

## **NOTE: SUPPORTED DECISION-MAKING IN THE LONE-STAR STATE**

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### **Reporter**

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\* Copyright © Eliana J. Theodorou. J.D., 2018, New York University School of Law; B.A., 2012, Wesleyan University. So many people helped make this Note possible. Thank you to everyone in Texas who shared this incredible story and provided me with helpful information and feedback: Belinda Carlton, Richard LaVallo, Helen A. Gaebler, Linda Logan, and Jessica Ramos. Thank you to Kristin Booth Glen for prompting me to take up this topic and to Matthew Smith for providing resources and information early on. Thank you to my advisor, Adam Samaha, whose insight shaped this piece, and to the members of the New York University Law Review, particularly Alexandra Ferrara.

### **Highlight**

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"Supported decision-making," an alternative to guardianship that allows an individual with an intellectual or developmental disability to retain his or her legal capacity and make decisions with the assistance of trusted supporters, has been gaining traction in the United States since the mid-2000s. Scholars have highlighted the significance of the UN Convention on the Rights of Persons with Disabilities (CRPD), which entered into force in 2006, in explaining the recent rise in interest in supported decision-making across the world. CRPD Article 12 recognizes that people with disabilities are entitled to equal recognition of their legal capacity by states parties and requires states parties to provide the support that people with disabilities may need in exercising legal capacity. In 2015, Texas became the first state in the United States to pass legislation formally recognizing supported decision-making agreements as alternatives to guardianship. Attention to Texas's experience suggests, however, that the CRPD may have limited salience in conservative state legislatures, and demonstrates that other forces are contributing to the appeal of supported decision-making in the United States today. Part I provides a brief overview of guardianship and supported decision-making, and discusses how supported decision-making has many features that are simultaneously appealing to actors within the disability rights movement and American political conservatives. Part I next discusses Texas's initial interest in supported decision-making and its 2009 supported decision-making pilot project. Part II identifies two issues that put guardianship in general on Texas legislators' agendas in the years leading up to the passage of supported decision-making legislation: the issue of guardianship abuse and concerns about the impact of the aging of the population on probate courts. Part III explains how advocates organized to draft and pass supported decision-making legislation and other guardianship reform bills. Section A provides an overview of the legislation ultimately passed; Section B focuses on the organization of the Guardianship Reform and Supported Decision-Making Workgroup (GRSDM) and its community-organizing style of work; Section C explores how GRSDM won the support of key, influential stakeholders; and Section D shows how different actors used different narratives to promote supported decision-making, with some emphasizing self-determination, while others emphasized efficiency and cost savings. Part IV discusses lessons that can be applied in other states and Texas's implementation efforts so far.

## Text

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### Introduction

In 2015 Texas became the first state in the country to pass legislation formally recognizing supported decision-making agreements as an alternative to guardianship.<sup>1</sup> Passage of the legislation is part of a global trend, which has been hailed as signaling a "paradigm shift"<sup>2</sup> [\*975] toward a world where individuals with disabilities are recognized as having the right to direct the courses of their own lives.<sup>3</sup> Broadly speaking, "**supported decision-making**" refers to an arrangement where an individual with a **disability** works with one or more trusted supporters who help him or her make important decisions.<sup>4</sup> A supporter might, for example, help the decision-maker understand information and make and communicate decisions related to healthcare, working or volunteering in the community, living arrangements, and financial planning.<sup>5</sup> While there is no single model of supported decision-making,<sup>6</sup> a unifying feature is that the decision-maker retains legal capacity - that is, the right to make decisions and have them recognized by law.<sup>7</sup>

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<sup>1</sup> S.B. 1881, 84th Leg., Reg. Sess. (Tex. 2015) (codified at Tex. Est. Code Ann. §§1357.001-.102 (West 2017)); Sean Burke, Person-Centered Guardianship: How the Rise of Supported Decision-Making and Person-Centered Services Can Help Olmstead's Promise Get Here Faster, 42 Mitchell Hamline L. Rev. 873, 881 (2016); David M. English, Amending the Uniform Guardianship and Protective Proceedings Act to Implement the Standards and Recommendations of the Third National Guardianship Summit, 12 NAELA J. 33, 42 (2016).

