

# THE FIGHT FOR PERSONHOOD, LEGAL CAPACITY, AND EQUAL RECOGNITION UNDER LAW FOR PEOPLE WITH DISABILITIES IN ISRAEL AND BEYOND

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*When Rachel<sup>1</sup> contacted Bizchut, the Israel Center for Human Rights of People with Disabilities, she was in the hospital in the final stages of terminal cancer. At seventy years old, she had no family, her condition was deteriorating, she had begun to use a wheelchair, and she was in a great deal of pain. In the past, she had been diagnosed with paranoid schizophrenia. Her doctors refused to release her from the hospital without the appointment of a guardian. Rachel had no guardian and she did not want one. Rachel was an intelligent and realistic woman who knew that if she had a guardian, she would not be allowed to make her own decisions. A stranger would be appointed as her guardian, and this stranger would be authorized to make all decisions about her life, including what treatment she would receive or refuse, when and if she could leave the hospital, and where she would live out her final days. She also knew that the guardian would have access to her medical information and communicate with her doctors and other third parties about her, without having to ask her for her preferences or opinion. When Rachel contacted Bizchut for legal assistance, all she asked for was help in avoiding the appointment of a guardian. Even as her death approached, Rachel was focused on one issue: how to prevent the appointment of a guardian so that she could remain legally entitled to make her own decisions during her last few months of life. Bizchut accepted Rachel's case and went to court on her behalf. In an unusual decision, the family court ruled against the physician and the welfare officials by outright refusing to appoint a guardian for Rachel. As a result of the court's decision, Rachel was released from the hospital. Her release came on the eve of Passover, the Jewish holiday marking the end of slavery of*

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*the Jews in Egypt. Upon her release, she noted the date and proclaimed: "This year, I too am freed." Eighteen months later, Rachel died. But until her death, Rachel retained control over her life and was able to make every decision about her treatment and the quality of her life in her final days. Rachel is not alone. Thousands of people in Israel and throughout the world risk losing their right to make decisions about their own lives as a result of guardianship laws.*

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## INTRODUCTION

In 2016, Israel became one of the first countries in the world to introduce supported decision-making as an alternative to guardianship in a nationwide law. The Israeli law was enacted as an amendment to

Israel's Guardianship and Legal Capacity Law. This amendment, known as Amendment Number 18 to the Legal Capacity and Guardianship Law 5776-2016, has the potential to affect the lives of more than 60,000 people who live under guardianship in Israel today. It also provides a model to other countries that are considering abolishing or revising their guardianship laws in light of the Convention on the Rights of People with Disabilities (CRPD).

The CRPD was adopted by the United Nations (UN) in 2006.<sup>2</sup> Article 12 of the CRPD recognizes the equal recognition of persons with disabilities and their right to legal capacity on an equal basis with all others.<sup>3</sup> As such, Article 12 envisions the end of substituted decision-making regimes included in most guardianship law. In its place, Article 12 envisions a system of support for people with disabilities who may need help in making decisions or carrying out their decisions. Although there remains disagreement regarding whether or not Article 12 specifically requires the abolition of guardianship laws,<sup>4</sup> there is now broad consensus that Article 12 contemplates the end of most guardianship laws as we know them today, and that it requires the introduction of a new system of supported decision-making. Further, there can be no dispute that Article 12 changes the focus of legal capacity decisions from a medical model of disability, that addresses the deficit of the individual and emphasizes protection, to a social model of disability, that honors the dignity of the individual and his or her right to exercise legal capacity on an equal basis with others, and with support, if needed. The CRPD Committee itself has written that the CRPD's "human rights-based model of disability implies a shift from the substitute decision-making paradigm to one that is based on supported decision-making."<sup>5</sup> The Committee has further explained that because

persons with disabilities have been [discriminatorily] denied their right to legal capacity in many areas . . . under substitute decision-making regimes such as guardianship . . . [t]hese practices must be abolished in order to ensure that full legal capacity is restored to

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<sup>2</sup> Convention on the Rights of Persons with Disabilities, Dec. 13, 2006, 2515 U.N.T.S. 3 [hereinafter CRPD].

<sup>3</sup> *Id.* art. 12.

<sup>4</sup> See ARLENE S. KANTER, THE DEVELOPMENT OF DISABILITY RIGHTS UNDER INTERNATIONAL LAW: FROM CHARITY TO HUMAN RIGHTS 236 (2015). Kanter and others have argued that Article 12 imposes a clear obligation on States to eliminate substituted decision-making regimes based on the language of Article 12, as well as in the overall purpose of the CRPD, which is to guarantee that people with disabilities are protected on an equal basis as people without disabilities. *Id.*; see also Eilionóir Flynn & Anna Arstein-Kerslake, *Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity*, 10 INT'L J.L. IN CONTEXT 81 (2014); Tina Minkowitz, *Norms and Implementation of CRPD Article 12* (Sept. 18, 2010) (unpublished paper), [https://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=2037452](https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2037452).

<sup>5</sup> Comm. on the Rights of Persons with Disabilities, Gen. Comment No. 1, U.N. Doc. CRPD/C/GC/1, ¶ 3 (2014).

persons with disabilities on an equal basis with others.<sup>6</sup>

Although guardianship began as a legal vehicle used to protect people whom society considered unable to protect themselves, it has become an outdated infringement on the human rights of persons with disabilities. This Article explores the legal and practical issues related to guardianship laws generally, and the rights of people like Rachel and others to retain control over their own lives. Such control is necessary in order to ensure the right to equal recognition under law for people with disabilities as part of the global movement for supported decision-making. In particular, the purpose of this Article is to examine the extent to which guardianship is compatible with the fundamental values of international human rights law, particularly Article 12 of the CRPD; and if not, what alternatives to guardianship should be introduced in domestic laws and implemented in various countries around the world.

Part I of this Article reviews the historical and legal background of the development of guardianship laws, including arguments against guardianship from different points of view. Part II of the Article discusses the right to equal recognition under law prior to the CRPD, which is the first international treaty dedicated to the rights of people with disabilities. Part III of the Article discusses the background and language of Article 12 of the CRPD, which specifically recognizes the right to legal capacity for all people with disabilities, as well as the right to support that some people with disabilities may need in order to exercise their right to legal capacity and decision-making. Part IV of this Article discusses the Israeli Legal Capacity and Guardianship Law of 1962 and the movement in Israel to include supported decision-making as an alternative to the substituted decision-making regime included in Israel's guardianship law. This Part also discusses recent Israeli Supreme Court decisions which perpetuate the unwarranted denial of legal capacity for people with disabilities despite the Court's human rights rhetoric. Part V of the Article discusses the background, language, and purpose of Israel's new amendment to its Legal Capacity and Guardianship Law. Although Israel is not the first country to authorize supported decision-making as a matter of law, it is one of the first countries to adopt a nationwide law that specifically includes supported decision-making as a legal alternative to guardianship. Part VI of the Article discusses developments in other countries around the world as they strive to conform their domestic guardianship laws to Article 12. This Article concludes with recommendations for other countries that are considering enacting laws that recognize the legal personhood and capacity of all people with disabilities in full compliance with Article 12 of the CRPD.

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<sup>6</sup> *Id.* ¶ 7.

## I. AN OVERVIEW OF GUARDIANSHIP LAWS

Throughout history, people have been denied equal rights based on perceived “differences.”<sup>7</sup> Under Roman law, guardianship limited the legal capacity of slaves, women, children, and foreign nationals.<sup>8</sup> Under various English laws, people referred to as “idiots” and “lunatics” have been denied legal capacity and subjected to guardianship.<sup>9</sup> Further, in most countries throughout history, women have been denied legal capacity and prohibited from voting, owning property, or even having custody of their own children without their fathers’ or husbands’ consent.<sup>10</sup> Although many (but not all) countries have abolished such practices for certain people, the denial of legal capacity continues today for men and women with disabilities throughout the world.

Guardianship laws have been used to deny young and older people with disabilities their legal personhood and legal capacity.<sup>11</sup> The Israeli Legal Capacity and Guardianship Law, for example, provides that any “person who, permanently or temporarily, is unable to look after all or any of his affairs, and has no person authorized or willing to do so on his behalf” may be appointed a guardian.<sup>12</sup> In practice, however, this test

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<sup>7</sup> Sagit Mor, *Between Political Conceptualization and Legal Recognition: Impediments to the Realization of the Rights of People with Disabilities*, in ACCESS TO SOCIAL JUSTICE IN ISRAEL 79, 97 (John Gal & Mimi Ajzenstadt eds., 2009) (Isr.).

<sup>8</sup> KANTER, *supra* note 4, at 238–39 (discussing the origin of guardianship laws being “traced back to the Ancient Roman Law of the Twelve Tables (450 B.C.E.), which authorized the appointment of guardians to manage the property of people considered incompetent” (citing Peter M. Horstman, *Protective Services for the Elderly: The Limits of Parens Patriae*, 40 MO. L. REV. 215, 218 (1975))); see also Edgar S. Shumway, *Freedom and Slavery in Roman Law*, 49 U. PA. L. REV. 636 (1901).

<sup>9</sup> KANTER, *supra* note 4, at 239 (noting that “[i]n English law, guardianship first appeared in the statute *De Praerogativa Regis*, which recognized guardianship as a duty of the sovereign to protect and care for the person and property of ‘idiots’ and ‘lunatics’”); see also Kristin Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond*, 44 COLUM. HUM. RTS. L. REV. 93, 102–03 (2012); Israel Doron, *From Lunacy to Incapacity and Beyond—Guardianship of the Elderly and the Ontario Experience in Defining “Legal Incompetence,”* 19 HEALTH L. CAN. 95, 96 (1999).

<sup>10</sup> See Booth Glen, *supra* note 9, at 104–05.

<sup>11</sup> There are almost no empirical studies into guardianship appointment practices. One exception is the important study conducted by Professor Israel Doron in 2004, in which 523 family court cases in Israel were thoroughly examined. Israel Doron, *The Invisibles: Older Persons Under Guardianship*, in SOCIAL EXCLUSION AND HUMAN RIGHTS IN ISRAEL 205 (Yair Ronen et al. eds., 2008) [hereinafter Doron, *The Invisibles*] (Isr.).

<sup>12</sup> Legal Capacity and Guardianship Law, 5722-1962, § 33(a)(4) (Isr.). We note that Section 8 of the law allows declaring “A person who, by reason of mental illness or a defect of is incapable of looking after his affairs” as incompetent. In practice, the Ministry of Welfare avoids asking for a declaration of incompetence. According to the Ministry of Justice, there are very few cases of persons declared incompetent per year. However, the distinction between a person deemed legally incompetent and a person under guardianship is not sufficiently clear, and in the eyes of welfare workers, service providers, and relatives, a person who has been put under guardianship has no legal capacity.

is applied selectively.<sup>13</sup> Although all persons with disabilities can be affected by the denial of legal capacity, persons with intellectual disabilities<sup>14</sup> and psychosocial disabilities<sup>15</sup> are disproportionately affected by the Israeli guardianship law. In Israel, there is no official breakdown of the demographics of those who are appointed guardians, but most people with guardians are either mentally disabled, elderly, or both.<sup>16</sup> Moreover, not only are there approximately 60,000 people under guardianship in Israel today<sup>17</sup>, but with each new year, at least 7000 additional people are denied their legal capacity with the appointment of guardians.<sup>18</sup> In fact, according to unofficial estimates, the number of people living under guardianship in Israel has doubled over the past fifteen years.<sup>19</sup> This number is exceedingly high, especially compared to

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<sup>13</sup> See *supra* note 12.

<sup>14</sup> According to the American Association of Intellectual and Developmental Disabilities, “[i]ntellectual disability is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills,” and which “originates before the age of 18.” *Definition of Intellectual Disability*, AM. ASS’N ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES, <http://aaid.org/intellectual-disability/definition#.WWQuiYjyuyI> (last visited Oct. 28, 2017). Sociologically, intellectual disability is defined in terms of the support needs of an individual. See *The Dorm Case, THROUGH SAME DOOR*, <http://www.throughthesamedoor.com/pages/dormcase.html> (last visited Oct. 28, 2017).

<sup>15</sup> Psychosocial disability is an internationally recognized term under the CRPD used to describe the experience of people who are perceived as limited in their participation in society due to a loss of ability to think clearly and manage social and emotional aspects of life. See Frank Quinlan, *Getting the NDIS Right for People with Psychosocial Disability*, MENTAL HEALTH AUSTL. (June 12, 2014), <https://mhaustralia.org/general/getting-ndis-right-people-psychosocial-disability> (arguing that “[t]hose affected are prevented from engaging in opportunities such as education, training, cultural activities, and achieving their goals and aspirations”).

<sup>16</sup> The division between persons with disabilities and older adults is artificial. Most older adults who are under guardianship also have either physical or psychosocial disabilities. Still, in Israel and abroad, the two groups are commonly distinguished, for better or for worse. For information on the interrelationship between the CRPD and the rights of older adults, see Arlene S. Kanter, *The United Nations Convention on the Rights of Persons with Disabilities and Its Implications for the Rights of Elderly People Under International Law*, 25 GA. ST. U. L. REV. 527 (2009). At the same time, some believe that the distinction is rooted in the unique social constructs of the two groups. See AGEISM IN ISRAELI SOCIETY: THE SOCIAL CONSTRUCTION OF OLD AGE (Israel Doron ed., 2013) (Isr.).

<sup>17</sup> These figures are an estimate as there are no exact public records. They also exclude thousands of individuals who are under guardianship with respect to personal matters only. See Response of General Guardian to Freedom of Information Application (Mar. 26, 2014) [hereinafter Response of General Guardian] (on file with authors) (Isr.).

<sup>18</sup> Note that there are almost no statistics on the number of guardianship appointments, or a breakdown of such appointments by type of disability, duration of appointments, whether the person under guardianship lives in their community or in an institution, etc. The lack of official statistics on disempowered groups has been observed in many other struggles. It undermines the ability of the affected group to formulate a strong identity and to prove the harm caused to it.

<sup>19</sup> According to media reports, in 1997, 21,000 people were under guardianship in Israel. Yaffa Nevo, *The Easiest Racket in Israel*, YEDIOTH AHARONOT: WEEKEND MAGAZINE, May 9, 1997.

other “developed” nations.<sup>20</sup>

Israel’s guardianship law is typical of guardianship laws in other countries. Guardians are usually appointed by a court once the court is convinced that a person is unable to care for himself or herself. In reaching a decision to appoint a guardian, courts are typically convinced that the denial of legal capacity and the appointment of a guardian will protect the person from harm, or is necessary to effect legal contracts or decisions for the person whom the court assumes is unable to understand the nature of his or her own actions. In essence, the guardianship appointment is the means by which the state exercises its role as *parens patriae*, the responsible parent, for adult citizens whom it considers are unable to care for themselves.<sup>21</sup> In this way, the appointment of a guardian is seen as an act of benevolence, not of punishment. Yet, as history has shown, such acts of benevolence can result in harm to the very people they were supposed to protect.<sup>22</sup>

For this reason, guardianship laws have come under fire by commentators, scholars, and policy makers in Israel and elsewhere. Some now refer to guardianship as “civil death.”<sup>23</sup> However, not all opponents of guardianship agree on why guardianship laws should be replaced or reformed. Those who oppose guardianship on moral grounds argue that guardianship laws are immoral *per se*. They reason that since all human beings are created equally, all people should have

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<sup>20</sup> “The fact that the rate of guardianship appointment in Israel is much larger than in other countries must be considered.” Shelly Levy, *Issues in Guardianship Appointments for Adults*, KNESSET RES. & INFO. CTR. 20 (June 12, 2011), <http://www.knesset.gov.il/mmm/data/pdf/m02882.pdf> (Isr.).

<sup>21</sup> For a discussion of the State as a substitute for parents in protecting vulnerable citizens, or the *parens patriae* doctrine, see A. Frank Johns, *Guardianship Folly: The Misgovernment of Parens Patriae and the Forecast of Its Crumbling Linkage to Unprotected Older Americans in the Twenty-First Century—A March of Folly? Or Just a Mask of Virtual Reality?*, 27 STETSON L. REV. 1 (1997).

<sup>22</sup> See KANTER, *supra* note 4, at 240 (citing John J. Regan, *Protecting the Elderly: The New Paternalism*, 32 HASTINGS L.J. 1111 (1981)). Until the reform movements of the 19th century, the State avoided interfering with parental authority. Another group targeted for society’s beneficence has been children. See, e.g., Robert M. Rolfe & Anne U. MacClintock, *The Due Process Rights of Minors “Voluntarily Admitted” to Mental Institutions*, 4 J. PSYCHIATRY & L. 333, 335–36 (1976). In response to this century’s developments in psychology, states allowed patients voluntarily to commit their children, which they did. See James W. Ellis, *Volunteering Children: Parental Commitment of Minors to Mental Institutions*, 62 CAL. L. REV. 840 (1974). In 1974, the Supreme Court upheld this tradition by giving parents the right to involuntarily commit their children without a hearing or other due process guarantees, as permitted under the *parens patriae* power of the State. *Parham v. J.R.*, 442 U.S. 584 (1979); see also *Bartley v. Kremens*, 402 F. Supp. 1039 (E.D. Pa. 1978), *vacated*, 431 U.S. 119 (1977).

