJiHug. Animal Services Investigators discovered more than 400 dead animals, including carcasses, in cages stored right next to live animals, dead animals wrapped in plastic bags and placed in freezers, and dead animals kept in feedbags. *Id.* Officials seized birds, tortoises, sugar gliders, and other animals, including some starving for food. *Id.* Deputies took the homeowner, Ignacio Dulzaides, for a psychological evaluation. *Id.* Dulzaides was arrested three times in the 1990's for keeping animals without food and water and other animal cruelty charges. *Id.* A High Springs, Florida couple who owned Haven Acres Cat Sanctuary was accused of hoarding 697 cats in 2011, which at the time was in the top three of biggest cat hoarding cases in U.S. history. News 4 Jax, *Couple Charged After 697 Cats Seized*, NEWS4JAX (Aug. 16, 2011, 5:37 AM), http://www.news4jax.com/news/Couple-Charged-After-697-Cats-Seized/1947478. About 100 of the cats had to be euthanized, while the rest received treatment and were spayed and neutered. *Id.* But the 2011 news story was not the first time the couple was in the news, in fact, the couple was cited in 2006 by the code department for having too many cats, and in 2009, faced the possibility of losing the required special-use permit to keep the several hundred cats. Cindy Swirko, *Cat Sanctuary May Have Already Used Up All Nine Lives*, GAINESVILLE.COM (Apr. 19, 2009, 12:01 AM), http://www.gainesville.com/article/20090419/
articles/904191012.

[164] For instance, in Dallas, Texas, a county medical examiner was forced to crawl through a window and over piles of debris to reach the body of a man found dead in a home. Lucia, *supra* note 3. Police believed the man was pinned under the weight of his possessions. *Id.* The search for the 67-year-old homeowner began when friends reported him missing after not seeing him for several days. *Id.* Firefighters first tried to push their way into the home but were blocked by a ten-foot wall of trash and were forced to cut a hole in the roof and enter the home through the attic. *Id.* A cadaver dog searched for but could not find the man, presumably because the dog was thrown off by the scent of dead animals. *Id.* After receiving a warrant to clear the home, a hazard materials cleaning team began to clean the home, which according to neighbors included jugs of urine and feces. *Id.* A neighbor also said she was told the home would be demolished and that she was advised to buy rat traps to keep the vermin from getting into her home. *Id.* Sometimes, it takes years, or even decades, for a person's remains to be discovered inside a hoarding home. Joel Currier, *Mummified Remains Found in Jennings Home after Owner's Death*, ST. LOUIS POST-DISPATCH (Mar. 8, 2011), http://www.stltoday.com/news/local/metro/article_22a7e62f-f70b-5f3d-b069-cbc01d3e0b64.html. After known hoarder, 75-year-old Gladys Bermeier, died on February 7, 2011, family members began to clean out her home in Jennings, Missouri. *Id.* But during the cleanup, family members found the mummified remains of a woman, believed to be the deceased homeowner's mother, who had not been seen for twenty years. *Id.* The remains were found wrapped in plastic and multicolored curtain, and were dressed in a pajama top with one sock on the right foot. *Id.* There appeared to be no trauma to the remains. *Id.* Although a date of death was not immediately known, investigators discovered an orange juice bottle with a 2003 expiration date between the plastic wrappings. *Id.* Although this is not definitive evidence of time of death, the orange juice bottle supports the possibility that the person died eight years before the remains were found in 2011. *Id.* An 80-year-old woman, believed to have died from natural causes, was found buried in the floor-to-ceiling garbage that filled the Chicago, Illinois home she shared with her son. *Elderly Hoarder Cecylia Opilka Found Buried in Home She Shared with Son*, HUFFINGTON POST (Apr. 1, 2011 2:47 PM ET), http://www.huffingtonpost.com/2011/04/01/

While some of the deceased, whether humans or animals, found in hoarding homes die due to natural causes, hoarding is often considered the cause of death or at least a contributing factor in the death of hoarders and animals in hoarding homes.[166] Hoarding related deaths are reported nationwide,[167] even in Florida, and such reports often involve the elderly.[168]

In Australia, hoarders have been found dead inside their homes, this includes the discovery of an 82-year-old woman found underneath a pile of garbage in her home after disappearing eighteen months earlier, as well as a man in his seventies who died in a fire at his home that raged out of control partially due to his belongings