<sup>2</sup> See, e.g., Kristin Booth Glen, Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship and Beyond, *44 Colum. Hum. Rts. L. Rev.* 93 (2012) (describing a series of historical "paradigm shifts" in the understanding of legal capacity, including the shift to supported decision-making); see also Robert D. Dinerstein, Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with **Disabilities**: The Difficult Road from Guardianship to **Supported Decision-Making**, 19 Hum. Rts. Brief, Winter 2012, at 8, 8, 72 n.3 (collecting sources that characterize the trend towards supported decision-making as a "paradigm shift").

<sup>3</sup> See, e.g., Glen, *supra* note 2, at 100 (explaining that the Convention on the Rights of Persons with Disabilities "sets forth a radically new principle of equality for persons with intellectual and psychosocial disabilities, in which, as a matter of international human rights law, all such persons are entitled to full 'legal capacity' and to make all personal and financial decisions for themselves").

<sup>4</sup> See Peter Blanck & Jonathan G. Martinis, "The Right to Make Choices": The National Resource Center for Supported Decision-Making, 3 Inclusion 24, 26 (2015); see also The Arc of Tex., Alternatives to Guardianship: Supported Decision-Making Agreements (2015), <https://www.thearcoftexas.org/wp-content/uploads/2016/06/Supported-Decision-Making-For-Families-UPDATED-Jan-2016.pdf> (providing an overview on how to implement supported decision-making). Supported decision-making is also being increasingly adapted for elderly and aging people. See, e.g., Rebekah Diller, Legal Capacity for All: Including Older Persons in the Shift from Adult Guardianship to Supported Decision-Making, *43 Fordham Urb. L.J.* 495, 520-37 (2016) (discussing how supported decision-making will need to be adapted to be used by elderly and aging populations); David Godfrey, Supported Decision Making in Later Life, in 2016 National Aging & Law Conference M-1 (Am. Bar Ass'n 2016), <https://www.americanbar.org/content/dam/aba/events/cle/2016/10/ce1610alc/ce1610alccor.authcheckdam.pdf> (providing information for attorneys about how to incorporate supported decision-making principles and less-restrictive alternatives to guardianship into planning for aging clients).

<sup>5</sup> See, e.g., **DisabilityRightsTx, Supported Decision-Making** in Action: Dawn and Belinda's Story, YouTube (June 29, 2016), <https://www.youtube.com/watch?v=ZAlcnUNMTHI> (featuring an adult woman who lives independently and uses a formal supported decision-making agreement to make decisions with the assistance of her mother).

<sup>6</sup> Blanck & Martinis, *supra* note 4, at 26.

<sup>7</sup> Glen, *supra* note 2, at 96 (defining legal capacity).

Scholars have highlighted the particular importance of Article 12 of the UN Convention on the Rights of Persons with ***Disabilities*** (CRPD) <sup>8</sup> in driving the recent paradigm shift. <sup>9</sup> Though ***supported [\*976] decision-making*** was adopted in Canada in the 1990s, <sup>10</sup> and versions of it have existed in parts of Europe since around the same time, <sup>11</sup> it has gained significantly more traction since the CRPD entered into force in 2006. <sup>12</sup> As Professor Kristin Booth Glen puts it, the CRPD's Article 12 "is ... the basis of the current, worldwide movement for supported decision-making ... as the means to advance and protect legal capacity and, ultimately, personhood, for individuals with intellectual or developmental disabilities ... as well as other cognitive disabilities." <sup>13</sup> Article 12 provides that states parties to the agreement "shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life." <sup>14</sup> Article 12 also places responsibility on states parties for ensuring that people with disabilities can meaningfully exercise legal capacity, providing that they "shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity." <sup>15</sup>

**[\*977]** There has indeed been a flurry of activity around supported decision-making in recent years. Since the passage of legislation in Texas in 2015, several additional states have passed laws formally recognizing supported decision-making, including Delaware, <sup>16</sup> Wisconsin, <sup>17</sup> and Washington, D.C. <sup>18</sup> Supported decision-making has

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<sup>8</sup> Convention on the Rights of Persons with Disabilities, adopted Dec. 6, 2006, 2515 U.N.T.S. 3 [hereinafter CRPD].