<sup>23</sup> The term civil death is often used to describe the experience of people living under guardianship. See, e.g., Comm’r for Human Rights, *Who Gets to Decide? Right to Legal Capacity for Persons with Intellectual and Psychosocial Disabilities* 9 (Apr. 2012), [http://www.coe.int/t/commissioner/source/prems/IP\\_LegalCapacity\\_GBR.pdf](http://www.coe.int/t/commissioner/source/prems/IP_LegalCapacity_GBR.pdf). For a general history of the concept of civil death, see Henry David Saunders, *Civil Death—A New Look at an Ancient Doctrine*, 11 WM. & MARY L. REV. 988 (1970).

the right to control their own destiny on an equal basis.<sup>24</sup> According to this argument, creating a distinct legal status for a class of human beings based on a medical diagnosis or a perceived difference is immoral on its face—it is simply wrong to single out a group of people as less worthy of exercising their human right to make decisions about their own lives.<sup>25</sup>

A second and related argument against guardianship is based on the fundamentals of human rights law, as contained in the Universal Declaration of Human Rights and other international human rights documents. According to this view, all human beings are entitled to be free from discrimination, and to enjoy their rights to independence, autonomy, liberty, dignity, and property on an equal basis under law. Since guardianship creates a group of people who are denied their basic human rights and are subjected to scrutiny and control by others in a way that people without guardians are not, guardianship represents a violation of the basic tenets of international human rights law.<sup>26</sup>

A third argument against guardianship is that it leads to the exclusion and marginalization of a segment of society, specifically people with certain disabilities and those who are elderly.<sup>27</sup> According to this argument, the imposition of guardians on persons who are elderly, disabled, or both is under-inclusive and over-inclusive.<sup>28</sup> It is under-inclusive because there are people who are elderly, disabled, or both, and are unable to care for themselves, but for whom the state does not seek guardians. At the same time, it is over-inclusive because it permits the appointment of guardians for people who are elderly, disabled, or both, and yet are perfectly capable of caring for themselves (and even others). According to this argument, therefore, the State's decision to classify a certain group of people as in need of protection is not a legitimate exercise of the State's *parens patriae* power, especially when the State also fails to provide adequate safeguards to protect the right of people under guardianship to express their preferences.

A fourth argument against guardianship focuses on the conduct of guardians themselves. Once a court appoints a person or entity as a guardian, the guardian has potentially unlimited power and control over the person, as well as over the person's decisions, actions, and property. Further, in many countries, there is no monitoring of guardians to

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<sup>24</sup> See Yotam Tolub & Arlene Kanter, *Whose Life is It Anyway? The Fight to Restore Autonomy and Legal Capacity for Persons with Disabilities*, 6 MA'ASEI MISHPAT 45 (2014) (Isr.).

<sup>25</sup> *Id.*

<sup>26</sup> See KANTER, *supra* note 4.

<sup>27</sup> See Leslie Salzman, *Guardianship for Persons with Mental Illness—A Legal and Appropriate Alternative?*, 4 ST. LOUIS U. J. HEALTH L. & POL'Y 279 (2011). For Israeli research pointing to procedural failures in guardianship appointment, see Yael Waxman, *Procedural Aspects of Guardianship Appointment for Adults—a Review of the Lacunas in the Legal Capacity and Guardianship Law and Suggestions for Change* (Dec. 2009) (unpublished LLM thesis, Hebrew University, Faculty of Law) (on file with authors) (Isr.).

<sup>28</sup> See KANTER, *supra* note 4, at 240.



protect against their abuse or exploitation of the people they are supposed to protect from harm. Indeed, studies in many countries have shown widespread abuse and exploitation by guardians, themselves.<sup>29</sup> Such abuse has provided the impetus for amendments to guardianship laws in the United States, which require greater oversight by courts as well as improved reporting standards for guardians in some states.<sup>30</sup> However, because the potential for abuse is so great, some scholars and advocates have called for an end to guardianship on that basis alone.<sup>31</sup>

A fifth argument against guardianship focuses on its inadequacy in addressing the very real need for support for a portion of the population of people with disabilities or who are elderly, and who need help. According to this argument, having a guardian does not guarantee that a person will receive the support or services they may want and need. For example, a guardian may refuse to pay for therapy or treatment that a person may need, and there is often nothing the person can do to challenge the guardian's decision. Even worse, guardianship itself may become a barrier that prevents people from securing the help and services they need to live as independently as possible. Moreover, while guardianship laws were designed to protect people whom the State decided needed protection, these laws instead may provide the State, as well as family members, with a false sense of security. Once a guardian is appointed, the court and family members may believe that the person will be protected from harm or exploitation, and that no additional services are needed. Especially in some countries where public services are becoming privatized, government agencies themselves may initiate the appointment of guardians for clients who have disabilities or who are elderly, as a way to pass on the responsibility of providing services to another agency or the court as the overseer.<sup>32</sup> Thus, rather than develop individualized support and services for people who may need help with

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<sup>29</sup> For a short review of incidents of exploitation and corruption by guardians throughout the world, see Doron, *The Invisibles*, *supra* note 11, at 207–08. See also Rachel Aviv, *How the Elderly Lose Their Rights*, *NEW YORKER* (Oct. 9, 2017), <https://www.newyorker.com/magazine/2017/10/09/how-the-elderly-lose-their-rights>.

<sup>30</sup> For example, a study conducted by the U.S. Government Accountability Office in 2010 reviewed a litany of cases in which guardians stole or illegally held property from individuals under their guardianship. U.S. GOV'T ACCOUNTABILITY OFFICE, *GAO-10-1046, GUARDIANSHIPS: CASES OF FINANCIAL EXPLOITATION, NEGLECT, AND ABUSE OF SENIORS* (2010) [hereinafter *GAO-10-1046*], <http://www.gao.gov/assets/320/310741.pdf>.

<sup>31</sup> See WORLD NETWORK OF USERS & SURVIVORS OF PSYCHIATRY, *LEGAL CAPACITY AS RIGHT, PRINCIPLE AND PARADIGM* (2011), [http://www.wnusp.net/documents/2012/WNUSP\\_Article12\\_Submission.doc](http://www.wnusp.net/documents/2012/WNUSP_Article12_Submission.doc); see also Yotam Tolub, *Legal Capacity and Guardianship—Changing Attitudes, Changing Legislation*, *BIZCHUT* 8 (2002) [hereinafter *BIZCHUT, Legal Seminar*], [goo.gl/CZtY5c](http://goo.gl/CZtY5c) (Isr.). For a short review of incidents of exploitation and corruption by guardians throughout the world, see Doron, *The Invisibles*, *supra* note 11, at 207–08. See also *GAO-10-1046, supra* note 30 (reviewing a litany of cases in which guardians stole or illegally withheld property from individuals under their guardianship).

<sup>32</sup> On the connection between privatization and human rights abuses, see Dafna Barak-Erez, *Human Rights in the Age of Privatization*, 8 *LAB. SOC'Y & L.* 209 (2001) (Isr.).

certain tasks, guardianship laws allow the State to simply pass off their responsibilities to the courts to appoint someone other than the State who will (supposedly) “take care” of the person.

A related argument against guardianship relates to the increased risk of institutionalization of those who are labeled as lacking legal capacity.<sup>33</sup> Once a person is labeled as incompetent or lacking legal capacity, as is required under most guardianship laws, the guardian may decide that the best setting for the person is in an institution. Placing a person in an institution relieves the guardian of the responsibilities for the person’s care, especially when support services in the community are difficult to access.<sup>34</sup> Indeed, obtaining support services for people with disabilities is challenging in many countries, including in Israel, where government agencies struggle to keep up with the increasing demand for community-based services.<sup>35</sup>

A final and important argument against guardianship is the psychological impact on the person who is subject to guardianship. Researchers have found that individuals under guardianship perceive themselves as less capable and unworthy, which may in turn result in the person acting less capable and losing self-esteem.<sup>36</sup> This phenomenon has been labeled as learned helplessness.<sup>37</sup> As some commentators have observed, a person who, before guardianship, may have been capable of doing many things, becomes more dependent once

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<sup>33</sup> On the thematic similarities between institutions and guardianship, see Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. COLO. L. REV. 157 (2010).

<sup>34</sup> On the importance of housing in the community and its incorporation into international and Israeli law, see Arlene S. Kanter, *There’s No Place Like Home: The Right to Live in the Community for People with Disabilities, Under International Law and the Domestic Laws of the United States and Israel*, 45 ISR. L. REV. 181 (2012). On the connection between guardianship appointment and institutionalization in the world, see *Stanev v. Bulgaria*, App. No. 36760/06, 2012 Eur. Ct. H.R. 46.

<sup>35</sup> According to the Israeli Central Bureau of Statistics, forty-six percent of the individuals receiving welfare services in 2006 were persons with disabilities. See COMM’N FOR EQUAL RIGHTS OF PEOPLE WITH DISABILITIES, PEOPLE WITH DISABILITIES IN ISRAEL 2011, <http://www.justice.gov.il/Units/NetzivutShivyon/sitedocs/reportnew.pdf>. The report of the Commission for Equal Rights of Persons with Disabilities shows that the number of persons with disabilities among welfare service recipients is double the number of persons with disabilities in the general population. *Id.*

<sup>36</sup> See Bruce J. Winick, *The Side Effects of Incompetency Labeling and the Implications for Mental Health Law*, 1 PSYCHOL. PUB. POL’Y & L. 6, 16–17, 20–22, 42 (1995). For research pointing to the connection between guardianship appointments and diminished abilities, see Arlene S. Kanter, *Guardianship for Young Adults with Disabilities as a Violation of the Purpose of the Individuals with Disabilities Education Improvement Act*, 8 J. INT’L AGING L. & POL’Y 1 (2015). See also Carrie E. Rood et al., *Presumption of Incompetence: The Systematic Assignment of Guardianship Within the Transition Process*, 39 RES. & PRAC. FOR PERSONS WITH SEVERE DISABILITIES 319 (2015); Shirley Werner & Rachel Lewengrove, *Guardianship, Autonomy and Decision-Making is Supported by People with Intellectual Disabilities and Among People with Mental Disabilities*, HEBREW U. JERUSALEM (July 25, 2013), <http://www.sw.huji.ac.il/files/745c2c6bddc49493d845ca0c562ert5/u53/shirly.doc> (Isr.).

<sup>37</sup> See Winick, *supra* note 36, at 14–20.

a guardian is appointed, resulting in the person's loss of capacity and lack of will.<sup>38</sup>

In addition to these substantive arguments, other arguments against guardianship laws focus on the procedural aspects of the operation of the system of guardianship itself. For example, in many jurisdictions, including in Israel, individuals who are subject to guardianship proceedings do not address the court or witnesses, if any, during the guardianship proceedings.<sup>39</sup> Thus, a court may order a guardian for a person whom the court has never even seen or heard.

Further, many judges are not even aware that they may order a limited, rather than a plenary, guardianship.<sup>40</sup> A plenary, or full, guardianship is the most comprehensive type of guardianship. Plenary guardians are authorized to make all decisions, including life and death medical decisions as well as decisions related to where the person will live, whom they will see, and what they may buy, do, or eat each day.<sup>41</sup> By contrast, in a limited guardianship, the guardian is responsible only for the specific areas assigned by the court.<sup>42</sup> Yet, regardless of whether it is a plenary or limited guardianship, the person under guardianship is denied equal recognition under the law.

Moreover, the lack of guidelines for regulating how guardians may act and the lack of monitoring of their actions by the State are two other widespread criticisms of current guardianship laws in Israel and elsewhere.<sup>43</sup> Such lack of monitoring has led to abuse of people by their

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<sup>38</sup> See Salzman, *supra* note 33; Kanter, *supra* note 36; Rood et al., *supra* note 36; Werner & Lewengrove, *supra* note 36.

<sup>39</sup> The 2004 State Comptroller's Report showed that applications for guardianship appointment are not sent to the individuals concerned and that the courts do not comply with their obligation to hear a person before making a decision. See MINISTRY OF JUSTICE, ANNUAL REPORT 54b, 663–64 (2004) (Isr.) (also including information from the 2012 and 2013 reports). Additionally, according to Professor Doron's study, ninety-five percent of the medical documents in the guardianship files that were examined stated that "the ward is unable to express his/her opinion," thus excluding individuals from the entire process. See Doron, *The Invisibles*, *supra* note 11, at 214. We note that a person's right to be present during a discussion of his matter is not a medical issue, but a human rights issue.

<sup>40</sup> Ninety percent of the appointments recorded by the General Guardian are full appointments (person and property). See Response of General Guardian, *supra* note 17.

<sup>41</sup> NAOMI KARP & ERICA WOOD, GUARDIANSHIP MONITORING: A NATIONAL SURVEY OF COURT PRACTICES 2 (2006), [https://assets.aarp.org/rgcenter/consume/2006\\_14\\_guardianship.pdf](https://assets.aarp.org/rgcenter/consume/2006_14_guardianship.pdf).

<sup>42</sup> *Id.*

<sup>43</sup> In a session of the Constitution, Law, and Justice Committee of the Knesset, the General Guardian stressed the lack of sufficient monitoring of staff positions and said that monitoring applies to property only, and that a pilot has been launched with respect to monitoring personal affairs. See Transcript of Session 94 of the Constitution, Law, and Justice Committee at 4, 19th Knesset (Dec. 10, 2013) (Isr.). According to figures provided by the General Guardian, fifty percent of the guardians never file the reports on which monitoring is based. See Response of General Guardian, *supra* note 17; see also File No. 2857/13 HCJ, *Law in the Service of Old Age v. Minister of Justice* (July 24, 2014), Nevo Legal Database (by subscription, in Hebrew) (Isr.) (involving a petition filed by a charity organization, Law in the Service of Old Age, seeking to instruct the establishment of an effective guardianship control and monitoring mechanism).

guardians, including cases of exploitation, theft, and negligence that have also resulted in public outcries against guardianship laws in many jurisdictions, including Israel.<sup>44</sup>

The final argument that has been presented against guardianships in Israel and elsewhere is the increasing privatization of guardianships. For example, private companies that serve as guardians in Israel have been found to provide substandard services to their clients,<sup>45</sup> partly due to insufficient staffing.<sup>46</sup> This situation forces people under guardianship themselves to pay for services that have been imposed on them and limits, rather than protects, their rights.<sup>47</sup>

In sum, the mounting criticism against guardianship laws in recent

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<sup>44</sup> In recent years, a number of cases of exploitation, fraud, and negligence by guardians have been exposed. The Dorei Dorot Foundation acted as guardian for about 200 individuals. Its executives are suspected of having fraudulently withdrawn monies from their wards' accounts while falsifying their reports to the General Guardian. See Noam Sharvit, *The Dori Dorot Foundation Corporation is Suspected of Illegally Issuing Funds*, GLOBES (June 16, 2009, 1:33 PM), <http://www.globes.co.il/news/article.aspx?did=1000458927> (Isr.); see also Response of Freedom of General Guardian to Freedom of Information Application (Apr. 27, 2011) (on file with author) (Isr.). In 2010, the General Guardian shut down the foundation. Yardena Nilman, a lawyer who ran a guardianship company and had charge of some 130 individuals, was arrested and convicted in 2011, based on her admission to document forgery and aggravated larceny of about seven million shekels taken from about twenty individuals under her guardianship. File No. 46535-03-10 CrimC (TA) State of Israel v. Yardena Nilman (Jan. 6, 2011), Nevo Legal Database (by subscription, in Hebrew) (Isr.); File No. 5115/12 CrimA State of Israel v. Nilman (June 10, 2013), Nevo Legal Database (by subscription, in Hebrew) (Isr.). An accounting report prepared for the General Guardian raised suspicions about the Sheffer Association, which served as guardian to over 1400 individuals. The association was suspected of serious irregularities, including concealment, inappropriate use of clients' monies, lack of record-keeping with respect to clients' affairs, failure to file reports, holding millions of shekels belonging to clients who had passed away, and more. Following the report, senior executives in the association were replaced twice in five years. See General Guardian, SHEFFER GUARDIAN SERVICE ASSOCIATION, REPORT OF THE GENERAL GUARDIAN (2012) (Isr.), <https://drive.google.com/file/d/0B0ResPwi8PY6bXd4ZmdHVXlzME0/view> (draft version); Or Kashti, *Report Suggests Embezzlement by Guardianship Association, Authorities Are Lenient*, HAARETZ (Oct. 25, 2013, 9:10 PM), <http://www.haaretz.co.il/news/education/.premium-1.2148926> (Isr.).

<sup>45</sup> STATE COMPTROLLER, SPECIAL FUNCTIONS UNIT MONITORING REPORT 79-93 (2011) (Isr.), [http://www.mevaker.gov.il/he/Reports/Report\\_140/fd23eb4c-7a99-4e3b-8a40-92c02891745d/6618.pdf](http://www.mevaker.gov.il/he/Reports/Report_140/fd23eb4c-7a99-4e3b-8a40-92c02891745d/6618.pdf).

<sup>46</sup> As of January 2011, there was a ratio of one treatment coordinator per 160 people in the Ward Treatment Foundation. See *id.* at 79. As of January 2012, there was a ratio of one treatment coordinator per 230 people in the Sheffer Association. SHEFFER GUARDIAN SERVICE ASSOCIATION, *supra* note 44, at 10.

<sup>47</sup> GENERAL GUARDIAN, WAGE AGREEMENTS FOR GUARDIANSHIP CORPORATIONS, <http://www.justice.gov.il/Units/ApotroposKlali/Documents/Fees2017.pdf> (Isr.). For criticism on shifting the cost of treatment and assistance provided to "dependents" on to the family unit while the State evades its responsibility, see Martha Albertson Fineman, *Cracking the Foundational Myths: Independence, Autonomy, and Self-Sufficiency*, 8 J. GENDER SOC. POL'Y & L. 13 (2000). With guardianship, the default is usually to appoint a relative at no cost. In other cases, when a guardianship corporation is appointed, the cost is usually borne by the person to whom a guardian is appointed. Either way, guardianship appointment expresses, on the part of the State, some degree of evasion of responsibility for persons with disabilities who are not independent. For an examination of Fineman's theory in the Israeli context, see Shiri Regev Maslam, *Following Fineman's Public Responsibility Theory: An Analysis of Israel's Care Regime*, 5 MA'ASEI MISHPAT 27 (2013) (Isr.), <http://din-online.info/pdf/maa5-3.pdf>.

years, based on moral, legal, substantive, and procedural grounds, has convinced many family members, as well as government officials, judges, service providers, lawyers, and the public at large to call for changes in guardianship laws. Such calls for change have been supported by the adoption of the CRPD, which recognizes, in Article 12, the legal capacity of all persons with disabilities. The next Part of this Article explores the background leading up to Article 12 of the CRPD, followed by a discussion of the scope and meaning of Article 12.