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elderly-hoarder-cecylia-o_n_843699.html. Workers had to force the door open because the home was so full of debris. Neighbors reported they had not seen the elder for some time, which prompted authorities to check the home. *Id.* Authorities believe Opilka died around December 2010 of natural causes, and police believe the deceased's 43-year-old's son knew she was dead, he may not have had the mental capacity to know he should have reported the death. *Id.* Both Opilka and her son were reportedly compulsive hoarders. *Id.* Billie Jean James, a lifelong pack rat, was found dead in her home, hidden in her hoard four months after she died. Sean Alfano, *Las Vegas Woman Missing for Four Months Found Dead Under Pile of Junk in Her House*, NEW YORK DAILY NEWS (Aug. 28, 2010), http://www.nydailynews.com/news/national/las-vegas-woman-missing-months-found-dead-pile-junk-house-article-1.206441. When Mrs. James could not be located, a massive search of the Las Vegas desert ensued but she was not found. *Id.* However, four months later, her husband, Bill James, noticed his 67-year-old wife's feet sticking out from under a ceiling high pile of junk in their home. *Id.*

[165] *Supra* notes 79–94 and accompanying text (evidence of dangers hoarding poses to elders).

[166] *See generally supra* note 163; *see also*, *Woman Dies After Fire Tears Through Davie Home: Officials*, NBC MIAMI (July 1, 2012), http://www.nbcmiami.com/news/local/Woman-Dies-After-Fire-Tears-Through-Davie-Home--160944805.html. Although the cause of the fire was not known, officials believed an elderly woman in Davie, Florida, who appeared to be a hoarder, died in a house fire because she was unable to make it to the door and exit the residence. *Id.* Firefighters were unable to put out the flames and later found the woman's body lying near the door. *Id.* It was reported that the woman used a walker but it was not found next to her body. *Id.* Fire officials' investigation of the home was made more difficult and delayed by the amount of debris in the home, which mostly consisted of newspapers. *Id.*

[167] *See generally supra* note 164. Sadly, hoarding related deaths do not appear to be uncommon, and news stories continue to appear nationwide. For instance, neighbors called for a welfare check on Charlie Wilson, who was in his seventies, after they had not seen him in weeks, but Moultrie, Georgia officers were surprised to discover his badly decayed body inside his home. Donnitra Gilbert, *Hoarder Found Dead, Buried Alive in Home*, WCTV.TV (Mar. 31, 2011, 6:16 PM), http://www.wctv.tv/home/headlines/Man_Found_Buried_Alive_in_Home_118995514.html. Outside of Wilson's home were piles of boxes, cars, and garbage, but officers said inside was even worse. *Id.* To get into the home and bring Wilson's body out officers had to break a window and create a path, but "fighting through the smell and the rubble was [not] easy." *Id.* Officers did not suspect foul play and believed he died from natural causes. *Id.* The City of Moultrie condemned Wilson's home. *Id.*

[168] *See supra* notes 162–163; 166; *infra* note 175, and accompanying text (providing examples of Florida hoarding stories).

fueling the fire.[169] There was also a man who was found dead on top of his belongings, "like a dragon guarding his gold."[170]

Similar stories exist in New Zealand; for example, in one home inspectors found piles of rubbish, cat feces, food waste and soiled furniture and bedding; and in another home the toilet was blocked, rubbish was piled higher than the furniture, and it was so unsanitary that workers had to wear masks.[171] But even more tragic stories exist, such as a home where a man lived in a shed while his dying wife lived inside their house, which was filled with several buckets of human waste.[172]

In England, tales of hoarding include a woman who saved every maxi pad she had ever used, and two concentration camp survivors turned hoarders who suffered a fire at their home, causing one of the survivors to commit suicide several weeks later.[173] It is also not uncommon to hear stories where hoarding not only affects the hoarders, but their neighbors and communities as well. For example, in Canada, a six-alarm fire that broke out in a hoarder's apartment displaced more than 1,700 other tenants for several months.[174]

Perhaps one the most disturbing hoarding stories from the U.S. in recent years is that of Gail Andrews, a 61-year-old woman