<sup>9</sup> See, e.g., Burke, *supra* note 1, at 880-82 (stating that adoption of the CRPD in 2006 "signaled an international shift in the focus and attention for persons with disabilities" and led to the passage of legislation in several jurisdictions in response to the declaration's standards); Glen, *supra* note 2, at 98 (arguing that the emerging paradigm that embraces supported decision-making and "insists on full legal capacity for every person with intellectual disabilities" is "premised on international human rights"); see also Nina A. Kohn et al., Supported Decision-Making: A Viable Alternative to Guardianship?, **117 Penn St. L. Rev. 1111, 1113 (2013)** (stating that the "rapidly gaining political momentum" to "replace surrogate decision-making ... with supported decision-making ... is attributable in part" to the CRPD's adoption); 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, 1173-79 (2013)** (discussing the CRPD, its importance, and its likely impact on guardianship practice).

<sup>10</sup> See, e.g., Tim Stainton, Supported Decision-Making in Canada: Principles, Policy and Practice, 3 Res. & Prac. Intell. & Developmental Disabilities 1, 4-6 (2016) (describing British Columbia's 1996 Representation Agreement Act).

<sup>11</sup> See Martha C. Nussbaum, *Frontiers of Justice: Disability, Nationality, Species Membership* 196 (2006) (discussing the Swedish approach, enacted in 1994, which creates a "mentorship" relationship between a person with a disability and a "god man"); *id.* at 197-98 (discussing a 1992 German law which barred guardianship if the person could manage with support from other social services, and mandated that the guardian "follow the wishes of the supported individual as long as the well-being of the handicapped person is not likely to be impaired" (quoting Stanley S. Herr, *Self-Determination, Autonomy, and Alternatives to Guardianship*, in *The Human Rights of Persons with Intellectual Disabilities: Different but Equal* 429, 441-42 (Stanley S. Herr et al. eds., 2003)); 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, 235-37 (2010)** (describing the Swedish model).

<sup>12</sup> E.g., Stainton, *supra* note 10, at 1 ("With the passage of the [CRPD], supported decision-making has taken on a much broader profile within the legal, professional, and activist discourse ...").

<sup>13</sup> Kristin Booth Glen, *Piloting Personhood: Reflections from the First Year of a Supported Decision-Making Project*, **39 Cardozo L. Rev. 495, 499 (2017)**.

<sup>14</sup> CRPD, *supra* note 8, art. 12, P 2.

<sup>15</sup> *Id.* art. 12, P 3. As the language suggests, the drafters of the CRPD had supported decision-making, in particular, in mind. 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, 447-52 (2007)**. Article 33 of the CRPD also contemplates a role for "civil society (including people with disabilities and their representative organizations)" by requiring states parties to provide for the participation in national implementation and monitoring mechanisms. Dinerstein, *supra* note 2, at 12.

<sup>16</sup> Del. Code Ann. tit. 16, §§9401A-9410A (West 2018).

also been the subject of international law reforms<sup>19</sup> and scholarly literature,<sup>20</sup> and has been taken up by a wide range of advocacy and professional groups.<sup>21</sup> Pilot projects are testing out different models across the United States and abroad.<sup>22</sup>

**[\*978]** This Note, however, cautions against overstating the salience of international human rights law in accounting for interest in supported decision-making in the United States. The role of international law - and particularly international human rights law - in the United States has long been fraught.<sup>23</sup> As is the case with numerous other treaties and conventions, the United States is a signatory to the CRPD but has not ratified it,<sup>24</sup> so

<sup>17</sup> [Wis. Stat. §§52.01-32](#) (2018).