## II. THE RIGHT TO LEGAL CAPACITY AND EQUAL RECOGNITION FOR PEOPLE WITH DISABILITIES PRIOR TO THE CRPD

The rights to legal capacity and equal recognition under law are core principles of international human rights laws. The Universal Declaration of Human Rights and the International Covenant on Civil and Political Rights (ICCPR) both specifically recognize the right to equal recognition before the law.<sup>48</sup> Article 4, paragraph 2 of the ICCPR even goes so far as to state that there may be no derogation of the right to equal recognition before the law, even in times of public emergency.<sup>49</sup> The right to equality before the law also is included in Article 15 of the Convention on the Elimination of All Forms of Discrimination Against Women, which requires the recognition of women's legal capacity on an equal basis with men, including with respect to entering into contracts, administering property, and exercising their rights in the justice system.<sup>50</sup> Similarly, Article 3 of the African Charter on Human and Peoples' Rights recognizes the right of every person to equality before the law and the right to equal protection of the law.<sup>51</sup> Article 3 of the Inter-American Convention on Human Rights also includes the right to recognition for all people before the law.<sup>52</sup>

Despite these international and regional laws, people with disabilities, particularly people labeled as mentally ill or intellectually disabled, have been routinely denied equal recognition before the law. In fact, several international documents adopted before the CRPD expressly permit restrictions on the legal capacity of a person with a disability. The 1971 Declaration on the Rights of the Mentally Retarded

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<sup>48</sup> International Covenant on Civil and Political Rights, Dec. 16, 1966, 999 U.N.T.S. 171; G.A. Res. 217A (III), Universal Declaration of Human Rights (Dec. 10, 1948).

<sup>49</sup> International Covenant on Civil and Political Rights, *supra* note 48, at 174.

<sup>50</sup> Convention on the Elimination of All Forms of Discrimination Against Women, Dec. 18, 1979, 1249 U.N.T.S. 13, 20.

<sup>51</sup> Org. of African Unity [OAU], *African (Banjul) Charter on Human and Peoples' Rights*, art. 3, OAU Doc. CAB/LEG/67/3 (Oct. 21, 1986), [http://www.achpr.org/files/instruments/achpr/banjul\\_charter.pdf](http://www.achpr.org/files/instruments/achpr/banjul_charter.pdf).

<sup>52</sup> Org. of Am. States [OAS], *American Convention on Human Rights*, "Pact of San Jose, Costa Rica," art. 3 (Nov. 22, 1969), <http://www.cidh.oas.org/basicos/english/basic3.american%20convention.htm>.

for example, permits restrictions on legal capacity and recognizes the right of guardians to make decisions for persons who are found lacking in legal capacity.<sup>53</sup> As the 1971 Declaration states, a “mentally retarded person has a right to a qualified guardian when this is required to protect his personal well-being and interests.”<sup>54</sup> Further, although the Declaration of the Rights of Disabled Persons, which was adopted by the United Nations in 1975, does not mention guardians, it does recognize that some people with disabilities will be unable to care for themselves.<sup>55</sup> The 1975 Declaration defines a “disabled person” as one who is “unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and/or social life, as a result of deficiency, either congenital or not, in his or her physical or mental capabilities.”<sup>56</sup>

Similarly, the Principles on the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (MI Principles), adopted by the United Nations in 1991, also authorize States to deprive persons labeled as mentally ill of their right to legal recognition, although they do require certain procedural protections. For example, MI Principle 1, paragraph 6 provides:

Any decision that, by reason of his or her mental illness, a person lacks legal capacity, and any decision that, in consequence of such incapacity, a personal representative shall be appointed, shall be made only after a fair hearing by an independent and impartial tribunal established by domestic law. The person whose capacity is at issue shall be entitled to be represented by counsel. If the person whose capacity is at issue does not himself or herself secure such representation, it shall be made available without payment by that person to the extent that he or she does not have sufficient means to pay for it. The counsel shall not in the same proceedings represent a mental health facility or its personnel and shall not also represent a member of the family of the person whose capacity is at issue unless the tribunal is satisfied that there is no conflict of interest. Decisions regarding capacity and the need for a personal representative shall be reviewed at reasonable intervals prescribed by domestic law. The person whose capacity is at issue, his or her personal representative, if any, and any other interested person shall have the right to appeal to a higher court against any such decision.<sup>57</sup>

In addition, the Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities

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<sup>53</sup> G.A. Res. 2856 (XXVI), Declaration on the Rights of Mentally Retarded Persons (Dec. 20, 1971).

<sup>54</sup> *Id.*

<sup>55</sup> G.A. Res. 3447 (XXX), Declaration on the Rights of Disabled Persons (Dec. 9, 1975).

<sup>56</sup> *Id.*

<sup>57</sup> G.A. Res. 46/119, Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care, Princ. 1, ¶ 6 (Dec. 17, 1991).

recognizes the legitimacy of a legal determination of incompetency.<sup>58</sup> Paragraph 2 of the Inter-American Convention states that “[i]f, under a state’s internal law, a person can be declared legally incompetent, when necessary and appropriate for his or her well-being, such declaration does not constitute discrimination.”<sup>59</sup>

Prior to 2006, when the United Nations adopted the CRPD, a momentum began to develop, internationally, calling for an end to the denial of legal capacity for people with disabilities. For example, in 2004, the first international document was developed calling for supported decision-making, as opposed to substituted decision-making, for people with intellectual disabilities.<sup>60</sup> This document, known as the Montreal Declaration on Intellectual Disabilities, rejects the use of guardians for people who are deemed lacking in capacity as a result of their diagnosis of intellectual disability.<sup>61</sup> Instead, the Montreal Declaration calls for addressing the needs of people who are considered “lacking capacity” not through laws that substitute a guardian’s decision for the decision of the individual, but with a new model of supported decision-making.<sup>62</sup> This new model recognizes that all people have the right to make decisions and choices about their own lives, while also acknowledging that, some people, including those with intellectual disabilities, may need help from family and friends in making and carrying out their decisions. It is this model of supported decision-making that is envisioned by Article 12 of the CRPD, as discussed in the next Section.

### III. THE CONVENTION ON THE RIGHTS OF PEOPLE WITH DISABILITIES AND THE RIGHT TO LEGAL CAPACITY AND EQUAL RECOGNITION UNDER LAW IN ARTICLE 12

In 2001, the UN embarked on the process of drafting a treaty on the human rights of persons with disabilities. This process was led by people with disabilities from all over the world.<sup>63</sup> Five years later, on December 13, 2006, the UN General Assembly adopted the final version of the CRPD.<sup>64</sup> The CRPD is based on the social model of disability, including respect for the individual’s autonomy and the right of all

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<sup>58</sup> Org. of Am. States [OAS], *Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities*, AG/RES. 1608 (XXIX-O/99) (June 7, 1999), <http://www.oas.org/juridico/english/treaties/a-65.html>.

<sup>59</sup> *Id.* art. I, ¶ 2.

<sup>60</sup> Pan-Am. Health Org. [PAHO], *Montreal Declaration on Intellectual Disabilities* (Oct. 6, 2004), <http://www.opadd.on.ca/News/documents/montrealdeclarationMTL.pdf>.

<sup>61</sup> *Id.*

<sup>62</sup> *Id.*

<sup>63</sup> On the unique drafting process of the CRPD, see generally Arlene S. Kanter, *The Promise and Challenge of the United Nations Convention on the Rights of Persons with Disabilities*, 34 SYRACUSE J. INT’L L. & COM. 287 (2006).

<sup>64</sup> CRPD, *supra* note 2.

people, with and without disabilities, to make decisions about their own lives.<sup>65</sup> In its fifty articles, together with its optional protocol, the CRPD addresses all aspects of life, including the right to independent living, accessibility of the environment, inclusive education, health, and access to justice.<sup>66</sup> The CRPD also recognizes the right to equal recognition before the law and legal capacity for all persons—with and without disabilities, regardless of their cognitive aptitudes or physical or sensory limitations.<sup>67</sup> As of October 2017, 174 countries have ratified the CRPD, including Israel, which ratified the CRPD on September 28, 2012.<sup>68</sup>

The CRPD is both a legal document and a moral declaration about the human rights of persons with disabilities. Its spirit, principles, and provisions now must find expression in domestic legislation and jurisprudence. Yet, even now, before such domestic laws are adopted, and alternative services to guardianship have been developed in the various countries, the CRPD has become the driving force for change in guardianship laws and practices all over the world.<sup>69</sup>

The overall goal of the CRPD is to ensure that people with disabilities are entitled to the full protection of existing human rights laws. As it states in Article 1, the purpose of the CRPD is “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.”<sup>70</sup> In essence, the CRPD is intended to eradicate legal distinctions based on unwarranted assumptions about a person’s abilities. Article 12, specifically, creates a new approach to decision-making and confers upon all people with disabilities legal capacity, while also recognizing that some people will need some type of assistance in order to exercise their legal capacity some, or all, of the time.<sup>71</sup> Article 12 of the CRPD explicitly affirms the right to equal recognition before the law for all adults with disabilities.<sup>72</sup> Article 12 therefore calls for the protection of the rights of persons with disabilities to legal capacity, while calling for a reconsideration of the substituted decision-making focus that is included in most, if not all, guardianship laws around the world.<sup>73</sup> As Article 12 states, “persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life,” and that States Parties must provide persons with disabilities with any

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<sup>65</sup> *Id.*

<sup>66</sup> *Id.*

<sup>67</sup> *Id.*

<sup>68</sup> See *Depositary*, UNITED NATIONS TREATY COLLECTION, [https://treaties.un.org/pages/ViewDetails.aspx?src=IND&mtdsg\\_no=IV-15&chapter=4&clang=\\_en](https://treaties.un.org/pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-15&chapter=4&clang=_en) (last visited Nov. 5, 2017).

<sup>69</sup> KANTER, *supra* note 4, at 235–90.

<sup>70</sup> CRPD, *supra* note 2, art. 1.

<sup>71</sup> *Id.* at art. 12.

<sup>72</sup> *Id.*

<sup>73</sup> Comm. on the Rights of Persons with Disabilities, General Comment on Article 12: Equal Recognition Before the Law, U.N. Doc. CRPD/C/11/4 (Nov. 25, 2013).



support they may require in order to exercise their legal capacity.<sup>74</sup> Article 12, paragraph 3 therefore provides that “States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”<sup>75</sup> Although this paragraph does not refer specifically to the term “supported decision-making,” its intent is to replace the substituted decision-making system in most guardianship laws with a new supported decision-making model.

Article 12, therefore, marks a departure from the substituted decision-making model that has been the basis for most guardianship laws around the world. It introduces a new alternative that has become known as “supported decision-making.” To safeguard a person’s right to make decisions, with support, as needed, Article 12 also includes a provision for safeguards in every measure relating to the exercise of legal capacity.<sup>76</sup> Finally, Article 12 emphasizes the right of individuals with disabilities to autonomy in financial affairs, including inheritance, property ownership, bank loans, and all types of credit.<sup>77</sup>

#### A. *The Drafting History of Article 12*

It is no surprise that an article which calls for the equal recognition under law of all people with disabilities caused some controversy. Although Article 12 was eventually approved by consensus, the history of the drafting process of Article 12 reflected deep divisions among countries regarding the very nature of human rights, generally, and the right to legal capacity for people with certain disabilities in their respective societies.<sup>78</sup> On one hand, some countries and organizations went on record contending that all people with disabilities have legal capacity and must be presumed to be legally competent. To these countries, legal capacity is a universal human right that must be protected unequivocally.

On the other hand, a minority of countries expressed an opposing view, arguing that legal capacity is not a universal right but rather one to which only competent people (as defined in their countries) are entitled. According to this view, states should be free to decide who is entitled to legal capacity and who is not. The Ad Hoc Committee on the CRPD

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<sup>74</sup> CRPD, *supra* note 2, art. 12.

<sup>75</sup> *Id.* ¶ 3.

<sup>76</sup> *Id.*

<sup>77</sup> *Id.*

<sup>78</sup> See Ad Hoc Comm. on a Comprehensive and Integral Int’l Convention on Prot. & Promotion of the Rights & Dignity of Persons with Disabilities, *Background Conference Document Prepared by the Office of the United Nations High Commissioner for Human Rights: Legal Capacity* (Aug. 2015), <http://www.un.org/esa/socdev/enable/rights/ahc6documents.htm>.

rejected this minority view, and Article 12 makes clear that the right to legal capacity applies to all people with all types of disabilities.<sup>79</sup>

The final version of Article 12, therefore, recognizes that while people have different needs and abilities, as well as different preferences regarding their support needs, their right to legal capacity is universal and unequivocal. This reading of Article 12 is supported by Article 2, which requires reasonable accommodations to be provided to ensure “persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.”<sup>80</sup> Such reasonable accommodations include the right to support, as mentioned in Article 12, paragraph 3.<sup>81</sup>

Paragraph 3 of Article 12 was specifically included to address the support needs of people who may not be able to make or carry out all of their decisions on their own. It provides that “States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”<sup>82</sup> Although Article 12, paragraph 3 does not refer specifically to the term “supported decision-making,” its intent is to replace substituted decision-making with a new supported decision-making model.

The drafters of the CRPD also included Article 12, paragraph 4 to ensure safeguards against abuse of support. Article 12, paragraph 4 reads as follows:

State Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.<sup>83</sup>

Article 12, paragraph 4 was added to protect people with disabilities who have high support needs, such as those unable to communicate verbally, or those who lack certain cognitive or functional abilities. Such people often are denied full personhood and legal capacity and would have continued to be denied legal capacity in many countries had Article 12 not included the right to support and safeguards against abuse contained in Article 12, paragraphs 3 and 4.

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<sup>79</sup> KANTER, *supra* note 4, at 258.

<sup>80</sup> CRPD, *supra* note 2, arts. 2, 12, ¶ 3.

<sup>81</sup> *Id.* at art. 12, ¶ 3.

<sup>82</sup> *Id.*

<sup>83</sup> *Id.* ¶ 4.

Indeed, the duty to provide support to enable even people with the most significant impairments their right to exercise legal capacity, together with the definition of disability that includes people with all types of disabilities, confirms that Article 12 was intended to confer legal capacity on all persons with disabilities, without exceptions.

Accordingly, the final version of Article 12, entitled “Equal Recognition Before the Law,” guarantees that *all* persons with all types of disabilities enjoy not only the right to legal capacity but also the right to exercise their legal capacity on an equal basis with others without disabilities.<sup>84</sup> As such, Article 12 challenges long-standing paternalistic laws and policies that had deprived people with disabilities throughout the world of their right to make and exercise decisions that people who are not labeled as disabled are free to make every day. By ensuring the right of legal capacity to all people, with all types of disabilities, the drafting Committee made clear that disability may never be a legitimate reason to deny anyone equal recognition before the law, at least not under international human rights law.

Interestingly, some have argued that Article 12 is not intended to extend legal capacity for all people with disabilities.<sup>85</sup> However, if the CRPD were intended to limit Article 12 to only some people with certain disabilities, then the Ad Hoc Committee on the CRPD would likely have included such language in the final version of Article 12. Indeed, the drafting Committee was not opposed to adding limiting language, as it did in Articles 2 and 5, where the Committee limited the right to accommodations to only those that are “reasonable.”<sup>86</sup> No such limiting language is included in Article 12, however.

### B. *The Language and Scope of Article 12*

The drafters of the CRPD were well aware of the fact that in many countries around the world, guardianship laws rely on a model of substituted decision-making in which guardians are not required to consult with the person under guardianship, not to mention make decisions that the person would have made. Indeed, because a guardian is free to substitute his own decision for the person's decision, the guardian is legally permitted to make decisions that the person may oppose. In such cases, there is little or no opportunity to overturn the guardian's decision. Accordingly, the drafters of Article 12 rejected the substituted decision-making model and included instead the

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<sup>84</sup> *Id.*

<sup>85</sup> See LAW COMMISSION ONT., LEGAL CAPACITY, DECISION-MAKING AND GUARDIANSHIP: FINAL REPORT (Mar. 2017), <http://www.lco-cdo.org/en/our-current-projects/legal-capacity-decision-making-and-guardianship>.

<sup>86</sup> CRPD, *supra* note 2, arts. 2, 5.

requirement of support for people who need help in exercising their legal capacity.<sup>87</sup> In fact, some scholars and activists alike argue that all determinations of incapacity must now be eliminated and must be replaced by a system of decision-making that is premised on a support model.<sup>88</sup>

Included within Article 12, are two related but distinct concepts: equal recognition before the law and legal capacity. The concept of equal recognition of the law refers to a “legal personality,” or the right of an individual to appear as a person before the law and to have the rights and obligations of a person recognized by the law. Generally, once a person becomes an adult, he or she is entitled to equal recognition of the law, which is a prerequisite for the enjoyment of any and all other human and civil rights. With equal recognition also comes the right to exercise one’s legal capacity. This entails the right to engage in legal transactions and, perhaps most importantly, to make decisions about one’s own life. Legal capacity, therefore, addresses the capacity of the individual to be the subject of rights and obligations under law as well as the capacity to act under law. Historically, people with disabilities have been denied their right to equal recognition under law. Such denial has been based on unwarranted assumptions about the mental capacity and decision-making abilities of people labeled as disabled. Without legal capacity, however, a person with a disability is denied the right to make all or some decisions and to act on those decisions.