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[169] Konrad Marshall, *All Too Much: The People Who Can't Let Go*, THE SYDNEY MORNING HERALD (Aug. 10, 2013), http://www.smh.com.au/lifestyle/life/all-too-much-the-people-who-cant-let-go-20130809-2rnca.html.
[170] *Id.*
[171] Bronwyn Torrie, *Filth, Waste, Stench in Hoarders' Dwellings*, STUFF.CO.NZ, http://www.stuff.co.nz/dominion-post/news/6297222/Filth-waste-stench-in-hoarders-dwellings (last updated Jan. 1, 2012 5:00).
[172] *Id.*
[173] Jennifer O'Brien, *London Fire Inspector James Hind Is Trying to Do Something About Hoarding*, THE LONDON FREE PRESS (July 11, 2014), http://www.lfpress.com/2014/07/11/london-fire-inspector-james-hind-is-trying-to-do-something-about-hoarding.
[174] Jenny Yuen, *Dirty Secret: Toronto Hoarder Comes Clean*, TORONTO SUN (Aug. 2, 2014), http://www.torontosun.com/2014/08/02/dirty-secret-toronto-hoarder-comes-clean.

from Fort Myers, Florida, who lived with her mother's skeleton for fourteen months.[175] Leading researcher on hoarding, Gail S. Steketee,[176] considered this an extreme case, which pointed to Andrews's "knowledge that her home and life were out of control and she could not see a clear way out of her wretched situation."[177]

A similar story is that of Bobbie Barnett Hancock, who made headlines for storing her 95-year-old mother's remains in a Clearwater, Florida storage unit.[178] However, unlike the story of Gail Andrews, whose mother's remains were stored in her home for approximately a year,[179] the remains of Hancock's mother were kept in the storage unit for as long as seventeen years, since her mother died in 1994 and her mother's remains were not discovered until 2012.[180]

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[175] Aisling Swift, *Whatever Happened to? Fort Myers Woman Who Kept Dead Mom in Home*, NAPLES DAILY NEWS (Dec. 24, 2010), http://www.naplesnews.com/news/state/whatever-happened-to-fort-myers-woman-who-kept-dead-mom-in-home-ep-392954309-343093612.html. Andrews, a Lee County, Florida teacher for twenty years, said, "things piled up in her home after she left her job to care for her ailing parents, her father . . . who died in 1999 at 83, and her mother who died at 88 [in 2009.]" *Id.* Andrews said she could not lift her mother up after a fall, so Andrews propped her up on with pillows, but her mother died two days later. *Id.* On June 4, 2010, Lee County Sheriff's deputies conducted a wellness check "after neighbors repeatedly complained about rats and odors, reporting their belief that Andrews' mother was dead and still inside." *Id.* Andrews told deputies her mother was in Connecticut visiting relatives, but after smelling a foul odor and seeing trash, rats, and mice inside, the deputies returned a week later with a search warrant. *Id.* Gladys Andrews's skeleton was found inside the home, wrapped in blankets. *Id.* Problems continued to escalate while Andrews asked for more time to fix the violations. *Id.* Despite living with her mother's skeleton for fourteen months and her home was filled with piles up to two feet high, she denied being a hoarder. *Id.* Andrews' trouble with hoarding was not her only problem; after her mother's death, Andrews continued to cash her mother's Social Security checks, adding up to $73,000. *Id.*

[176] Gail S. Steketee, Ph.D., is a Dean and Professor at Boston University School of Social Work. Boston University School of Social Work, *About Faculty*, B.U. SCHOOL OF SOCIAL WORK, http://www.bu.edu/ssw/about/faculty/full-time-faculty/steketee/ (last visited July 18, 2016). Dr. Steketee currently conducts research in various areas including body dysmorphic disorder and "assessment and treatment for compulsive hoarding problem, including in elderly people." *Id.* She has published three books on compulsive hoarding, as well as articles and chapters in other publications. *Id.*

[177] Swift, *supra* note 175.

[178] Michael Sheridan, *'Hoarder' Kept Her 95-Year-Old Mother's Body in Florida Storage Unit: Family*, NEW YORK DAILY NEWS (Jan. 29, 2012 1:44 PM), http://www.nydailynews.com/news/national/hoarder-95-year-old-mother-body-florida-storage-unit-family-article-1.1013665.

[179] Swift, *supra*, note 175.