<sup>18</sup> [D.C. Code §§7-2131-2134](#) (2018). Many other states have passed laws ordering studies on supported decision-making. See, e.g., H.P. 900, 127th Leg., 2d Reg. Sess. (Me. 2016) (resolving that the Probate and Trust Law Advisory Commission examine supported decision-making and make recommendations about inclusion in the Probate Code); H.J. Res. 190, 2014 Leg. Reg. Sess. (Va. 2014) (ordering a study on supported decision-making).

<sup>19</sup> See, e.g., Dinerstein, *supra* note 2, at 11-12 (discussing international implementation of Article 12).

<sup>20</sup> See, e.g., Burke, *supra* note 1; Diller, *supra* note 4; Glen, *supra* note 2; Kohn et al., *supra* note 9; Salzman, *supra* note 11.

<sup>21</sup> In August 2017, the ABA House of Delegates adopted a resolution urging legislatures to amend their guardianship statutes to require supported decision-making to be considered as a less-restrictive alternative before imposing guardianship, and urging courts to consider supported decision-making as a less-restrictive alternative to guardianship. Am. Bar Ass'n, Res. 113 (2017), <https://www.americanbar.org/content/dam/aba/images/abanews/2017%20Annual%20Resolutions/113.pdf>; see also Am. Bar Ass'n House of Delegates, Proposed Resolution 113 and Report (2017), <https://www.americanbar.org/news/reporter/resources/annual-meeting-2017/house-of-delegates-resolutions/113.html> (available for download) [hereinafter ABA Proposed Resolution 113 and Report]. The National Guardianship Association "supports ongoing research to determine the effectiveness of supported decision-making models as alternatives to guardianship." Position Statement on Guardianship, Surrogate Decision Making, and Supported Decision Making, Nat'l Guardianship Ass'n (Sept. 20, 2017), <https://www.guardianship.org/wp-content/uploads/2017/07/SDM-Position-Statement-9-20-17.pdf>. Numerous other organizations have also taken up supported decision-making in recent years. See Supported Decision Making & the Problems of Guardianship, ACLU, <https://www.aclu.org/issues/disability-rights/integration-and-autonomy-people-disabilities/supported-decision-making> (last visited June 18, 2018) (describing the problems with guardianship and presenting supported decision-making as an alternative); Autonomy, Decision-Making Supports, and Guardianship, The Arc (Apr. 20, 2016), <https://www.thearc.org/who-we-are/position-statements/rights/Autonomy-Decision-Making-Supports-and-Guardianship> (stating positions on guardianship and supported decision-making and recommending system-wide reforms, which are endorsed by the Arc Board of Directors, Chapters of the Arc, and the American Association on Intellectual and Developmental Disabilities Board of Directors); The Right to Make Choices: New Resource on Supported Decision-Making, Autistic Self Advocacy Network (Feb. 1, 2016), <http://autisticadvocacy.org/2016/02/the-right-to-make-choices-new-resource-on-supported-decision-making/> (announcing the creation of a guide on supported decision-making).

<sup>22</sup> See, e.g., Glen, *supra* note 13, at 502, 505-07, 509-17 (describing pilot projects in Bulgaria, the Czech Republic, Massachusetts, Israel, Australia, and New York).