Article 12 addresses both legal personhood and legal capacity to act. It clarifies that it is a violation of international human rights law, *per se*, for any individual to be denied recognition before the law or legal capacity on the basis of disability. The right to equal recognition before the law for all people with disabilities is included in paragraph 1 of Article 12 which “reaffirm[s] that persons with disabilities have the right to

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<sup>87</sup> General Comment on Article 12: Equal Recognition Before the Law, *supra* note 73, intro. ¶ 7.

<sup>88</sup> KANTER, *supra* note 4, at 236 (citing Tina Minkowitz, *The United Nations Convention on the Rights of Persons with Disabilities and the Right to be Free from Nonconsensual Psychiatric Interventions*, 34 SYRACUSE J. INT’L L. & COM. 405 (2006)). On the importance of a careful reading of Article 12, see Amita Dhanda, *Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?*, 34 SYRACUSE J. INT’L L. & COM. 429, 445, 460–61 (2007) (noting that although the text of Article 12 does not prohibit substituted decision-making, it represents a paradigm shift). See also Michael L. Perlin, “*Striking for the Guardians and Protectors of the Mind*”: *The Convention on the Rights of Persons with Mental Disabilities and the Future of Guardianship Law*, 117 PENN. ST. L. REV. 1159 (2013); Salzman, *supra* note 27; Salzman, *supra* note 33. See generally Oliver Lewis, *Advancing Legal Capacity Jurisprudence*, 6 EUR. HUM. RTS. L. REV. 700 (2011); MICHAEL BACH & LANA KERZNER, LAW COMM’N ONT., A NEW PARADIGM FOR PROTECTING AUTONOMY AND THE RIGHT TO LEGAL CAPACITY: ADVANCING SUBSTANTIVE EQUALITY FOR PERSONS WITH DISABILITIES THROUGH LAW, POLICY AND PRACTICE (Oct. 2010), <https://www.lco-cdo.org/wp-content/uploads/2010/11/disabilities-commissioned-paper-bach-kerzner.pdf>; *Legal Opinion on Article 12 of CRPD*, INT’L DISABILITY ALL. (2010), <http://www.internationaldisabilityalliance.org/resources/legal-opinion-article-12-crpd>.

recognition everywhere as persons before the law.”<sup>89</sup> This statement is based on Article 16 of the ICCPR that had previously recognized “everyone” “everywhere” as persons before the law.<sup>90</sup> Consequently, Article 12, paragraph 1 of the CRPD reiterates that the everyone of Article 16 does not exclude persons with disabilities.<sup>91</sup> Thus, the effect of Article 12, paragraph 1 is to impose on States Parties the obligation to repeal any laws or policies that include distinctions based on disability. Any law or practice by which a person with a disability is not registered at birth, refused a document of identity, disqualified from inheriting property, or otherwise recognized under law would be a violation of Article 12, paragraph 1.

The second paragraph of Article 12 specifically affirms the right of “persons with disabilities [to] enjoy legal capacity on an equal basis with others in all aspects of life.”<sup>92</sup> This provision relates to the right of a person to exercise his or her legal capacity and to act on it.

Article 12, paragraph 3 places on States Parties the obligation to make provisions for support for people who need it to exercise their legal capacity.<sup>93</sup> The type of support envisioned in Article 12, paragraph 3 could be family, friends, personal assistants, or simply a written declaration stating the person’s preferences regarding certain decisions. Further, Article 12, paragraph 3 requires that the support should also be based on trust, and be provided with respect and not against the will of the person with a disability. One of the reasons for the requirement of support is to encourage people to seek assistance, which they often do not do for fear of being subjected to guardianship or worse—neglect, physical abuse, or involuntary institutionalization.

Article 12, paragraph 4 also recognizes the need for support for some people with disabilities.<sup>94</sup> Therefore, this paragraph requires that safeguards be put in place to protect people with disabilities from abuse.<sup>95</sup> However, such safeguards must be proportional to the degree to which such measures affect the person’s rights and interests.<sup>96</sup>

Finally, Article 12, paragraph 5 requires States Parties to ensure that people with disabilities are protected with respect to financial and property transactions.<sup>97</sup> This paragraph requires States Parties to take all appropriate and effective measures to ensure the equal rights 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

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<sup>89</sup> CRPD, *supra* note 2, art. 12, ¶ 1.

<sup>90</sup> International Covenant on Civil and Political Rights, *supra* note 48, 999 U.N.T.S. at 177.

<sup>91</sup> CRPD, *supra* note 2, art. 12, ¶ 1.

<sup>92</sup> *Id.* ¶ 2.

<sup>93</sup> *Id.* ¶ 3.

<sup>94</sup> *Id.* ¶ 4.

<sup>95</sup> *Id.*

<sup>96</sup> *Id.*

<sup>97</sup> *Id.* ¶ 5.

of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.”<sup>98</sup> Insofar as domestic laws may disqualify some persons with disabilities from managing their own financial affairs, ratifying countries would be required to repeal such laws and replace them with laws that authorize appropriate support in order to meet the requirements of Article 12, paragraph 5.

In sum, Article 12 marks an important paradigm shift from the practice of depriving people of their right to personhood simply on the basis of their perceived lack of capacity to the promotion of national policies and laws that comport with well-established international human rights principles of autonomy, dignity, and independence. In this way, Article 12 of the CRPD calls into question the entire system of guardianship that is used in many countries throughout the world. According to Article 12, the fact that a person with a disability may need assistance, even a great deal of assistance, does not provide a legal justification for the State to deny the person the right to make his or her own decisions.<sup>99</sup> Because Article 12 also recognizes that some people may need help in making decisions some or all of the time, it also requires the State to develop systems of support, with protections against abuse, to be implemented in proportion to the degree of support needed. Thus, for the first time under international human rights law, Article 12 establishes not only the right to equal recognition before the law for all people with disabilities, but also the new right to support in decision-making.<sup>100</sup>

Since its adoption, Article 12 has become the focus of domestic reform in several countries. As discussed below, these countries are now choosing to re-evaluate their domestic guardianship laws. Courts, too, have begun to approach guardianship with more skepticism. In addition, civil society and disabled people’s organizations have begun to develop supported decision-making models that guarantee full legal capacity, even to individuals who need a great deal of support in order to exercise their right to decision-making. The following Part is a discussion of developments in Israel with respect to implementation of Article 12, followed by a discussion of legislative developments in other countries in Europe and the Americas.

#### IV. ISRAEL’S RESPONSE TO ARTICLE 12 OF THE CRPD

Israel is an example of a country that has worked to develop a

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<sup>98</sup> *Id.*

<sup>99</sup> See generally *id.* at art. 12.

<sup>100</sup> See KANTER, *supra* note 4, at 5 (arguing that although the drafters of the CRPD did not intend to create any new human rights, the CRPD does include the new human right to “support”).

domestic law that complies with Article 12. Over the last twenty years, especially since the enactment of the Israeli Equal Rights Law in 1998, Israeli society has begun to abandon the medical model of disability in favor of the social model of disability, at least with respect to people with physical and sensory disabilities. For people with intellectual and psychosocial disabilities as well as people with autism, the medical model of disability remains a barrier to their full inclusion in society. Individuals with physical and sensory disabilities are now integrated into ordinary workplaces, but many people with intellectual and psychosocial disabilities as well as autism remain segregated in institutions and group homes; and if they do find work, it is often in sheltered workshops and segregated factories rather than in mainstream workplaces.<sup>101</sup> Moreover, while accommodations in workplaces are now legally required and often provided by employers for persons with mobility or sensory impairments, accommodations for people with intellectual disabilities or autism (such as job coaches and other workplace adjustments) are generally unavailable. Moreover, while neighbors may welcome the integration of individuals with physical disabilities or people who are blind, deaf, or hard of hearing in their communities, neighbors often object to people with intellectual disabilities, psychosocial disabilities, or autism living next door.<sup>102</sup> As described more fully below, unlike people with physical and sensory disabilities, people with intellectual disabilities, psychosocial disabilities as well as autism and other communication issues, are often denied legal capacity. Nonetheless, in the last three years this situation has begun to change, especially with the adoption of an amendment to the Israeli Legal Capacity and Guardianship Law in 2016. The following Sections of this Article provide the background leading up to this amendment, an

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<sup>101</sup> This situation is especially disappointing since Israel passed a law allowing employers to pay people with disabilities less than the minimum wage as a way to promote employment of people with disabilities. In 2006, Israel adopted a new minimum wage law that allows employers to pay a person with a disability according to the person's work ability. As such, the law allows employers to pay workers with disabilities an adjusted (or lower) minimum wage of about one-half or one-third of the national minimum wage. This subminimum wage is used most often in employment settings that involve manufacturing or other repetitive tasks. See Ruth Sinai, *Bosses Allowed to Pay Disabled People Less Than Minimum Wage*, HAARETZ (Oct. 31, 2006, 12:00 AM), <http://www.haaretz.com/news/bosses-allowed-to-pay-disabled-people-less-than-minimum-wage-1.203818>; see also Michal Soffer et al., *Sub Minimum Wage for Persons with Severe Disabilities: Comparative Perspectives*, 13 J. COMP. POL'Y ANALYSIS: RES. & PRAC. 265, 267 (2011).

<sup>102</sup> An indication of the gap between how society treats persons with physical and sensory disabilities, and how it treats persons with intellectual psychosocial impairments, can be found in a study on inclusion which found that society clearly disfavors persons with intellectual disabilities compared to persons with physical disabilities in thought, emotion, behavior, and conceptualization of rights. See SHIRLI WERNER, INDEX FOR THE INCLUSION OF PERSONS WITH INTELLECTUAL DISABILITIES IN ISRAELI SOCIETY (Jan. 2013), <http://www.news1.co.il/uploadFiles/897442042827607.pdf> (Isr.). For instance, forty percent preferred not to have a person with an intellectual disability as a neighbor, and more than fifty percent preferred not to become friends with a person with an intellectual disability. *Id.*

overview of the amendment itself, as well as the changes that have resulted since its adoption.

A. *The Situation Prior to the Amendment to Israel's Legal Capacity and Guardianship Law*

1. Israel's Legal Capacity and Guardianship Law of 1962

The 1962 Israeli Legal Capacity and Guardianship Law 5722-1962 (Israeli Guardianship Law) was one of the oldest guardianship laws in the world, until it was amended in 2016.<sup>103</sup> The Israeli Guardianship Law, like other guardianship laws worldwide, regulates one of the most fundamental of human rights—the right of an individual to legal capacity and to be recognized under law.<sup>104</sup>

The Israeli Guardianship Law refers to two types of legal capacity.<sup>105</sup> The first type of legal capacity recognizes the right of an individual to have rights as well as obligations under law.<sup>106</sup> The second type of legal capacity, commonly referred to as the “capacity to act,” applies to an individual’s right to perform legal acts connected with his rights and obligations, or the person’s right to legal agency.<sup>107</sup> Without legal capacity, a person in Israel (and elsewhere) is not seen as a person under law, and as such, has no right to make any decisions about his own life.

Under the Israeli Guardianship Law, a guardian could be appointed for “a person who . . . is unable to look after all or any of his affairs.”<sup>108</sup> The appointment of a guardian was considered by the State as the best way to protect people with disabilities against exploitation and

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<sup>103</sup> The following was stated in a study ordered by the Israeli parliament, the Knesset, comparing Israeli law to laws in various western countries (e.g., the United Kingdom, Canada, Australia):

Legal Capacity and Guardianship Law 5722-1962, which regulates guardianship in Israel was enacted some 50 years ago, and it is one of the oldest of the laws reviewed in this document. For the sake of comparison only, the second oldest law reviewed in this document was enacted only 25 years ago (the law in Victoria was enacted in 1986). Different countries around the world exhibit a trend toward a re-examination and rephrasing of guardianship arrangements in order to adjust them to current needs.

*Issues in Guardianship Appointments for Adults: Comparative Review*, KNESSET RESEARCH AND INFORMATION CENTER 19 (2011), <http://www.knesset.gov.il/mmm/data/pdf/m02882.pdf> (Isr.). As mentioned below, the Ministry of Justice has completed an amendment bill for the Legal Capacity and Guardianship Law.

<sup>104</sup> Legal Capacity and Guardianship Law, 5722-1962, §§ 1, 2 (Isr.).

<sup>105</sup> *Id.*

<sup>106</sup> *Id.*

<sup>107</sup> *Id.*

<sup>108</sup> *Id.*



was preferable (and even easier) than developing effective monitoring tools that could more directly prevent or end such exploitation. Thus, in theory, this law applied neutrally to all people, not singling out any particular person or diagnosis. However, in practice, the law applied only to persons with intellectual disabilities, psychosocial disabilities, and autism, as well as elderly adults.<sup>109</sup> In fact, up to a few years ago, the Israeli Ministry of Welfare protocols for out-of-home housing services required guardianship appointments for all persons with intellectual disabilities, regardless of their functioning ability.<sup>110</sup>

Not only was the law applied disproportionately to people with certain disabilities, but it also resulted in lifelong plenary guardianships for most people. Until recently, most family court judges ordered guardianships in almost all cases (ninety-four percent of cases).<sup>111</sup> Of those guardianships, most (ninety percent) were plenary guardianships as opposed to limited guardianships. Further, over the past fifteen years, the number of plenary guardianships has doubled in Israel, as has the overall number of individuals living under guardianship.<sup>112</sup>

In addition, the Israeli Guardianship Law allowed the court to order guardianships without even meeting the person and without any evaluation of the person's functioning ability. Although the law did not require medical documentation in support of guardianship, in practice, courts refused to appoint, limit, or end the appointment of a guardian without a medical opinion.<sup>113</sup> Moreover, the only way a person could

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<sup>109</sup> While the Israeli Guardianship Law applies to all types of disabilities, some countries have several legal capacity laws that are adjusted to different groups of people. This serves to intensify discrimination against some groups of people with disabilities. For instance, New York has a general legal provision for guardianship appointment. See N.Y. MENTAL HYG. LAW §§ 81.10, 81.11, 81.15 (McKinney 2006) (which includes many procedural protections—a hearing, the right to legal counsel, mandatory presence at the hearing, and a requirement to provide reasons for the decision). On the other hand, there is another statute dedicated to the appointment of guardians for persons with intellectual disabilities, N.Y. Surr. Ct. Proc. Act §§ 1750, 1754 (McKinney 2011), which allows for full guardianship appointment without representation and without the person's presence, based on a medical diagnosis that makes no reference to different aspects of functioning.

<sup>110</sup> The Israeli Ministry of Welfare regulations from 2003 stipulate: "Housing schemes shall not accept a resident who is over age 18, unless s/he has lawfully been appointed a guardian, and there is court confirmation for said appointment. In exceptional cases, residents may be admitted whilst still undergoing guardianship appointment proceedings." See Ministry of Welfare, Department for Persons with Mental Retardation (Policy Standards, Procedures, and Guidelines on Community Housing for Persons with Mental Retardation), 5773–2012, 49, <http://www.molsa.gov.il/Focus/Documents/%D7%93%D7%95%D7%97%20%D7%95%D7%A2%D7%93%D7%AA%20%D7%94%D7%91%D7%93%D7%99%D7%A7%D7%94.pdf> (Isr.). Continuing this trend, many diagnosis committees exceed their authority and repeatedly rule that persons with intellectual disabilities must be under guardianship.

<sup>111</sup> See Doron, *The Invisibles*, *supra* note 11, at 215.

<sup>112</sup> See Tolub & Kanter, *supra* note 24.

<sup>113</sup> In a survey conducted by Professor Doron in 2004, ninety-nine percent of the files enclosed medical documents. See Doron, *The Invisibles*, *supra* note 11, at 214; see also Legal Capacity and Guardianship (Legal Procedures and Implementation) Regulations 5730-1970, §§ 5, 7 (Isr.) (listing the documents required for filing an application to declare a person

object to the guardianship petition was with a doctor's statement that the person did not need a guardian. Such a statement was, and is, difficult to obtain. This reliance on medical opinions in guardianship cases violates the basic principle of the CRPD which recognizes disability as a human rights issue, not a medical one. Therefore, although Israel ratified the CRPD in 2012, at the time of its ratification, its guardianship law clearly violated Article 12.<sup>114</sup>

## 2. The Role of the Courts in Protecting the Right to Legal Capacity Prior to the Amendment

The Israeli Supreme Court was well aware of the potential deprivation of rights resulting from the Israeli Guardianship Law. Indeed, it repeatedly ruled that appointing a guardian for an adult constituted a violation of his fundamental rights. Yet, as the following discussion illustrates, there is a great difference between the Court's general statement of principles in favor of the rights of people with disabilities to be free from guardianship and the Court's rulings in specific cases.<sup>115</sup>

One of the most significant statements against guardianships was by former Israeli Supreme Court Justice Englard, after he stepped down from the Court. In 1995, Justice Englard published a book about Israel's Basic Law: Human Dignity and Liberty, a law which was enacted in 1992, and one that enjoys constitutional status in Israel.<sup>116</sup> In the chapter on legal capacity, Justice Englard wrote that the Israeli Guardianship and Legal Capacity Law "must be interpreted in a manner that strives to realize the purpose of the Basic Law, which is to protect a person's dignity and liberty, even if this results in somewhat of a departure from the original intent of the Legal Capacity Law."<sup>117</sup>

Following this publication, Justice Englard's view was adopted by

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incompetent and an application for guardianship appointment). Section 5, on declaring incompetence, notes that a physician's report is required in order to file the application, while Section 7, on guardianship appointment applications, does not require a physician's report. *Id.*

<sup>114</sup> There is scant Israeli literature calling for reducing the use of guardianship and considering alternatives. See Doron, *The Invisibles*, *supra* note 11, at 223–25; see also Meytal Segal Reich & Michael (Michy) Schindler, *The Butterfly Effect—from Guardianship for Older People to Supported Decision Making*, 7 MA'ASEI MISHPAT 129 (2015), <http://din-online.info/pdf/maa7-8.pdf> (Isr.); Michael (Micky) Schindler, *Protecting the Welfare of the Elderly and Guardianship Appointment*, 27 HEVRA URVAHA 315 (2007) (Isr.). The Knesset Constitution, Law, and Justice Committee held a session dedicated to "Developing Alternatives to Guardianship." See Transcript of Session 492 of the Constitution, Law, and Justice Committee, 18th Knesset (Dec. 6, 2011) (Isr.).