[180] Sheridan, *supra* note 178 and accompanying text. The elderly woman died in 1994 but the planned funeral never took place; instead, nearly seventeen years later, the woman's body was found in a storage unit. *Id.* The ex-husband of Hancock's daughter said Hancock's habit of hoarding was the reason she secretly kept her mother's remains hidden in the storage unit. *Id.* The elderly woman

The remains of hoarders who live alone have also been found inside homes, such as Bruce Meredith, a 61-year-old St. Petersburg, Florida man known in his neighborhood as "the hoarder," who was found dead with a gunshot wound to his chest inside his burning home.[181] Sometimes hoarders may survive fires at their hoarding homes, such as the concentration camp survivor couple mentioned earlier, but the same is not always true for their possessions or even animals at the home. For example, although St. Petersburg, Florida homeowner Bill LaBarre was not harmed in the fire that firefighters struggled to contain due to the vast amount of personal possessions and likely hoarding, it is believed that three of his cats died in the blaze.[182] Cases also exist where both the hoarder and his or her animals must be removed from a hoarding home for their own health and safety, however, the Department of Children and Families (DCF) in Florida, or similar state agencies in other states, and law enforcement then face whether or not the person has the mental capacity to choose how to live or if guardianship proceedings should be initiated.[183]

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was "supposed to be laid to rest in Alabama in a blue coffin made [e]specially for her by a grandson;" instead, the blue coffin was found when the family could no longer pay for the storage unit and the items inside were going to be sold at an auction. *Id.*

[181] Alison Barnwell, *Hoarder Found Dead Inside Burning St. Petersburg Home*, TAMPA BAY TIMES (Aug. 23, 2013, 8:02 AM), http://www.tampabay.com/news/publicsafety/fire/man-dies-in-house-fire-in-st-petersburg/2137928. Detectives who searched Meredith's home also said he was a hoarder. *Id.* A police spokesman said there were all kinds of things in the home, including "lots and lots of newspapers." *Id.* The man's next-door neighbor said the deceased homeowner never came outside anymore. *Id.*

[182] Dan Sullivan, *St. Petersburg Firefighters Struggle to Contain Fire at Possible Hoarder's Home*, TAMPA BAY TIMES (Oct. 10, 2012 8:59 PM), http://www.tampabay.com/news/publicsafety/fire/st-petersburg-firefighters-struggle-to-contain-fire-at-possible-hoarders/1255821. St. Petersburg Fire Chief Neil Crumity said the firefighters could only move inches inside the home and even had to cut a hole in the roof to move items out of the way. *Id.* Furniture and other items were stacked wall-to-wall inside the home, and several pet cats unfortunately died in the fire. *Id.* It was determined that the fire started in the kitchen and was electrical, with firefighters saying every room had items stacked floor to ceiling. *Id.* The homeowner had even been cited and fined several times in the past five years for violations relating to the storage of items in his yard. *Id.*

[183] Ann Mariani, *Authorities Investigate How Valrico Woman Found Among Cats, Clutter Came to Live That Way*, TAMPA BAY TIMES (June 28, 2009), http://www.tampabay.com/news/publicsafety/authorities-investigate-how-valrico-woman-found-among-cats-clutter-came-to/1014083. The Valrico, Florida woman was removed from home alone with cats (eight dead and fifteen alive), because both appeared neglected and the woman showed signs of hoarding. *Id.* DCF regional director David Cox discussed that before intervening with force,

While the reports of hoarding are troubling, it is even more concerning that hoarding is considered a hidden problem.[184] Although there are hoarding stories from around the world reported in the news every day, it is unknown how many hoarding cases go unreported. Additionally, even though a state or country does not include hoarding as a form of self-neglect within its Adult Protective Services statute,[185] that does not mean the state is immune from the hoarding problems faced by other states, as evidenced by the variety of hoarding stories reported worldwide in recent years.[186] Instead, the lack of statutes that specifically include hoarding as a form of self-neglect is evidence that many states have not addressed the significant disorder of hoarding. In order to provide better means and resources to address hoarding disorder, statutes that include this form of self-neglect must be enacted. Otherwise, those affected by hoarding will continue to slip through the cracks of these statutes and fail to receive the protective services they are designed to provide.