<sup>23</sup> See generally Michael Ignatieff, Introduction: American Exceptionalism and Human Rights, in *American Exceptionalism and Human Rights* 1, 3 (Michael Ignatieff ed., 2005) (describing "American exceptionalism" in this area as having "at least three separate elements": (1) "signing onto international human rights and humanitarian laws conventions and treaties and then exempting itself from their provisions by explicit reservation, nonratification, or noncompliance"; (2) maintaining "double standards," and (3) "denying jurisdiction to human rights law within its own domestic law"). Numerous Supreme Court decisions grapple with the appropriate role of international law in United States jurisprudence. See, e.g., [Roper v. Simmons, 543 U.S. 551, 575-78 \(2005\)](#) (plurality opinion) (discussing and weighing "the overwhelming weight of international opinion against the juvenile death penalty"); [id. at 622-28](#) (Scalia, J., dissenting) (heavily criticizing the plurality's reliance on international law). The United States' withdrawal from the UN Human Rights Council is a new chapter in the United States' fraught relationship with human rights. See Gardiner Harris, Trump Administration Withdraws U.S. from U.N. Human Rights Council, N.Y. Times (June 19, 2018), <https://www.nytimes.com/2018/06/19/us/politics/trump-israel-palestinians-human-rights.html>.

Article 12 lacks the force of law.<sup>25</sup> The CRPD has played a significant role in galvanizing action around supported decision-making among government actors at the federal level,<sup>26</sup> and among advocates and professional organizations in the United States.<sup>27</sup> Legal capacity, though, is defined at the state level,<sup>28</sup> and [\*979] states have been at the forefront of efforts to adopt supported decision-making.<sup>29</sup> Yet it is far from clear that invoking international human rights norms is a persuasive tactic in many state legislatures. Indeed, since 2010, legislatures in half of the states have proposed bills or state constitutional amendments designed to restrict the use of international and foreign law by state and sometimes federal courts.<sup>30</sup> Consistent with its storied reputation for independence, Texas is one of two states where an anti-international law was enacted in 2017.<sup>31</sup> Furthermore, conservative suspicion of the United Nations and the international human rights regime was a key factor in the Senate's failure to ratify the CRPD.<sup>32</sup>

<sup>24</sup> See Convention on the Rights of Persons with Disabilities: Senate Consideration of Treaty Document 112-7, Congress.gov, <https://www.congress.gov/treaty-document/112th-congress/7> (last visited June 18, 2018); see also Curtis A. Bradley, Unratified Treaties, Domestic Politics, and the U.S. Constitution, *48 Harv. Int'l L.J.* 307, 309-13, 309 n.5 (2007) (discussing the United States' historical and continuing practice of signing but not ratifying treaties).

<sup>25</sup> Glen, *supra* note 2, at 161-62; see also Bradley, *supra* note 24, at 313-18 (explaining that "although signing [a treaty] is not typically viewed as a manifestation of consent to be bound to a treaty, many international law academics and lawyers contend that signing does impose certain obligations on the signatory country," chiefly to "refrain from acts which would defeat the object and purpose' of the treaty" (quoting Vienna Convention on the Laws of Treaties art. 18, Apr. 24, 1970, 1155 U.N.T.S. 332)).

<sup>26</sup> See, e.g., President's Comm. for People with Intellectual Disabilities, Report to the President: Strengthening an Inclusive Pathway for People with Intellectual Disabilities and Their Families 61-69 (2016) (invoking the CRPD to urge adoption of recommendations regarding the promotion of supported decision-making in various government programs); see also Glen, *supra* note 13, at 500 (noting that supported decision-making has been "embraced by officials at the U.S. Agency for Intellectual and Developmental Disability," which is now a part of the Administration for Community Living).

<sup>27</sup> See, e.g., Glen, *supra* note 2, at 138-39 (discussing how human rights rhetoric influenced the National Guardianship Association's decision to incorporate principles of supported decision-making into its recommendations at the Third National Guardianship Summit). The ABA has repeatedly called on members of Congress to take steps towards ratifying the CRPD. See, e.g., Am. Bar Ass'n House of Delegates, Recommendation 108B and Report (2010), [https://www.americanbar.org/content/dam/aba/directories/policy/2010\\_my\\_108b.authcheckdam.pdf](https://www.americanbar.org/content/dam/aba/directories/policy/2010_my_108b.authcheckdam.pdf); Letter from James R. Silkenat, President, Am. Bar Ass'n, to Robert Menendez, Chairman, Senate Comm. on Foreign Relations, & Bob Corker, Ranking Member, Senate Comm. on Foreign Relations (Nov. 5, 2013).