<sup>115</sup> For a review of judgments regarding guardianship, human rights and legal capacity, and implementation with respect to older adults, see Schindler, *supra* note 114.

<sup>116</sup> IZHAK ENGLARD, LEGAL CAPACITY AND GUARDIANSHIP 5722-1962, 14 (2d ed. 1995) (Isr.).

<sup>117</sup> *Id.*

other Israeli Supreme Court Justices in subsequent cases. For example, in 1995, Justice Strassberg-Cohen ruled that under the Basic Law, care should be exercised when considering the appointment of a guardian. As the Justice wrote:

The Legal Capacity Law is located on the fine line between a person's rights to liberty, dignity, autonomy and property, and society's power, even duty, to ensure that a person who is unable to look after his or her own affairs receives protection in the form of a guardian. When using this power, one must take care to avoid being overly concerned while exhibiting protective paternalism, which in fact constitutes coercion, limits the person's liberty and violates his or her dignity.<sup>118</sup>

This statement by Justice Strassberg-Cohen provided the basis for decisions in other cases in which Israeli courts have held that persons with guardians retain full legal capacity so long as they have not been declared incompetent by the family court.<sup>119</sup>

Although the Israeli Supreme Court has not equated guardianship with incompetency, which seems to comply with a human rights approach towards people with disabilities, this view has not resulted in changed practices towards people with cognitive and psychosocial disabilities. Guardians, as well as service providers, lawyers, family members, and even judges continue to treat individuals who have guardians as incompetent, and as lacking legal capacity. The effect of this approach is particularly disturbing, as the following cases illustrate.

In one case, the Israeli Supreme Court denied standing to a woman who had a guardian and had asked to join as a party to an appeal against a decision to appoint a non-family member as the guardian.<sup>120</sup> The woman sought to inform the Court of her objection to the appointment of the guardian and to ask that her mother be named guardian in place of the organization that sought the guardianship.<sup>121</sup> The Israeli Supreme Court held, however, that "[o]nce the applicant has been declared a ward and appointed a guardian, her legal capacity to act on her own

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<sup>118</sup> File No. 1233/94 LCA, A v. Attorney General (1995), Nevo Legal Database (by subscription, in Hebrew) (Isr.). For similar statements, see CA 4377/04 Holzberg v. Miraz 62(2) PD 661, ¶ 16 (2004) (Isr.) (opinion of Justice Arbel).

<sup>119</sup> This issue has come up in such cases as when a person under guardianship signs a contract without the guardian's approval, and the guardian seeks to cancel the contract on the basis of the person's status as being under guardianship. The Israeli Supreme Court has repeatedly ruled, however, that a person under guardianship is not incompetent and therefore his signature confirming a contract is valid. See, e.g., File No. 6397/04 LCA, Musa Ahmad Hussein Musa al-'Abasi v. ELAD Association (Dec. 6, 2009), Nevo Legal Database (by subscription, in Hebrew) (opinion of Justice Handel) (Isr.). In the *ELAD Association* case, the Court suggested other ways to cancel such agreements, using the general remedies offered in contract law, such as lack of *animus contrahendi*, misrepresentation, and exploitation. *Id.*

<sup>120</sup> File No. 2019/09 CSA, A v. Attorney General via Ministry of Welfare Counsel (May 18, 2009), Nevo Legal Database (by subscription, in Hebrew) (Isr.).

<sup>121</sup> *Id.*

behalf has been denied and she may not join as party to the proceeding.”<sup>122</sup> Thus, even here, when the woman under guardianship sought only to participate in the guardianship proceeding itself to share her view regarding who she preferred as her guardian, and not to object to the appointment of the guardian itself, she was denied the right to participate.<sup>123</sup>

In another Israeli Supreme Court decision concerning requests by individuals under guardianship to move out of institutions into community housing, the Court held that once a guardian had been appointed, the individual under guardianship could not appeal the decision to place him or her in an institution without the guardian’s approval, or a family court order.<sup>124</sup>

Similarly, in a third case, the Israeli Supreme Court ruled that a person under guardianship can take no legal action, or even hire a lawyer to oppose the guardianship, without the guardian’s approval.<sup>125</sup> As the Court wrote:

The guardian, in effect, replaces the will of the ward in matters in which it has been determined the ward is unable to make a decision. Whereas, when a person is a ward, but there is no guardian acting on his or her behalf, the person cannot and may not employ his or her will for the purpose of legal activities. Even if the ward had been represented by counsel, he or she would have been unable to use counsel’s services to the full extent, given his or her inability to consent to having certain acts carried out on his or her behalf.<sup>126</sup>

In short, the gap between what the Israeli Supreme Court may believe with respect to the right to legal capacity for people with disabilities, and what the Court actually decided in specific cases, illustrates the challenges facing people with disabilities who are subjected to guardianship in Israel and perhaps elsewhere as well. On one hand, the Israeli Supreme Court acknowledged that guardianship limits the exercise of the human rights of people with disabilities; but on the other hand, it has been unable to prohibit the use of guardianship, even when the Court itself recognizes the inconsistency between

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<sup>122</sup> *Id.* ¶ 6. The appeal was filed by the mother, who generally opposed the appointment of a guardian, and particularly the appointment of an external guardian. The Court noted that the woman in question was not acting according to her free will, and that she was under undue influence from her mother. Though the court should consider this factor when making a substantive decision, it is insufficient for denying standing in court.

<sup>123</sup> *Id.*

<sup>124</sup> File No. 1989/11 HCJ, A v. Ministry of Welfare and Social Services (Aug. 17, 2011), Nevo Legal Database (by subscription, in Hebrew) (Isr.).

<sup>125</sup> File No. 326/07 LCA, A v. Harel Insurance Ltd. (July 30, 2009), Nevo Legal Database (by subscription, in Hebrew) (Isr.) (opinion of Justice Arbel). It should be noted that the Court could have reached the same conclusion without stating that the person cannot and may not employ his will for the purpose of legal activities.

<sup>126</sup> *Id.*

guardianship and established norms of human rights laws and principles.

Within this context, a 2005 judgment issued by Justice Shapira of the District Court of Jerusalem is especially significant because it rejected the use of guardianship on the grounds that it violates human rights laws and principles.<sup>127</sup> In this case, a sixty-nine-year-old woman who was diagnosed with bipolar disorder and objected to guardianship appealed her guardianship order.<sup>128</sup> The State had initiated the guardianship proceeding against her based on a physician's recommendation.<sup>129</sup> In support of the guardianship petition, the State cited the uncleanliness of her home as evidence of her inability to care for herself.<sup>130</sup> The court rejected the State's position and cancelled the guardianship appointment by adopting a new test for the appropriateness of guardianship. In this case, the court stated that a guardian should be appointed based on the principle of proportionality.<sup>131</sup> In other words, if protection of the person can be achieved only with a guardian, then the guardian may be appointed; but, if there are other ways to protect the particular person, then those alternatives should be considered before a guardian may be appointed. The court in this case refused to appoint the guardian, but did order a co-signer for certain financial transactions.<sup>132</sup> According to the court's order, the woman would be able to withdraw up to half of her monthly income from her bank account but any additional withdrawals would require the co-signer's signature.<sup>133</sup> It is important to note, too, that the woman in this case did not object to the co-signing arrangement and that the court required the co-signer to be someone whom the woman chose.<sup>134</sup>

In short, this case provides an example of how alternatives to

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<sup>127</sup> File No. 815/05 CSA (Jer), A v. Attorney General (Nov. 30, 2005) (Isr.) (unpublished).

<sup>128</sup> *Id.*

<sup>129</sup> *Id.*

<sup>130</sup> *Id.* This case demonstrates many of the arguments we make in this Article. Many homes are not clean but this would only serve as reason to deny legal capacity when the person involved has a disability. The description of the woman that appears in the judgment is based on the medical diagnosis (i.e., that she lacked judgment, and was restless and depressive, etc.) and strips her of any personal and human attributes, such as her preferences, lifestyle, profession, etc. Counsel for the Attorney General based her position primarily on this medical opinion, thus giving a psychiatrist the power to determine human rights questions.

<sup>131</sup> *Id.*

<sup>132</sup> *Id.*

<sup>133</sup> *Id.*

<sup>134</sup> File No. 18541-05-12 DC (PT), A v. B (Jan. 31, 2012) (Isr.) (unpublished guardianship application where the court ordered a cap on withdrawals and a requirement for an additional signature, while refraining from appointing a guardian for a person with psychosocial and mental disabilities who has a history of debt; there are negative alternatives in the medical sphere as well, which include, in rare cases, intervention in treatment options without the appointment of a guardian, whether through a judicial injunction or an ethics committee decision ordering the performance of a medical act under the Patients' Rights Law, 5756-1996, § 15(2)).

guardianship have been used in Israel and may be developed elsewhere in the context of individual guardianship cases, even in the absence of domestic law authorizing supported decision-making. In this case, the court recognized that in order to preserve the person's legal status, less restrictive, but no less effective, measures could be put in place to limit the person's decision-making regarding the use of her property. Although such restrictions are still objectionable under the CRPD since they limit the right of a person with a disability to make some decisions (i.e., financial), allowing the woman to select and use a co-signer, in this case, allowed her to live her life according to her preferences, and to retain her legal capacity under law.

In 2013, another important case was decided by an Israeli family court judge, in which the court introduced supported decision-making for the first time in Israel.<sup>135</sup> In this case, Dana, a thirty-seven-year-old woman who had been diagnosed with an intellectual disability, was appointed a guardian to handle her financial affairs after her parents passed away.<sup>136</sup> Dana expressed reservations about having a guardian, particularly her guardian's decision not to allow her to take a university entry-exam preparation course.<sup>137</sup> The guardian had objected to the course because the guardian thought Dana's chance for success on the exam was low.<sup>138</sup> With the legal assistance of Bizchut, Dana petitioned the family court to end her guardianship.<sup>139</sup> In an unusual step, the Office of the State Attorney General, as well as Dana's welfare worker, supported her petition.<sup>140</sup> The court approved the petition and, for the first time in Israel, the court recognized supported decision-making as an alternative to guardianship.<sup>141</sup> Justice Esperanza Alon of the Haifa Family Court revoked Dana's guardianship and restored her legal capacity.<sup>142</sup> The court ordered Dana to receive the support she needs to manage her own affairs, rather than have a guardian manage her affairs for her.<sup>143</sup> The court also found that when the guardian did manage Dana's affairs in the past, Dana felt humiliated by being denied the right to make her own decisions.<sup>144</sup> Dana also asked the court to appoint an accountant to support her in her financial decisions as well as to approve bank withdrawals above a certain amount.<sup>145</sup> The court accepted Dana's suggestion based on the 1962 Israeli Guardianship Law

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<sup>135</sup> File No. 50389-02-13 DC (Hi), Attorney General v. A (Aug. 26, 2013) (Isr.) (unpublished guardianship application).

<sup>136</sup> *Id.*

<sup>137</sup> *Id.*

<sup>138</sup> *Id.*

<sup>139</sup> *Id.*

<sup>140</sup> *Id.*

<sup>141</sup> *Id.*

<sup>142</sup> *Id.*

<sup>143</sup> *Id.*

<sup>144</sup> *Id.*

<sup>145</sup> *Id.*

which enables the judge to take any measures needed to promote the interests of the person.<sup>146</sup> In its decision, the court also defined, for the first time in Israel, the role and obligations of the supporter, which are: (1) to help Dana gather and receive, from any person or institution, any information she requires in order to make decisions; (2) to help Dana understand the information relevant to the decisions she has to make; (3) to help Dana state her decisions to any person or institution, or to state them for her, according to her decision; (4) to help Dana act on her decisions; and (5) to represent Dana to any person or institution where such representation is necessary.<sup>147</sup> Justice Alon's ground-breaking ruling in this case demonstrates how an Israeli court used existing law to conform with the CRPD's mandate of legal capacity for all.

Two years later, the same judge issued another landmark ruling, explaining why supported decision-making should replace guardianship in Israel.<sup>148</sup> In this case, the court appointed a supporter (a friend) for a woman with Alzheimer's Disease who was represented by Legal Aid.<sup>149</sup> As the judge wrote:

The proposed model has many advantages—it does not deny the Petitioner/Supported Person full control over her life, quality of life and wellbeing. It empowers her, provides her with security, reinforces her sense of independence and does not veto control over her life, as in the principle of “do not cast me off in the time of old age” (Psalm 71). The guidance she receives from the Supporter is given supervision and control with respect to the quality and nature of management and the satisfaction of her needs. The Supporter is obligated to allow the Supported Person to protect her independence, free will and choice. Her consent to the provision of support is gratuitous and voluntary, and in consequence of the longstanding acquaintance of the two of them. The Supporter knows that the Supported Person may at any time unilaterally notify her of the cancellation of support and that this is sufficient to invalidate the support on her behalf. The Supporter is obligated to submit a notice to the Haifa Municipality Welfare Department, without delay. The Supporter undertakes to participate in the professional meeting to take place once a month . . . . Looking to the future, I foresee that the implementation of the model in the field will bring about doubts and difficulties—a blurring of the boundaries between this model and the existing and conservative model—of guardianship, situations of crisis between the Supporter and the Supported Person, whether a professional and external supporter is preferable, or whether priority should be accorded to a familiar figure, whether the proposed model

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<sup>146</sup> *Id.*

<sup>147</sup> *Id.*

<sup>148</sup> File No. 43640-01-15 DC (Hi), A v. Custodian General (Isr.) (unpublished guardianship application).

<sup>149</sup> *Id.*

gives guidance which befits cases where the property aspects are more complex or whether it should only be adopted in cases where income is limited and known and other questions which will be raised and brought from the field of experience. However, I believe that this model should be adopted and implemented, which grants the Petitioner autonomy, respects her dignity and independence, with proportional protection. The nature and quality of the guidance are subject to supervision and control on an ongoing basis. The Petitioner is tailored with a “custom suit” fitted to her needs and she benefits from the personal and close guidance. This mechanism also provides a response to the immense burden on the welfare services, although not exempting the welfare services from their function and obligation.<sup>150</sup>

This decision was another important step towards the realization of supported decision-making under Israeli law, and may provide a model for court decisions elsewhere.

## V. ISRAEL'S NEW SUPPORTED DECISION-MAKING LAW

### A. *Background of the Amendment to the Legal Capacity and Guardianship Law*

On March 29, 2016, the Israeli Parliament voted in favor of amending the Legal Capacity and Guardianship Law. On April 11, 2016, the law came into effect.<sup>151</sup> This amendment recognizes supported decision-making for the first time in an Israeli law. Although the amendment fails to prohibit the use of guardianship in all cases, it does limit its use as a last resort, and only when no less-restrictive alternatives are available. The Israeli Ministry of Justice originally proposed the amendment. However, it was civil society that played a critical role in drafting the language of the amendment and working for its passage.

The leading civil society organization in this effort was Bizchut, the Israel Center for Human Rights of People with Disabilities, that has devoted much of its work over the past few years to raising awareness about the problems with guardianship. Bizchut's efforts include

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<sup>150</sup> *Id.*

<sup>151</sup> See Suzanne Cannon, *Supported Decision-Making Law Approved by the Knesset*, NAT'L RES. CTR. FOR SUPPORTED DECISION-MAKING (Apr. 4, 2016), <http://www.supporteddecisionmaking.org/news/supported-decision-making-law-approved-knesset>; see also Yair Altman, *Guardianship Law Amendment Approved Ministerial Legislation Committee*, ISR. TODAY, Mar. 27, 2016 (Isr.); Shirit Avitan-Cohen & Makor Rishon, *Their Independent Day*, MAKOR RISHON, Apr. 1, 2016 (Isr.); Yigal Arnon et al., *Amendment to the Law of Legal Capacity and Guardianship Ongoing Power of Attorney and Decision Making Support*, LEXOLOGY (May 4, 2017), <https://www.lexology.com/library/detail.aspx?g=41bd4350-47a2-4631-bc7a-d45c88f0f034>.



publishing toolkits on alternatives to guardianship<sup>152</sup>; creating YouTube video testimonies of people who were under guardianship<sup>153</sup>; advocating in court for alternatives to guardianship in specific cases, as discussed above; and, participating in international discussions and conferences on implementation of Article 12 in domestic law.

In 2014, Bizchut initiated two specific projects designed to raise awareness about the need to reform Israeli's Guardianship Law. The first project was to organize a broad coalition of nineteen different organizations to work together to promote legal capacity. This coalition included organizations of people with disabilities, disability rights organizations, parents' organizations, human rights organizations, and organizations representing elderly people. It was the first time that organizations of people with disabilities worked together with organizations representing elderly people to draft a new law. As this coalition was meeting, the government was drafting its own proposal for an amendment to the Israeli Guardianship Law. After a year of meetings, the coalition developed its own list of changes in the law that were not included in the government's proposed amendment, including, and most importantly, supported decision-making as an alternative to guardianship.