B. Illinois's Statute Specifically Enumerates Hoarding as a Form of Self-Neglect

Despite affecting a significant segment of the United States population,[187] hoarding is only included as a form of self-neglect in Illinois.[188] The Illinois Adult Protective Services statute defines self-neglect as:

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officials must believe the person is at risk. *Id.* The issue that DCF and law enforcement faces is whether the person has the mental capacity to choose how they live. *Id.* In this case, there were roaches in plain sight, cat feces littered the floor, piles of purchases and collected items in the home, along with a high pile of garbage in the kitchen. *Id.* The 74-year-old woman was sent to Baylife Crisis Center initially because she appeared to be in poor physical and mental health, as well as emaciated. *Id.*

[184] Interview with Amanda Medley Raines, *supra* note 28 and accompanying text, which supports hoarding being called a hidden problem.

[185] FLA. STAT. § 415.102(16) (2016).

[186] *See, e.g.*, *supra* notes 162–183 and accompanying text.

[187] U.S. Census Bureau, *supra* note 50 and accompanying text (providing estimate that hoarding affects two to five percent of the U.S. population).

[188] 320 ILL. COMP. STAT. 20/2 (i-5) (including and defining compulsive hoarding as a form of self-neglect). Massachusetts has introduced a bill that would amend its definition of elder abuse to include compulsive hoarding, but the proposed change has not been approved nor enacted. The proposed amendment is:

> [A] condition that is the result of an eligible adult's inability, due to physical or mental impairments, or both, or a diminished capacity, to perform essential self- care tasks that substantially threaten his or her own health, including: providing essential food, clothing, shelter, and health care; and obtaining goods and services necessary to maintain physical health, mental health, emotional well-being, and general safety. The term includes compulsive hoarding, which is characterized by the acquisition and retention of large quantities of items and materials that produce an extensively cluttered living space, which significantly impairs the performance of essential self- care tasks or otherwise substantially threatens life or safety.[189]

> SECTION 1. Section 14 of Chapter 19A of the General Laws, as so appearing, is hereby amended by striking out the first paragraph and inserting in place thereof of the following paragraph:
> Abuse, an Act or omission which results in serious physical or emotional injury to an elderly person or financial exploitation of an elderly person; or the failure, inability or resistance of an elderly person to provide for him one or more of the necessities essential for safety, physical and emotional well-being without which the elderly person would be unable to safely remain in the community. The term includes compulsive hoarding, which is characterized by the acquisition and retention of large quantities of items and materials, resulting in an extensively cluttered living space that substantially impedes the performance of essential self-care tasks or threatens the health and safety of the resident. Hoarding is often characterized by a lack of insight into the health/safety risks caused by the hoarding. No person shall be considered to be abused or neglected for the sole reason that such person is being furnished or relies upon treatment in accordance with the tenets and teachings of a church or religious denomination by a duly accredited practitioner thereof.

S. 359, 189th Gen. Ct. of the Commw. of Mass., (Mass. 2015), *available at* https://malegislature.gov/Bills/189/Senate/S359 (referred by Senate to committee on Elder Affairs on April 15, 2015).

[189] *Id.*

However, Illinois only recently added hoarding to its Adult Protective Services statute.[190] In 2009, Illinois's House Bill 2388 amended the Elder Abuse and Neglect Act[191] by adding hoarding language to the section of the Act that defines self-neglect.[192] Although Illinois has made it clear that hoarding is a form of self-neglect, which can require Adult Protective Services depending on the severity of the case, the state's new hurdle is funding programs

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[190] H.B. 2388, 96th Gen. Assemb., (Ill. 2009) (enacted) (Representative Elizabeth Hernandez proposed the amendment to Illinois's Adult Protective Services statute on Feb. 19, 2009 and it was ultimately signed into law on Aug. 18, 2009).

[191] 320 ILL. COMP. STAT. 20/1– 20/3 (2013).

[192] 320 ILL. COMP. STAT. 20/2 (i-5) (current definition of self-neglect); *see also* State of Illinois, 96th General Assembly, Regular Session, Senate Transcript, 48th Legislative Day (May 14, 2009). On May 14, 2009, Senator Hunter presented House Bill for its third reading. Senator Hunter stated the bill:

> [B]asically redefines 'self-neglect' under the Elder Abuse and Neglect Act to include compulsive hoarding. It also requires the Department of Aging to provide temporary housing, counseling and caseworker services to eligible adults who have been removed from their homes for cleanup/repairs. It also expands the definition of 'self-neglect' to include self-hoardiness [sic] characterized by the acquisition -- and unwillingness or the inability to discard, large quantities of useless objects. I'm carrying this bill for the Department of Aging and AARP. And I ask for a favorable vote.

Id. The Illinois Senate's vote on House Bill 2388, returned 54 Ayes, 0 voting Nay, and 0 voting Present and since the bill received the required constitutional majority, it was declared passed on May 14, 2009. *Id.* The amended Elder Abuse and Neglect Act was signed into law on August 18, 2009 as Public Act 96-0572 and became effective on January 1, 2010. Illinois General Assembly, *Bill Statute of HB2388, 96th General Assembly,* http://www.ilga.gov/legislation/BillStatus.asp?DocNum=2388&GAID=10&DocTypeID=HB&SessionID=76&GA=96 (last visited June 26, 2016). House Bill 2388 amended Illinois's definition of self-neglect as follows:

> (i-5) "Self-neglect" means a condition that is the result of an eligible adult's inability, due to physical or mental impairments, or both, or a diminished capacity, to perform essential self-care tasks that substantially threaten his or her own health, including: providing essential food, clothing, shelter, and health care; and obtaining goods and services necessary to maintain physical health, mental health, emotional well-being, and general safety. *The term includes compulsive hoarding, which is characterized by the acquisition and retention of large quantities of items and materials that produce an extensively cluttered living space, which significantly impairs the performance of essential self-care tasks or otherwise substantially threatens life or safety.*

Id. (emphasis added to show the wording included in the definition on self-neglect pursuant to Public Law 96-0572).

that provide vital assistance and resources to citizens affected by hoarding.[193]

C. Adult Protective Services Reports of Neglect

Even though the National Center on Elder Abuse includes hoarding as a behavior that constitutes self-neglect,[194] no other state has followed Illinois's example by amending its statute to include hoarding as a form of self-neglect.[195] Recent statistics show that self-neglect is the leading form of elder abuse reported to Adult Protective Services in the United States.[196] Reports of self-neglect comprised nearly thirty percent of elder abuse reports to Florida's Adult Protective Services in the 2012–2013 fiscal year.[197] Other states have reported even more staggering rates of self-neglect, such as Virginia, where fifty-five percent of the substantiated abuse reported to Adult Protective Services was self-neglect.[198]

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[193] Interview with Charles P. Golbert, *supra* note 37.

[194] Nat'l Ctr. on Elder Abuse, Admin. on Aging, *Frequently Asked Questions*, NAT'L CTR. ON ELDER ABUSE, ADMIN. ON AGING, https://ncea.acl.gov/faq/index.aspx (last visited July 23, 2016).

[195] *Compare supra* notes 123–129 (examples of statutes from various states not including hoarding as a form of self-neglect) *with supra* note 189 (Illinois's statute specifically includes hoarding as a form of self-neglect).

[196] Linda M. Woolf, *Elder Abuse and Neglect*, http://faculty.webster.edu/woolflm/abuse.html, WEBSTER U., http://faculty.webster.edu/woolflm/abuse.html (last visited July 23, 2016). Self-neglect, if included statistically as a form of elder abuse, represents the highest percentage of cases of elder abuse. *Id.* The Public Policy Institute of AARP estimated that self-neglect represents forty to fifty percent of cases reported to states' Adult Protective Services. *Id.*

[197] Fla. Dep't of Elder Aff., *The Power to Prevent Elder Abuse Is in Your Hands*, FLA. DEP'T OF ELDER AFF., http://elderaffairs.state.fl.us/doea/elderabuseprevention/Elder%20Abuse%20Brochure%20-%20English2015.pdf (last visited July 23, 2016). Although self-neglect is not used within Florida's Adult Protective Services Statute, the term is defined in the brochure and statistics are given for the category of self-neglect. *Id.* The definition of self-neglect used in the brochure is "[w]hen individuals fail to provide themselves with whatever is necessary to prevent physical or emotional harm or pain." *Id.*

[198] Department for Aging and Rehabilitative Services, *Adult Protective Services in the Commonwealth*, http://partnership.vcu.edu/servicesfacilitators/Module%204-PartA/downloadables/Adult%20Protective%20Services%20in%20the%20Commonwealth.pdf (last visited Nov. 11, 2016).