The second project of Bizchut, a project of the European Union, was the design and implementation of a supported decision-making pilot. This pilot involved twenty-two people with a wide range of disabilities who were given a supporter in order to avoid the initial appointment of a guardian or to end the need for their guardian. This pilot was the first of its kind in the world. Further, some of the people with disabilities who participated in the pilot later addressed Parliament in support of the amendment.<sup>154</sup>

#### B. *The 2016 Amendment to the Legal Capacity and Guardianship Law*

Five months after the amendment to the Israeli Guardianship Law was introduced, and after nearly twenty different Parliamentary sessions on the bill, the Israeli Parliament voted in favor of amending the Law. The amendment includes several significant changes to Israeli law.<sup>155</sup> These changes include the legal recognition of supported decision-

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<sup>152</sup> See YOTAM TOLUB, BIZCHUT, ALTERNATIVES TO GUARDIANSHIP IN FINANCIAL AFFAIRS (Apr. 3, 2016), <http://bizchut.org.il/en/573>.

<sup>153</sup> See Suzanne Cannon, *Article 12 Comes to Youtube*, BIZCHUT (Feb. 15, 2016), <http://bizchut.org.il/en/551>.

<sup>154</sup> For more information regarding the pilot, see BIZCHUT, SUPPORTED DECISION-MAKING SERVICE FOR PERSONS WITH DISABILITIES: SERVICE MODEL (Maya Johnston trans., 2016), <http://bizchut.org.il/he/wp-content/uploads/2017/06/Support-system-Model-Bizchut.pdf>.

<sup>155</sup> For a more detailed introduction to the amendment, see *id.* at 57–60. See also Legal Capacity and Guardianship Law, 5722-1962 (Isr.).

making for the first time in an Israeli law; the legal recognition of enduring powers of attorney; revocation of the term “ward”; a limitation on the use of guardians to only those cases in which guardians are necessary to prevent harm to the person in question and when no less restrictive measure is available; and, a prohibition on the appointment of a plenary guardian as well as the requirement that the court specify the matters which a guardian may decide.<sup>156</sup> The amendment also defines a person’s wishes rather than the best interest of the person as the guiding principle for a guardian’s decision-making. In addition, the amendment recognizes certain substantive rights of people under guardianship, including the right to receive information from the guardian, the right to free legal counsel in cases involving medical decisions, the right to independence, and the right to privacy.<sup>157</sup> The amendment also limits the guardian’s ability to “impose a decision on fundamental issues.”<sup>158</sup>

The new amendment also includes two alternatives to guardianship, both of which emphasize the right of the person to exercise his or her will and autonomy.<sup>159</sup> The first alternative is the legal recognition of supported decision-making.<sup>160</sup> This provision allows the court to designate one or more persons to help someone who is having difficulties making decisions. The person has to agree to receive the supporter and the supporter cannot make any decisions on behalf or instead of the person. The role of the supporter is only to assist the person in making decisions according to the person’s wishes by obtaining information relevant to the decision, explaining alternatives, or assisting the person to realize his or her own decision. The amendment regulates supported decision-making by defining the role and power of the supporter.

The second alternative to guardianship is the “enduring power of attorney,” which allows a person (while he or she is mentally competent) to appoint a representative who will be authorized to act on his or her behalf and make his or her decisions, in the event the person, at some point, loses the ability to make decisions.<sup>161</sup> This alternative is still based on the substitute decision-making model although it enables the person to have more control in some situations.

The Israeli government has offered its own praise for the amendment in the Country Report it submitted to the CRPD

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<sup>156</sup> Legal Capacity and Guardianship Law, 5722-1962, arts. 33a(a), 33a(d), 67(b), 67f(b) (Isr.).

<sup>157</sup> *Id.*

<sup>158</sup> See art. 67(f) (mainly concerning medical and other important personal decisions such as where to live).

<sup>159</sup> *Id.*

<sup>160</sup> *Id.* art. 67(b).

<sup>161</sup> *Id.* arts. 32a–33.

Committee.<sup>162</sup> All countries that ratify the CRPD are required to submit their first report to the CRPD Committee, within two years of ratification, according to Article 35 of the CRPD.<sup>163</sup> The Israeli government submitted its first report in 2017.<sup>164</sup> In it, Israel affirms that the amendment is based on the following principles which are consistent with the CRPD:

- a. The ‘necessity principle’-a guardian should not be appointed for a person, unless there is a genuine necessity to protect that person’s rights and interests.
- b. The ‘least restrictive measure principle’-no measures that limit the rights of the person or her/his freedom should be used if there is a less restrictive measure that fulfills the same purpose . . . [and] no guardian shall be appointed if it is possible to fulfill the purpose by using less restrictive measures . . .<sup>165</sup>

Although civil society pushed to annul the “best interest principle” and change it to require that decisions be made according to the person’s will and preferences, this proposal was not accepted.<sup>166</sup> Nonetheless, the amendment, as passed, still obliges the guardian to decide according to the person’s will unless that decision will cause harm to the individual, and in that case, the best interest standard may prevail over the person’s expressed will and preferences.<sup>167</sup>

- d. The ‘self-determination principle’-a person should have the right to make [their] own decisions, if possible, regarding [their] body, property and life, for as long as [they] are able to do so.
- e. The ‘participation principle’-a guardian or any other authority that was appointed to assist the person, has to share all information with the person regarding [their] own matters, to consult with [them] when making the decisions and to take into consideration [their] wishes.
- f. [The principle of s]afeguarding the autonomy of the person and [their] involvement in society-the guardian should, as far as possible, act in a manner that . . . allow[s] the person to preserve [their] independence and autonomy as well as be involved in the person’s social life and protect [their] cultural and religious needs.<sup>168</sup>

Thus, while the new amendment represents an enormous

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<sup>162</sup> See MINISTRY OF JUSTICE, INITIAL REPORT CONCERNING THE IMPLEMENTATION OF THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (2017), <https://drive.google.com/file/d/0B0ResPwi8PY6RXNzeUNqOTdXcUE/view>.

<sup>163</sup> CRPD, *supra* note 2, art. 35; MINISTRY OF JUSTICE, *supra* note 162.

<sup>164</sup> See MINISTRY OF JUSTICE, *supra* note 162.

<sup>165</sup> See *id.* at 23–25.

<sup>166</sup> See *id.*

<sup>167</sup> See *id.*

<sup>168</sup> See *id.*

improvement over the 1962 Israeli Guardianship Law, it still does not fully conform to Article 12. Even with the new amendment, the law does not revoke the concept of legal incapacity in Israeli law; it does not require that the person appear in all court proceedings pertaining to that person; nor does it require legal representation for all persons subject to guardianships. The amendment also permits guardians to make decisions using the best interest standard, rather than making decisions based on the person's will and preferences. The amendment also fails to include a time limit on guardianships and it does not require periodic review of the appointment of a guardian. Finally, the amendment offers no solutions for situations in which third parties (such as banks and physicians) doubt a person's legal capacity and seek the appointment of a guardian in order to execute legal transactions. Moreover, many questions remain unanswered in the amendment, including who can be appointed as a supporter, what the supporter's responsibilities are, and how to deal with situations of risk or harm to the person by the supporter. Many of these questions may be resolved in the regulations on supported decision-making, which are expected to be finalized by March of 2018. These new regulations will also state, for the first time, that medical documentation will not be allowed to include any recommendation regarding the need for guardianship. Nonetheless, despite the many improvements in the amendment as compared to the 1962 Law, the new amendment continues to perpetuate the distinction between people with and without legal capacity and, as such, fails to fully conform to the CRPD.

### C. *From the New Amendment to a New Reality*

Since the adoption of the amendment to the Israeli Guardianship Law, Israeli advocates and self-advocates have continued to work on expanding the use of supported decision-making and alternatives to guardianship. Bizchut has published its model on supported decision-making<sup>169</sup> and held several training courses for supporters, people with disabilities, and others who support alternatives to guardianship. Bizchut is also working with the Ministry of Education in Israel and the municipality of Be'er Sheva to promote supported decision-making instead of guardianship for students in special education as they reach the age of eighteen. In addition, Legal Aid has successfully litigated over thirty cases in which courts have ordered supported decision-making rather than guardianships.<sup>170</sup> The government is also taking measures to

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<sup>169</sup> See BIZCHUT, *supra* note 154.

<sup>170</sup> See, e.g., File No. 34820-03-15 CSA (Nz), A v. Attorney General (July 6, 2015), Nevo Legal Database (by subscription, in Hebrew) (Isr.); File No. 51985-05-15 CSA (Krayot), A. v. Attorney General (July 6, 2015), Nevo Legal Database (by subscription, in Hebrew) (Isr.).

implement the new law. A new pilot project is scheduled to take place in the southern part of Israel that will include up to one hundred people who will have the opportunity for supported decision-making instead of guardianships. The government also is developing courses for people who want to be supporters and for people who want to receive support. Finally, there are discussions underway regarding how to provide supported decision-making services for people who have no support or who do not want to be formally supported by family or friends. Interestingly, in 2016, there was a decline in the number of guardianship appointments in Israel for the first time.<sup>171</sup> Time will tell if this trend will continue, and whether Israel will eventually abolish guardianship altogether as a violation of Article 12 of the CRPD.

#### VI. DOMESTIC IMPLEMENTATION OF ARTICLE 12 BY COUNTRIES AROUND THE WORLD

In addition to Israel, many other countries have begun reviewing their laws and practices to determine the extent to which they may comply, or not comply, with Article 12. Depending on the countries' traditions, legal system, and culture, there are different approaches that countries may take to address the problems of their own guardianship laws. Before we review examples from specific countries, we will first provide an overview of different alternatives that are available to countries that are working to conform their domestic laws to Article 12.

Some countries have begun amending their domestic laws or introducing new laws, policies, and practices in order to conform to Article 12. Such new laws and policies may choose to focus on the principle of proportionality, seeking simply to reduce the use of guardianship, and minimize its impact by employing it only as the least restrictive measure in the fewest possible situations. With this goal in mind, domestic laws may limit the duration or scope of guardianship, or avoid guardianship altogether when other less drastic measures are available.

A second path that some countries may choose is to leave the standards for guardianships intact, but to develop new procedural tools to guarantee due process to individuals subjected to guardianship proceedings. Such laws would require the person who is to be placed under guardianship to be represented by legal counsel, to be present at all relevant hearings, to have an opportunity to address the court or witnesses, and to limit the use of expert opinions, as well as require the court to periodically review the continuing need for the appointment of

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<sup>171</sup> Ori Shlomai & Yotam Tolub, *From Caring to Human Rights in Guardianship Procedures*, L. STUD. BAR ILAN U. (forthcoming 2018).

a guardian.

A third path that countries may take as they consider alternatives to guardianship is to develop and use legal planning tools that can replace the need for guardians altogether, such as powers of attorney, health care proxies or medical powers of attorney, advance directives, and legal representation agreements.

A fourth way in which countries may respond to Article 12 is for the State to identify alternatives to guardianship that seek to offer protection from harm without denying legal capacity. Examples of such alternatives may include co-signers on bank accounts and guarantors for certain property transactions. Outpatient commitment—which requires a person considered in need of mental health treatment to comply with a treatment regimen outside of a hospital setting, and, if not, to be involuntarily committed—also has been suggested as an alternative to guardianship for people with psychosocial disabilities. But since outpatient commitment imposes significant infringements on a person's right to liberty, dignity, and autonomy,<sup>172</sup> it does not solve the problem of the denial of legal capacity inherent in guardianship laws, and, therefore, is not a viable alternative to guardianship that would conform to Article 12.

In addition, some countries may choose to comply with Article 12 by replacing the substituted decision-making model in its guardianship law with supported decision-making. As discussed above, supported decision-making, unlike substituted decision-making, guarantees full legal capacity to all individuals with disabilities. It provides the opportunity for a person who may need help in making decisions to secure assistance from someone or a group of people who can “support” the person in their decision-making. This model is based on the individual's wishes and preferences, rather than what someone else (i.e., the court or the guardian) decides or considers to be in the person's “best interests.”<sup>173</sup> Supported decision-making is the only path that fully embraces the principles of the social model of disability and complies with the mandate of Article 12.<sup>174</sup> Supported decision-making also adheres to the CRPD's focus on society's obligation to assist individuals who seek such assistance to overcome difficulties associated with their disabilities by providing support in the form of assistance and accommodations. The following is an overview of how different countries are responding to Article 12.

Canada is the country with the longest history of developing alternatives to guardianship. Legislation on supported decision-making

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<sup>172</sup> For more information on the problems of involuntary outpatient commitment in Israel and the United States, see Arlene S. Kanter & Uri Aviram, *Israel's Involuntary Outpatient Commitment Law: Lessons from the American Experience*, 29 *ISR. L. REV.* 565 (1995).

<sup>173</sup> BACH & KERZNER, *supra* note 88.

<sup>174</sup> See KANTER, *supra* note 4, 235–90; see also BACH & KERZNER, *supra* note 88.

in some Canadian provinces actually predates the CRPD. Various provincial laws in Canada offer a number of alternatives, although none completely eliminate the use of guardianship, particularly for people with intellectual disabilities. In British Columbia, for example, a 1996 law allows individuals with cognitive and psychosocial disabilities to sign representation agreements, giving another person legal authority to represent them in dealings with third parties.<sup>175</sup> The criteria for whether a person is capable of making a representation agreement are liberal, and based on trust between the individual and the person representing them. In Alberta, for example, the law offers many alternatives to guardianship, including co-decision-making, supported decision-making, and enduring powers of attorney, all of which may obviate the need for a guardian.<sup>176</sup> In Ontario, over the past several years, a process has begun toward drafting a new law that would completely abolish guardianship in favor of supported decision-making. According to the draft bill presented by the Ministry of Justice, every person would enjoy full legal capacity, and have the option of having a supporter, representative, or facilitator appointed.<sup>177</sup> The role of the appointed person would be to assist the individual and represent him or her in dealings with third parties, according to his or her wishes.<sup>178</sup>

Like Canada, the United States has no nationwide guardianship law. In the United States, each state may opt to enact its own state guardianship law. Despite the lack of federal guidance, however, most state guardianship laws in the United States are strikingly similar. Since the 1990s, many states have reformed their guardianship laws, in large part due to model laws proposed by the American Bar Association (ABA). These new laws seek to provide greater protections against exploitation and abuse of people under guardianship, while also calling for greater use of limited rather than plenary guardians (who may be called conservators in some states, such as in California), and for greater due process protections for persons subjected to guardianships, including their right to legal representation, to appear before the court, to examine witnesses, and, in some states, to have periodic reviews for the continuing need for guardians. Such laws are also intended to give greater weight to the wishes and preferences of the person under guardianship than had been available under previous state laws. The ABA also recently issued a report calling for additional changes to state

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<sup>175</sup> British Columbia, Representation Agreement Act of British Columbia, R.S.B.C. 1996, c 405, § 7(1) (Can.); KANTER, *supra* note 4, 270–71.

<sup>176</sup> For information on the Alberta law, see Adult Guardianship and Trusteeship Act, S.A. 2008, c A-4.2 (Can.). See also LANA KERZNER, PAVING THE WAY TO FULL REALIZATION OF THE CRPD'S RIGHTS TO LEGAL CAPACITY AND SUPPORTED DECISION-MAKING: A CANADIAN PERSPECTIVE (Apr. 2011), [http://supporteddecisionmaking.org/sites/default/files/paving\\_the\\_way\\_for\\_crpdcanada.pdf](http://supporteddecisionmaking.org/sites/default/files/paving_the_way_for_crpdcanada.pdf).

<sup>177</sup> Substitute Decisions Act, 1992, S.O. 1992, c 30; see KANTER, *supra* note 4, 271.

<sup>178</sup> See BACH & KERZNER, *supra* note 88.

guardianship laws, including requiring supported decision-making as a less restrictive alternative before guardianship is imposed.<sup>179</sup>

New York, however, is one state that has singled out people with intellectual disabilities for fewer due process protections. Article 17a of the New York Surrogate Law was enacted to streamline New York's general guardianship law as a way to assist families of adult children with certain disabilities.<sup>180</sup> All that is required for a family member in New York to secure guardianship under Article 17a is certification from a physician and psychologist (or two physicians) that the adult child has an intellectual or developmental disability which causes an "impaired ability [of the person] to understand and appreciate the nature and consequences of decisions which result in such person being incapable of managing himself or herself and/or his affairs . . ."<sup>181</sup> Unlike New York's general guardianship law—Article 81 of the Mental Hygiene Law, which provides extensive due process protections for people facing guardianship—Article 17a provides no due process protections nor does the court have the discretion or authority to limit or tailor the powers of a guardian under Article 17a.<sup>182</sup> Thus, in a recent case, the court

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<sup>179</sup> On August 14, 2017, the American Bar Association's House of Delegates adopted Resolution 113, urging state, territorial, and tribal legislatures to (1) amend their guardianship statutes to require that supported decision-making be identified and fully considered as a less restrictive alternative before guardianship is imposed, and (2) require that decision-making supports that would meet the individual's needs be identified and fully considered in proceedings for termination of guardianship and restoration of rights. The Resolution further urges courts to consider (1) supported decision-making as a less-restrictive alternative to guardianship, and (2) decision-making supports that would meet the individual's needs as grounds for termination of a guardianship and restoration of rights. See ABA Comm'n on Disability Rights, Resolution 113 (2017), [https://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2017\\_SDM\\_%20Resolution\\_Final.authcheckdam.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/2017_SDM_%20Resolution_Final.authcheckdam.pdf).