In New Zealand, ten to fifteen percent of abuse cases seen by Age Concern's Elder Abuse and Neglect Prevention Services involved self-neglect.[199] Although self-neglect cases exist in New Zealand, government funding does not extend to cases of self-neglect because it is not considered a form of elder abuse, which requires the abuse to "occur within a relationship of trust" between the abuser and the victim.[200] The lack of government funding for self-neglect cases is of particular concern because self-neglect affects "the most common aspects of life," such as nutrition, household management, personal hygiene, and other health related needs,[201] all of which are essential to a person's health and wellbeing.

In 2011, hoarding comprised three percent of all abuse allegations reported to the Cuyahoga County, Illinois's Department of Senior and Adult Services, and self-neglect comprised forty-two percent.[202] Just two years later, the Cuyahoga County Division of Senior and Adult Services reported that the number of abuse allegation reports based on hoarding had doubled to six percent, while the number of reports based on self-neglect remained at forty-two percent.[203] Cuyahoga County responded in part to their increasing rates of hoarding by creating the Cuyahoga County Hoarding Connection.[204] Further evidencing the prevalence of this

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[199] Age Concern N.Z., *What's Happening in New Zealand?*, AGE CONCERN N.Z., http://www.ageconcern.org.nz/ACNZPublic/Services/EANP/ACNZ_Public/Elder_Abuse_and_Neglect.aspx (last visited July 23, 2016).

[200] Age Concern N.Z., *Elder Abuse and Neglect Prevention: Challenges for the Future*, AGE CONCERN N.Z. 14 (Oct. 1, 2007), http://www.ageconcern.org.nz/files/EANP/Challenges%20for%20the%20Future,%20Stats%20report%20for%20Age%20Concern%202004-07.pdf.

[201] *Id.* at 36.

[202] Cuyahoga Cnty. Div. Senior & Adult Serv., *Adult Protective Services Statistics: Elder Abuse, Neglect and Exploitation*, CUYAHOGA CNTY. DIV. SENIOR & ADULT SERV, http://dsas.cuyahogacounty.us/en-US/adult-protective-services-statistics.aspx (last visited July 23, 2016).

[203] Cuyahoga Cnty. Div. Senior & Adult Serv., *2013 Statistics Performance Report*, CUYAHOGA CNTY. DIV. SENIOR AND ADULT SERV., http://dsas.cuyahogacounty.us/pdf_dsas/en-US/DSAS-2013-APR-Rvsd-03-2014.pdf (last visited July 23, 2016) (also finding that 46% of all clients served by APS were 80 years or older).

[204] Hoarding Connection of Cuyahoga Cnty., *Home*, HOARDING CONNECTION OF CUYAHOGA CNTY., http://hoardingconnectioncc.org/index.cfm (last visited July 23, 2016). The 2nd Annual Hoarding Connection Conference on May 9, 2014, was advertised on the website. *Id.*

issue, one report even found that sixty-one percent of the elder mistreatment reported in Texas from 1999 to 2004 involved allegations of self-neglect.[205] As statistics show, self-neglect rates are high, and because hoarding is categorized as a form of self-neglect, all states, and in particular Florida, due to its large elderly population, must statutorily recognize hoarding in order to provide assistance to those in need.

D. Amending Adult Protective Services Statutes to Include Hoarding as a Form of Self-Neglect

All elder abuse and self-neglect statutes should include hoarding as a form of self-neglect because hoarding poses increased dangers to the elderly,[206] is more prevalent among the elderly,[207] and since the already large elderly population is projected to grow in the future,[208] the amount of elders who hoard will also grow, it is basic math. Current estimates about the prevalence of self-neglect and hoarding, based on statistics from adult protective services reports, can be applied to elderly population demographics to calculate the current and estimated future number of elders who hoard.

For instance, since the elderly in the United States account for 14.1% of all Americans, or 44.7 million people,[209] and the rate of hoarding among the elderly in the United States is estimated to as high as 6.2%,[210] an estimated 2.77 million elderly hoarders could be living in the United States. While this number may not seem large,

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[205] *See* Carmel Bitondo Dyer et al., *Self-Neglect Among the Elderly: A Model Based on More Than 500 Patients Seen by a Geriatric Medicine Team*, 97 AM. J. PUB. HEALTH 1671, 1671 (2007). The report also cited to two national studies that reported prevalence of self-neglect to be 50.3% and 39.1% among cases reported to Adult Protective Services. *Id.*

[206] *See supra* notes 79–94 and accompanying text (evidence of dangers hoarding poses to elders).

[207] *See* Samuels et al., *supra* note 4 and accompanying text.