<sup>180</sup> N.Y. SURR. CT. PROC. ACT §§ 1750, 1750-a (McKinney 2011). The law includes those whose developmental disability is "attributable to cerebral palsy, epilepsy, neurological impairment, autism or traumatic head injury," and dyslexia resulting from a disability that originates before the age of twenty-two, provided, however, that no such age of onset applies to the person with a traumatic head injury. § 1750-a.

<sup>181</sup> § 1750-a.

<sup>182</sup> N.Y. MENTAL HYG. LAW § 81.22 (McKinney 2006). Article 81 applies to anyone who is determined to be incapacitated in one or more areas of personal care or property management, including people with intellectual or developmental disabilities otherwise subject to Article 17A. § 81.02. Article 81 authorizes a guardian the power to make decisions regarding the individual's routine or major medical or dental treatment, personal care, social environment, travel, driving, access to confidential records, education, benefits, and housing. § 81.22. The stated purpose of Article 81 is to:

promote the public welfare by establishing a guardianship system which is appropriate to satisfy either personal or property management needs of an incapacitated person in a manner tailored to the individual needs of that person, which takes in account the personal wishes, preferences and desires of the person, and which affords the person the greatest amount of independence and self-determination and participation in all the decisions affecting such person's life.

§ 81.01. Under Article 81, the person may be appointed a guardian based on "clear and convincing evidence and shall consist of a determination that a person is likely to suffer harm because: [(1)] the person is unable to provide for personal needs and/or property management;



observed that Article 17a is the “most restrictive type of guardianship available” in New York because it “completely removes that individual’s legal right to make decisions over her own affairs and vests in the guardian virtually complete power over such individual.”<sup>183</sup> Other courts have reached similar conclusions as they have denied requests for guardianships.<sup>184</sup>

Article 17a is currently under review in New York State based on growing support in New York (as in other states) for introducing supported decision-making. New York State also has recently introduced a pilot project to show the efficacy of supported decision-making as a precursor to amendments to its statewide guardianship laws, as has Massachusetts.<sup>185</sup> Both the New York and Massachusetts pilots have followed Israel’s lead by not only preventing guardianship appointments but also by helping people pursue court actions to end their guardianships.

Two other states in the United States, Texas and Delaware, have already enacted new state laws mandating supported decision-making as an alternative to guardianship. Other states will likely follow their lead. In 2015, Texas became the first state to pass a law recognizing supported decision-making as an alternative to guardianship.<sup>186</sup> While the Texas law still contains a guardianship provision, it does require probate courts to consider less restrictive alternatives before placing an individual under guardianship. Under the Texas law, a guardian can be appointed only if the court finds by clear and convincing evidence that utilizing alternative services and support would not be feasible for the

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and [(2)] the person cannot adequately understand and appreciate the nature and consequences of such inability.” § 81.02. At the hearing to assess the need for a guardian under Article 81, the person has the right to counsel of his choice, to be present, and to examine and cross examine witnesses. § 81.11. If the person is found to be “incapacitated” at the hearing, the court may order a guardian or less restrictive “protective” measures instead of the appointment of a long-term guardian. § 81.16.

<sup>183</sup> *In re* Guardian for Michelle M., No. 2014-XXX, 2016 WL 3981204, at \*2 (N.Y. Sur. Ct., Kings Co. July 22, 2016) (stating that although J. Lopez Torres had no doubt that the petitioners loved and wanted to protect their daughter who has Down’s syndrome, the standard for appointing a guardian was not whether they could make better decisions for their daughter, but rather, whether she had the capacity to make decisions for herself, which was not in dispute).

<sup>184</sup> See, e.g., *In re* Guardianship of Dameris L., 956 N.Y.S.2d 848 (N.Y. Sur. Ct., N.Y. Co. 2012).

<sup>185</sup> The New York pilot, directed by Kristen Booth Glen is discussed in Kristin Booth Glen, *Piloting Personhood: Reflections from the First Year of a Supported Decision-Making Project*, 39 CARDOZO L. REV. 495 (2017). For information about the Massachusetts pilot, see THE CPR-NONOTUCK SUPPORTED DECISION-MAKING PROJECT, SUPPORTED DECISION-MAKING: A PROMISING ALTERNATIVE TO GUARDIANSHIP, <http://supporteddecisions.org/wp-content/uploads/2016/10/SDM.brochure.Version.6.1.pdf> (last visited Nov. 7, 2017); *Developmental Disabilities Planning Council, Supported Decision-Making*, N.Y. ST., <https://ddpc.ny.gov/supported-decision-making-0> (last visited Nov. 7, 2017).

<sup>186</sup> Press Release, Disability Rights Tex., Texas First State to Pass Supported Decision-Making Law (Mar. 9, 2016), [https://www.disabilityrightstx.org/files/SDM\\_press\\_release.pdf](https://www.disabilityrightstx.org/files/SDM_press_release.pdf).

individual.<sup>187</sup>

The new Delaware law, enacted in 2016, authorizes people with disabilities to form legally recognized supported decision-making agreements which allow a person with a disability to designate another person to act as his or her supporter to assist the person making medical, psychological or educational as well as everyday decisions.<sup>188</sup> The supporter does not make the decision for the person, but rather helps the person understand the issues relevant to the decision, make appointments with professionals such as doctors to carry out medical and related decisions, and otherwise assist the person in ensuring that the person's views are heard and followed.

Even before these legislative initiatives in the United States, the Council of Europe, in the 1990s, undertook an extensive review of guardianship laws, culminating in the publication of a series of recommendations for guiding principles for legislation concerning the legal capacity of adults.<sup>189</sup> The resulting recommendations document concedes that some people with disabilities may need guardians, so it is not fully compliant with Article 12 of the CRPD.<sup>190</sup> It recommends that when guardians are authorized, courts must use the principle of least restrictive alternatives, proportionality, the right to due process, and ensuring weight to the person's wishes.<sup>191</sup> However, less than fifteen years later, the Council of Europe's Commissioner for Human Rights published a document rejecting any denial of legal capacity for persons with disabilities and urging member states to adopt a model of legal capacity for all, in full compliance with the CRPD.<sup>192</sup>

Several individual countries in Europe and Scandinavia also have abolished guardianship altogether, replacing it with more proportionate alternatives that still partially limit an individual's legal capacity, however. For example, Sweden removed guardianship from its legal system in 1989 and replaced it with two alternatives: a Godman, which resembles a trustee entrusted with managing the individual's affairs according to his wishes, and Forvaltare, which, like guardians, limit the capacity of the individual to whom they are assigned, but their activities are limited to financial matters, leaving the person's legal capacity intact

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<sup>187</sup> *Id.*

<sup>188</sup> DEL. CODE ANN. tit. 16, §§ 9402A–9410A (2016). This law is modeled after a model law developed by the Autistic Self Advocacy Network, an organization of people with autism that works with states to implement supported decision-making laws. See AUTISTIC SELF ADVOCACY NETWORK, MODEL LEGISLATION, <http://autisticadvocacy.org/wp-content/uploads/2014/07/ASAN-Supported-Decisionmaking-Model-Legislature.pdf> (last visited Nov. 7, 2017).

<sup>189</sup> Council of Eur. Comm. of Ministers, *Recommendation No. R(99)4 on Principles Concerning the Legal Protection of Incapable Adults* (Feb. 23, 1999), [https://www.coe.int/t/dg3/healthbioethic/texts\\_and\\_documents/Rec\(99\)4E.pdf](https://www.coe.int/t/dg3/healthbioethic/texts_and_documents/Rec(99)4E.pdf).

<sup>190</sup> *Id.*

<sup>191</sup> *Id.*

<sup>192</sup> Comm'r for Human Rights, *supra* note 23.

in other matters.<sup>193</sup>

Hungary, too, reformed its civil code in 2009 and abolished its guardianship mechanism to give authority instead to those appointed as “decision-making supporters.”<sup>194</sup> However, the law has not yet come into force.<sup>195</sup> Latvia, however, successfully abolished full guardianship in 2012, opting instead for a co-decision-making model with time-limited appointments.<sup>196</sup> Latvia also introduced the option of advanced directives into its law for the first time.<sup>197</sup> The Czech Republic also reformed its civil code in 2012, abolishing full guardianship, and setting time limits on limited guardianship appointments, as well as recognizing supported decision-making as the preferred alternative to guardianship.<sup>198</sup> Bulgaria and Australia also have recently launched supported decision-making pilot programs to test alternatives to guardianship with smaller groups of individuals with disabilities.

In 2015, Ireland replaced its old guardianship law—the Lunacy Regulation (Ireland) Act 1871—with the Assisted Decision Making (Capacity) Act of 2015.<sup>199</sup> This Act is based on a report of the Parliamentary Joint Committee on Justice, Defence, and Equality, which call for abolishing guardianship. The Assisted Decision Making (Capacity) Act embraces the human rights principles of proportionality and due process and recognizes the right of all people with disabilities to make decisions, even bad ones. Accordingly, it replaced the best interest standard with the requirement that decisions be made based on the person’s will and preferences. It uses a functional test to determine a person’s mental capacity and because of this, and its retention of forms of substituted decision-making, the Act does not fully comply with Article 12 of the CRPD. The Act provides for three different types of supported decision-making: decision-making assistance agreements, co-decision-making agreements, and decision-making representatives, for

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<sup>193</sup> See Booth Glen, *supra* note 9, at 140–41. For a review of reforms in Germany and Sweden, see Israel Doron, *Elder Guardianship Kaleidoscope—A Comparative Perspective*, 16 INT’L J.L. POL’Y & FAM. 368 (2002).

<sup>194</sup> Act CXX of 2009 on the Hungarian Civil Code was passed on November 9, 2009. However, it was not implemented due to a decision of the Constitutional Court of Hungary. Then, Act V of 2013 promulgating the Civil Code was published on February 26, 2013. See Act V of 2013 on the Civil Code (Hung.), [http://www.ilo.org/dyn/natlex/docs/ELECTRONIC/96512/114273/F720272867/Civil\\_Code.pdf](http://www.ilo.org/dyn/natlex/docs/ELECTRONIC/96512/114273/F720272867/Civil_Code.pdf) (providing a translation from the original Hungarian).

<sup>195</sup> The Hungarian Constitutional Court has halted the implementation of the law. See *Hungary*, MDAC, <https://mdac.org/en/Hungary> (last visited Nov. 20, 2017).

<sup>196</sup> *Latvia Abolishes Plenary Guardianship*, MDAC (Dec. 5, 2012), <http://mdac.info/en/05/12/2012/latvia-abolishes-plenary-guardianship>.

<sup>197</sup> *Id.*

<sup>198</sup> Zákon č. 89/2012 Sb., §§ 56, 460, 471 (Czech).

<sup>199</sup> Assisted Decision-Making (Capacity) Act 2015 (Act No. 64/2015) (Ir.), <http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html>; see also Gerard Quinn, Professor at Ctr. for Disability Law & Policy, Address at Tbilisi State University: From Civil Death to Civil Life Perspectives on Supported Decision-Making for Persons with Disabilities (Dec. 20, 2015).

individuals whose capacity “is in question or may shortly be in question.”<sup>200</sup> The decision-making assistance agreement is the lowest level of support and is based on an agreement signed between the individual and a trusted person.<sup>201</sup> In those situations, where further support is needed, a co-decision-making representative may be appointed to make decisions jointly with the individual whose capacity is in question. As a last resort, a decision-making representative may be appointed by the court when it believes that a person lacks capacity to the extent that decisions need to be made on his behalf. All three methods of support must follow the person’s will and preferences rather than the best interest standard. In addition, although Irish law already provides for enduring powers of attorney in financial matters, the Act also introduces enduring powers of attorney for other matters, along with monitoring and reporting mechanisms in cases of suspected abuse on the part of supporters.<sup>202</sup> In October 2016, sections of the Act were implemented, including those that relate to the establishment of the Decision Support Service, the support agreements, and the drafting of codes of practice.<sup>203</sup>

Similarly, in Croatia, the new Family Act of 22 September 2015 (Family Act),<sup>204</sup> abolishes plenary guardianship. The law also provides that within the next five years, courts should review all guardianships for restoring partial or full legal capacity. However, courts in Croatia may still restrict legal capacity and apply partial guardianship as a last resource in order to “ensure the protection of the rights and interests in areas where a person’s legal capacity has been limited by a court decision.”<sup>205</sup> The deprivation of legal capacity is based on a medical expert who assesses the health condition impacts on the ability of the person to protect or endanger their rights and interests.<sup>206</sup> The new Family Act also introduces, for the first time in Croatian law, the concept of supported decision-making for persons with disabilities.<sup>207</sup> However, supported decision-making is applied only for people who are deprived of legal capacity, rather than as an alternative to guardianship. Although the Family Act urges guardians to respect the personal preferences of the person under guardianship, it also states that the

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<sup>200</sup> Assisted Decision-Making (Capacity) Act 2015, *supra* note 199, pt. 3.

<sup>201</sup> *Id.*

<sup>202</sup> *Id.* at pt. 7.

<sup>203</sup> Assisted Decision-Making (Capacity) Act 2015 (Commencement of Certain Provisions) Order 2016 (SI 515/2016) (Ir.), <http://www.irishstatutebook.ie/eli/2016/si/515/made/en/print>; Assisted Decision-Making (Capacity) Act 2015 (Commencement of Certain Provisions) (No. 2) Order 2016 (SI 517/2016) (Ir.), <http://www.irishstatutebook.ie/eli/2016/si/517/made/en/print>.

<sup>204</sup> Obiteljski Zakon [Family Act of 22 September 2015] (Sept. 22, 2015) (Croatia), <http://www.ilo.org/dyn/natlex/docs/ELECTRONIC/101656/122585/F1052999276/HRV101656%20Hrv.pdf>.

<sup>205</sup> Family Act of 22 September 2015, art. 219 (Croatia).

<sup>206</sup> *Id.* at art. 234(3).

<sup>207</sup> *Id.* at art. 233(4).

guardian may ignore the person's personal preferences when they are deemed contrary to the "best interests" of the concerned person.<sup>208</sup> In such cases, the guardian retains the power to make decisions for the person based on the substitution decision-making regime.

Further, in Georgia, changes to the law on legal capacity have been made by the Constitutional Court rather than the Parliament. On October 8, 2014, the Georgian Constitutional Court decided the landmark case of *Irakli Qemoklidze and Davit Kharadze, Citizens of Georgia v. the Parliament of Georgia*.<sup>209</sup> The two individuals challenged the provisions of the Civil Code that denied people with psychosocial disabilities legal capacity, which meant they were denied such rights as access to the courts, the right to marry, or to engage in transactions.<sup>210</sup> A person with no legal capacity would be rendered unable to exercise his legal personhood since their expression of will was considered void under the Civil Code. Under the Georgia Civil Code, the denial of legal capacity denies the "ability of a natural person to acquire and exercise his/her civil rights in full by his/her free will and action."<sup>211</sup> Depriving a person of their legal capacity under the Georgia Civil Code was referred to as "civil death."<sup>212</sup> This situation was exacerbated by the fact that a person found incapable would retain this status indefinitely.<sup>213</sup>

In addition, for the past few years, the Indian Ministry of Law and Justice also has been leading efforts toward legislative amendments and the enactment of three new laws to address legal capacity. The draft Rights of Persons with Disabilities Bill of 2011 abolishes full or plenary guardianship, introduces a transitional mechanism of limited guardianship, and stipulates that no one will be placed under guardianship going forward (including limited guardianship), but rather that persons with disabilities will receive support in decision-making.<sup>214</sup>

In South America, Peru was one of the first countries in the region to engage in reform to ensure legal capacity for all persons with disabilities. The Peruvian General Law on Persons with Disabilities, Act Number 29973,<sup>215</sup> enacted in 2012, adopts the social model of disability

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<sup>208</sup> *Id.* at art. 233(5).

<sup>209</sup> The authors were not able to secure a copy of the case in English but it is discussed in: Vakhtang Menabde, *Georgian Constitutional Court: The System of Legal Capacity of Natural Persons and its Impact upon the Georgian Legislation*, 10 VIENNA J. ON INT'L CONST. L. 458 (2016).

<sup>210</sup> *Id.* at 458.

<sup>211</sup> *Id.*

<sup>212</sup> *Id.*

<sup>213</sup> *Id.*

<sup>214</sup> CTR. FOR DISABILITY STUDIES, THE RIGHTS OF PERSONS WITH DISABILITIES BILL, 2011 (June 30, 2011) (India), [http://www.internationalcentregoa.com/pdf/The\\_Rights\\_of\\_Persons\\_with\\_Disabilities\\_Bill2011.pdf](http://www.internationalcentregoa.com/pdf/The_Rights_of_Persons_with_Disabilities_Bill2011.pdf).

<sup>215</sup> The General Law on Persons with Disabilities, Act No. 29973, was published on December 24, 2012. It was product of a citizen's initiative where disabled people organizations and civil society worked to collect signatures. Ley General de la Persona con Discapacidad (Ley

and affirms the right of people with disabilities to equal recognition before the law in accordance with Article 12 of the CRPD. The law specifically protects the right of some, but not all, people with disabilities, to own and inherit property, to enter into contracts, and to marry, have children, and exercise their sexuality.<sup>216</sup> On the other hand, the Civil Code in Peru presumes the “incapacity” of persons with intellectual or psychosocial disabilities, and permits guardianships for them under a substitution decision-making regime.<sup>217</sup> In fact, the Civil Code states that “those who for whatever reason are deprived of judgment” can be declared absolutely incapable of exercising their rights.<sup>218</sup> Similarly, it stipulates that people who are “mentally retarded” and “[t]hose who suffer from mental impairments that prevents them from expressing their free will” can be declared as unable to exercise their rights.<sup>219</sup> Moreover, the judge may decide the scope and powers of the guardian, based on the judge’s determination of the degree of “incapacity of the person,”<sup>220</sup> which is determined by a medical diagnosis.

In response to this apparent contradiction between the Peruvian Disability Law and the Civil Code, the Special Commission to revise the Civil Code drafted a new law, Bill 4601/2014-CR, to ensure the legal capacity of all persons with disabilities. However, the bill was not approved (due to a change in the Congress’s composition in 2016). Recently, however, a Working Group on Civil Code reform submitted a new proposal with the support of civil society organizations. This new text recognizes the legal capacity of all persons with disabilities, and replaces guardianship with a support system that allows the person to decide who will provide support, as well as the scope and duration of support. Moreover, all supporters will be registered with a judge or notary. The proposed text also authorizes the use of advance directives.<sup>221</sup> Nevertheless, the proposed text does not include safeguards to prevent abuse of the person and conflicts of interest that may arise between the supporter and the person. For its part, the Judiciary also has published a directive limiting guardianships and narrowing the functions of guardians. In this context, a family court in Cusco recently held that the right to a pension cannot be made

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no. 29973) [General Law on Persons with Disabilities (Law No. 29973)] (Peru), [http://www.internationaldisabilityalliance.org/sites/default/files/documents/peru\\_general\\_law\\_on\\_persons\\_with\\_disabilities.english.pdf](http://www.internationaldisabilityalliance.org/sites/default/files/documents/peru_general_law_on_persons_with_disabilities.english.pdf).

<sup>216</sup> Law No. 29973, art. 9.

<sup>217</sup> See *Código Civil Decreto Legislativo* [Civil Code] No. 295, Artículos 43, 44, 564 (July 25, 1984) (Peru), [http://www.oas.org/juridico/pdfs/mesicic4\\_per\\_cod\\_civil.pdf](http://www.oas.org/juridico/pdfs/mesicic4_per_cod_civil.pdf).

<sup>218</sup> *Id.* at art. 43(2).

<sup>219</sup> *Id.* art. 44(2), 44(3).

<sup>220</sup> *Id.* at art. 581.

<sup>221</sup> *Report on IDA’s Follow-up Mission to Peru*, INT’L DISABILITY ALL. 16–17 (2017), <http://www.internationaldisabilityalliance.org/ida-follow-up-peru-oct2015>.

conditional upon the denial of legal capacity, and that the Civil Code is incompatible with the CRPD and the Constitution.<sup>222</sup> In sum, Peruvian civil society has been working with the government to reform its law to conform fully with Article 12. If the current proposed text is adopted, it will dramatically improve the Peruvian Civil Code and guarantee supported decision-making for all people with disabilities in Peru.

Argentina also has reformed its National Code of Civil and Commercial Procedure (CCCN), Act Number 26.994,<sup>223</sup> to ensure legal capacity of all persons.<sup>224</sup> However, under this law, the judge may restrict the capacity for certain acts of persons who “suffer from an addiction or permanent or prolonged mental disorder,” when the court decides that the exercise of their legal capacity may harm them or their property.<sup>225</sup> In such cases, the judge may authorize support to promote the person’s autonomy and respond to the preferences of the person involved. Argentina also amended its law to provide supported decision-making. The CCCN also establishes, for first time in Argentina, a new supported decision-making system, which defines “support” as any judicial or extrajudicial measure that facilitates the decision-making of a person, manages his assets, and enforces civil acts.<sup>226</sup> The purpose of such support is to promote the person’s autonomy, facilitate communication with and by the person, and to effectuate the will for the person to exercise his or her rights. The person is also permitted to propose to the judge the person(s) whom he chooses to act as a supporter.<sup>227</sup> The only exception to this new law, when substituted decision-making is permitted, is when the person is “absolutely unable” to interact with their environment and express his will, and when the support system is ineffective. In such cases, the judge may declare the “incapacity” of the person and designate a guardian.<sup>228</sup>

In Costa Rica, the Law for Promoting the Personal Autonomy of People with Disabilities, Act Number 9379,<sup>229</sup> enacted in 2016, recognizes the legal capacity of all persons with disabilities.<sup>230</sup> At the

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<sup>222</sup> 3<sup>o</sup> Juzgado Familia de Cusco [Third Family Court of Cusco], No. 01305-2012-0-1001-JR-FC-03, ¶ 9.2(H) (June 15, 2015) (Peru) (on guardianship).

<sup>223</sup> CÓDIGO PROCESAL CIVIL Y COMERCIAL DE LA NACIÓN [CÓD. PROC. CIV. Y COM.] [CIVIL AND COMMERCIAL PROCEDURE CODE] (2014) (Arg.), <http://servicios.infoleg.gob.ar/infolegInternet/anexos/235000-239999/235975/texact.htm>.

<sup>224</sup> CIVIL AND COMMERCIAL PROCEDURE CODE, art. 31 (Arg.).

<sup>225</sup> *Id.* at art. 32.

<sup>226</sup> *Id.* at art. 43.

<sup>227</sup> *Id.*

<sup>228</sup> *Id.* at art. 32.

<sup>229</sup> LEY PARA LA PROMOCIÓN DE LA AUTONOMÍA PERSONAL DE LAS PERSONAS CON DISCAPACIDAD [LAW FOR THE PROMOTION OF AUTONOMY PERSONNEL OF PERSONS WITH DISABILITIES] N° 9379 (2016) (Costa Rica), <http://www.tse.go.cr/pdf/normativa/promocion-autonomiapersonal.pdf>.

<sup>230</sup> LAW FOR THE PROMOTION OF AUTONOMY PERSONNEL OF PERSONS WITH DISABILITIES, art. 5(a) (Costa Rica).

same time, this Act establishes the “guarantors for the legal equality of persons with disabilities” and the figure of “human personal assistance.”<sup>231</sup> The function of the guarantor is to assist the person in his personal and financial acts, following his will and preferences.<sup>232</sup> The courts are limited to establishing safeguards for avoiding abuses by these guarantors, who replace the guardians. The Costa Rican law also creates a Unit of Personal Autonomy and Independent Living of the Council of Persons with Disabilities, which is in charge of the Program for Promotion of the Personal Autonomy of Persons with Disabilities.<sup>233</sup> The functions of the Unit of Personal Autonomy and Independent Living include evaluating, approving, and coordinating the provision of support between different public and private entities, in accordance with the will and preferences of each person; and, approving and reviewing an individual plan of support, among others.<sup>234</sup> Despite these advances, the Costa Rican law allows the judge to reach its decision without consulting the person or a report from a social worker. In practice, however, the court will typically defer to the medical doctor.<sup>235</sup> Nor does the law contain any information about advance directives. Moreover, the role of the guarantor is still uncertain. Some sections consider the guarantor as a support person while other sections seem to portray the guarantor as the person charged with protecting the interests of the person. In such cases, there may be a conflict of interest between the guarantor’s role to both support and protect the person with a disability.<sup>236</sup>

Most recently, in 2017, a bill for establishing the exercise of legal capacity of all persons with disabilities has been introduced in Colombia.<sup>237</sup> This bill established legal capacity for all persons with disabilities and adopts the social model of disability.<sup>238</sup> It focuses on ensuring effective and voluntary access to support mechanisms for people who may need help in making and carrying out their decisions. Accordingly, there is a presumption of legal capacity for all adults with disabilities.<sup>239</sup> Not only is guardianship now eliminated as an option, but current guardianship orders are also suspended.<sup>240</sup> Furthermore, the bill

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<sup>231</sup> *Id.* at art. 1; *see also* LAW FOR THE PROMOTION OF AUTONOMY PERSONNEL OF PERSONS WITH DISABILITIES, art. 11 & 12 (Costa Rica).

<sup>232</sup> LAW FOR THE PROMOTION OF AUTONOMY PERSONNEL OF PERSONS WITH DISABILITIES No. 9379, art. 11.

<sup>233</sup> *Id.* at art. 16.

<sup>234</sup> *Id.* at art. 20.

<sup>235</sup> *Id.* at art. 37.

<sup>236</sup> *Id.* at art. 2(a), 4(a), 11.

<sup>237</sup> Proyecto de ley 248 de 2017 Cámara [Draft Law 248 of 2017 Camera] (Colom.), [http://www.imprenta.gov.co/gacetap/gaceta.mostrar\\_documento?p\\_tipo=05&p\\_numero=248&p\\_consec=47650](http://www.imprenta.gov.co/gacetap/gaceta.mostrar_documento?p_tipo=05&p_numero=248&p_consec=47650) (last visited July 16, 2017).

<sup>238</sup> Draft Law 248 of 2017 Camera.

<sup>239</sup> *Id.* at art. 5.

<sup>240</sup> *Id.* at art. 48, 50–51.



includes voluntary agreements and advance directives.<sup>241</sup> Moreover, the principle of autonomy of the will of the person governs the determination of support, rather than the best interest standard.<sup>242</sup> However, if the person is “absolutely unable to interact with the environment by any means, and that condition is proven,” then the court may order support, particularly to avoid situations of abuse.<sup>243</sup>

In addition to these legislative developments other countries have opted to forego legislative changes and proceeded to develop supported decision-making services for persons with disabilities. These services are based on research which has shown that not only do many individuals with disabilities have the ability to make their own decisions with some support, but that doing so is beneficial for them.<sup>244</sup> Alternatives to guardianship, such as supported decision-making, circles of support, and other decision-making models, enable individuals with disabilities to make their own choices and exercise self-determination.<sup>245</sup>

Sweden, for example, offers support services for persons with various disabilities with proven results in enhancing autonomy and reducing days spent in the hospital and cost to the public.<sup>246</sup> Support circles or circles of friends for persons with intellectual and psychosocial disabilities are also used in some states in the United States as well as in some provinces in Canada, the United Kingdom, Australia, Bulgaria, and the Czech Republic.<sup>247</sup> Each such support circle is typically comprised of a professional support worker and individuals selected and trusted by the person with a disability. These supporters are available to help the individual make decisions and to realize his choices and wishes. In the United States, there are hundreds of personal support services that are entirely based on people’s wills and choices, which help people with disabilities make decisions and live according to their

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<sup>241</sup> *Id.* at art. 14, 33.

<sup>242</sup> *Id.* at art. 4.3, 13.2.

<sup>243</sup> *Id.* at art. 12.4, 23–26.

<sup>244</sup> See, e.g., Jonathan G. Martinis, *Supported Decision-Making: Protecting Rights, Ensuring Choices*, 36 BiFOCAL 107, 108 (2015).

<sup>245</sup> *Id.* at 109–10.

<sup>246</sup> See Tommy Björkman & Lars Hansson, *Case Management for Individuals with a Severe Mental Illness: A 6-Year Follow-up Study*, 53 INT’L J. SOC. PSYCHIATRY 12, 12, 20 (2007).

<sup>247</sup> *Support Circles, Clusters, and Networks*, ONT. ADULT AUTISM RES. & SUPPORT NETWORK, <http://www.ont-autism.uoguelph.ca/STRATEGIES7.shtml> (last visited Nov. 7, 2017); NIDUS: PERS. PLAN. RESOURCE CTR. & REGISTRY, <http://www.nidus.ca> (last visited Nov. 7, 2017); *Welcome to Circles Network!*, CIRCLES NETWORK, [http://www.circlesnetwork.org.uk/home.asp?level=0z&parent\\_id=1](http://www.circlesnetwork.org.uk/home.asp?level=0z&parent_id=1) (last visited Nov. 7, 2017); *Decision Making: Supported Decision Making*, ADVOKIT BY DANA, <http://www.advokit.org.au/decision-making/supported-decision-making> (last visited Nov. 7, 2017); MENTAL DISABILITY ADVOCACY CTR., GUARDIANSHIP AND HUMAN RIGHTS IN BULGARIA: ANALYSIS OF LAW, POLICY AND PRACTICE 5 (2007), <http://www.mdac.info/en/resources/guardianship-and-human-rights-bulgaria>; *Onás*, SPOLEČNOST PRO PODPORU LIDÍ S MENTÁLNÍM POSTIŽENÍM V ČESKÉ REPUBLICĚ, Z. S., <http://www.spmpr.cz/o-nas> (last visited Nov. 7, 2017) (Czech).

preferences.<sup>248</sup>

In southern Australia, for example, the Public Advocate launched an assisted decision-making pilot for persons with intellectual disabilities as a first step toward reducing the use of guardianship.<sup>249</sup> A similar pilot has recently been launched in Massachusetts and New York, as mentioned above. Recent research also highlights the ability of people with intellectual disabilities to make decisions for themselves, or with circles of friends, without the need for guardians.

For example, a recent study in Syracuse, New York, explores how people with intellectual disabilities, without guardians, make decisions.<sup>250</sup> The researchers found that circles of support play a key role in helping people achieve the independence they desire. As one of the interviewees, Roger explained, “each person in my circle has a different expertise in a certain area so that’s why I picked them.”<sup>251</sup> Roger also explained that he develops friendships with people who work in different service fields, so they are able to share their experiences with him to help him make informed decisions.<sup>252</sup> Meanwhile another interviewee, Eric, described a smaller support network that includes his sister, a special education teacher who can offer him her expertise.<sup>253</sup> Another participant, Molly, stated, “I just need my mom . . . [;] there are some people who don’t have the support of their family and stuff [but] I have a really supportive family.”<sup>254</sup> The researchers also found that having more information, resources, and support available to the person with a disability as well as his family, will better enable the supporters to provide the support that their loved ones with disabilities may need to maintain their independence, and without the need for guardians.<sup>255</sup>

In sum, there is growing recognition in many countries throughout the world that alternatives to guardianship which support the person with a disability making his or her own decisions not only comply with Article 12, but also have the potential to enhance the quality of life, independence, and contributions of people with disabilities to society.

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<sup>248</sup> For example, Florida’s Self-Directed Care Program, Oregon’s Brokerage Services, and Michigan’s CLS, are all organizations that offer support and assistance intended to help persons with disabilities live independently in the community.

<sup>249</sup> *Assisting Someone with Decision Making*, OFFICE OF THE PUB. ADVOCATE, [http://www.opa.sa.gov.au/making\\_decisions\\_for\\_others/assisting\\_someone\\_with\\_decision\\_making](http://www.opa.sa.gov.au/making_decisions_for_others/assisting_someone_with_decision_making) (last visited Nov. 7, 2017).

<sup>250</sup> Arlene Kanter, *Study on Decision-Making by Adults with Intellectual Disabilities Without Guardians* (May 2017) (on file with author). This project began in 2014 and the study was completed in May 2017, with the assistance of the following current and former Syracuse University students: Judy Kopp, Joan Cornachio, Alyssa Galea, Christina Farrell, Jamie Glashow, Steve Kassirer, and Inviolata Sore.

<sup>251</sup> *Id.*

<sup>252</sup> *Id.*

<sup>253</sup> *Id.*

<sup>254</sup> *Id.*

<sup>255</sup> *Id.*

## CONCLUSION

The fight for the right of persons with disabilities to legal personhood and equal recognition under law that honors their legal capacity is, to a large extent, a fight for the basic human rights of people with disabilities. People without disabilities take for granted their right to legal capacity. That has not been the case for people with disabilities, especially people with intellectual or psychosocial disabilities. Although the CRPD represents an enormous step forward in the recognition of equal rights of people with disabilities under international law, challenges remain, particularly with respect to domestic implementation of Article 12. The CRPD Committee has begun to articulate what countries must do to fully comply with Article 12 in their responses to country reports. In the more than 100 country reports that have been filed to date, no country claims full compliance with Article 12. To the extent that most countries continue to have laws that authorize the denial of legal capacity and guardianship for people with certain disabilities, no country has yet fully complied with Article 12. Nonetheless, the CRPD Committee has made clear in its responses to the country reports that it views the denial of legal capacity and guardianship laws, which rely on a substituted decision-making model, as a violation of Article 12.

Yet even with this clarification by the CRPD Committee, questions remain. Is supported decision-making always applicable to all people, with all types of disabilities, all of the time? Are there situations in which guardians could still be appointed in compliance with Article 12, and if so, under what circumstances? Can such guardianships be limited to protect a person's right to autonomy and decision making? How can supported decision-making be applied to people who cannot communicate at all with anyone or are in a coma? Should there be a different analysis with respect to guardianship laws for people who become disabled in old age and others who are disabled throughout their lives? What role will parents of adult children with disabilities play, if any, as their adult children seek to exercise their right to self-determination and independence? Who can or should act as a supporter? Should supporters be monitored, and if so, how and by whom? What action should be taken when the supporter is suspected of exploiting or harming the person? How can new supported decision-making laws avoid turning into a new form of state control and paternalistic intervention into the lives of adults with disabilities? These are just some of the questions that are eagerly debated on the international scene.

Israel provides an important example to other countries regarding the potential for change on behalf of equal recognition under law for men and women with disabilities. In addition to changing its law, based

on the advocacy of civil society organizations and people with disabilities themselves, the experience of Israel in engaging in guardianship reform shows the important role of courts in moving policy from principle to action. Moreover, with its recent implementation of a new support system for people who had been subjected to guardianship or are at risk of guardianship, Israel also provides an example of how to translate new supported decision-making laws and court cases into practice.

Yet as Israel and other countries that have ratified the CRPD now consider implementing supported decision-making as an alternative to guardianship in their respective domestic laws, a fundamental question remains. To what extent are societies willing to protect the rights of all persons to decide the course of their own lives, including those who are labeled with an intellectual disability, a psychosocial disability, autism, or another disability that may limit a person's ability to communicate his wishes and desires to others? In many ways, the situation of persons under guardianship presents one of the most fundamental questions in any democratic society: Are any limits on equality and personhood acceptable? For that reason, the fight for legal personhood and freedom from guardianship for persons with disabilities may be seen as a continuation of the fight for basic human rights that has been waged by others throughout human history.