[208] *See supra* notes 95–111 and accompanying text (explaining the past, present, and future of the elderly population nationwide and internationally).

[209] *Supra* notes 95–99.

[210] Samuels et al., *supra* note 4.

the effects of hoarding cases can be severe, harming not only the hoarder, but animals and even the community at large. With international statistics on hoarding reportedly similar to those reported in the United States, hoarding can no longer be ignored because hoarders, and more specifically elderly hoarders, comprise a large part of the worldwide population. The U.S. Census Bureau estimated the world population to be over 7 billion people in 2012, which would equate to anywhere from 140 million to 350 million potential hoarders worldwide.[211]

Community organizations, including senior centers, churches, as well as professionals such as doctors and attorneys, should take an active role in not only educating seniors but also family members about the dangers of hoarding and resources available to assist those in need. As evidenced by the numerous articles and studies on hoarding, there are experts across the country who understanding the serious dangers of hoarding, especially by the elderly, who can offer guidance to communities in how to assist the elderly suffering from hoarding disorder. Just as there are many workshops scheduled by local organizations or attorneys about the importance of every person having a will or health care surrogate, the same attention must be given to hoarding disorder, which affects the elderly while they are still living. Additionally, every state must recognize that hoarding disorder is not an issue that will resolve itself without funding to provide the services and assistance necessary to address the disorder.

Amending state Adult Protective Services statutes to include hoarding as a form of self-neglect is preferable to allowing individual counties to address the issue, because state statutes create legal uniformity and more consistent regulation. Just as Illinois consulted with a hoarding expert before amending its statute,[212] it is

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[211] *Supra* notes 49–50 (estimating that 2% to 5% of the population are compulsive hoarders).

[212] Email from Holly Zielke, N. Region Coordinator, Ill. Dep't on Aging to Hannah Tyson, Author, *Illinois Statute- Self-Neglect and Hoarding*, (Mar. 19, 2014) (copy on file with Author). Ms. Zielke explained that statewide there was a trend in many cases where self-neglect/hoarding was an issue. *Id.* Illinois consulted with a hoarding expert, Dr. Christiana Bratitotis, who was trained by Dr. Randy O. Frost and Dr. Gail S. Steketee. *Id.* Ms. Zielke noted that self-neglect is currently an unfunded

recommended that state and international legislatures do the same. Changing statutes is a serious matter, but so is hoarding. Other states should follow Illinois' lead in amending their Adult Protective Services statutes to include hoarding, however, such legislatures should also address funding issues prior to such amendments. Funding Adult Protective Services prior to amending statutes to define hoarding as a type of self-neglect will ensure that services are provided to those in need at the time they need them. Merely having a statute that includes hoarding as a form of elder mistreatment will not properly address the dangerous disease of hoarding. To truly assist those in need, funding provisions must be made to provide services, such as home cleaning, organization, and therapy for people suffering from hoarding disease.

V. CONCLUSION

Due to the worldwide growth of the elderly population and the often devastating and life threatening effects of hoarding, states and countries should follow Illinois's direction and amend their Adult Protective Services statutes to include hoarding as a form of self-neglect.

This proposition is not radical because most Adult Protective Services statutes already include neglect and self-neglect as a form of abuse or have at least recognized self-neglect as a problem and, therefore, is not adding a completely new abuse category to the statutes. Instead, the proposal to include hoarding as a form of self-neglect is a way to clarify Adult Protective Services statutes so everyone will know that hoarding is a serious problem, which can trigger, if funding has been made available, the provision of much

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mandate in the Act, but is expected to receive funding within the next few year, which might be allocated to start the program. *Id.* Dr. Bratiotis is currently serving as an Assistant Professor in the College of Social Work at the University of Nebraska at Omaha. U. of Neb. at Omaha, *Christiana Bratiotis, Ph.D.*, U. NEB. AT OMAHA, http://www.unomaha.edu/college-of-public-affairs-and-community-service/social-work/about-us/directory/christiana-bratiotis.php (last visited July 23, 2016).

needed services. Amending these statutes to include and define hoarding would provide guidance to people who may be questioning whether or not behavior of a family member, neighbor, patient, or friend must be reported. Therefore, legislatures should amend their Adult Protective Services statutes to include hoarding as a form of self-neglect in order to better assist those most affected by the disorder, and to better protect the elderly and even society as a whole.