<sup>28</sup> See ABA Proposed Resolution 113 and Report, *supra* note 21, at 2-3 (explaining that guardianship is governed by state law).

<sup>29</sup> See *supra* notes 16-18 and accompanying text.

<sup>30</sup> Aaron Fellmeth, International Law and Foreign Law in U.S. State Legislatures, Insights (May 26, 2011), <https://www.asil.org/insights/volume/15/issue/13/international-law-and-foreign-laws-us-state-legislatures#> edn20. Several of these bills were explicitly concerned with banning the application of Sharia Law. *Id.*; see also Hatewatch Staff, Anti-Sharia Law Bills in the United States, S. Poverty Law Ctr., (Feb. 5, 2018), <https://www.splcenter.org/hatewatch/2018/02/05/anti-sharia-law-bills-united-states> (charting the introduction and passage of anti-Sharia laws in state legislatures).

<sup>31</sup> Hatewatch Staff, *supra* note 30. Though Texas's law specifically bans the application of "foreign law" in certain family law cases, it is widely understood to be an "anti-Sharia law" bill. See H.B. 45, 85th Leg., Reg. Sess. (Tex. 2017); see also Action Alert: Oppose House Bill 45, CAIR Tex. (Apr. 3, 2017), <http://cairtexas.com/action-alert-oppose-house-bill-45/> (urging "members of the Muslim community and their interfaith partners to attend a public hearing ... to show public opposition to House Bill 45, which [CAIR] believes is designed to negatively impact Muslims' civil rights and demonize their faith"); Merrill Hope, Texas Enacts 'Anti-Sharia' Law, Breitbart (June 16, 2017), <http://www.breitbart.com/texas/2017/06/16/texas-enacts-anti-sharia-law/> (characterizing the "American Laws for American Courts Act" as an "'anti-Sharia' law").

<sup>32</sup> See Rosalind S. Helderman, Senate Rejects Treaty to Protect Disabled Around the World, Wash. Post (Dec. 4, 2012), [https://www.washingtonpost.com/politics/senate-rejects-treaty-to-protect-disabled-around-the-world/2012/12/04/38e1de9a-3e2c-11e2-bca3-aadc9b7e29c5\\_story.html](https://www.washingtonpost.com/politics/senate-rejects-treaty-to-protect-disabled-around-the-world/2012/12/04/38e1de9a-3e2c-11e2-bca3-aadc9b7e29c5_story.html) (noting that conservatives who voted against ratification "were deeply suspicious of the

The story of the passage of supported decision-making legislation in Texas is important because it illustrates how forces other than the CRPD are driving interest in and shaping supported decision-making in the United States. Texas's story demonstrates the impact of nationwide concern about the ability of state courts to process and monitor [\*980] the enormous influx of guardianship cases predicted to accompany the aging of the population, making supported decision-making an attractive policy to pursue for stakeholders like state legislators, judges, and court administrators.<sup>33</sup> Texas's experience also shows how increasing national attention to guardianship abuse<sup>34</sup> is making supported decision-making a particularly appealing policy option.<sup>35</sup> While versions of supported decision-making were first adopted in countries known to be progressive and to have generous social safety nets,<sup>36</sup> the Texas experience also reveals that at least some versions of supported decision-making can be extremely appealing to conservatives who favor small government. Supported decision-making locates support in trusting, personal relationships,<sup>37</sup> which accords with the traditionally conservative belief that family and private charity, not the state, should provide support to those who need assistance.<sup>38</sup> In addition, the Texas experience shows that supported decision-making is gaining traction in the United States because it accords with the fundamental concepts of independence and autonomy,<sup>39</sup> which have long resonated both with conservatives and disability civil rights activists.

This Note proceeds in four parts. Part I provides a brief overview of guardianship and **supported decision-making** and discusses how, like many of the American **disability** rights movement's projects before it, **supported decision-making** has strong appeal for conservatives who favor small government while also promoting the true goals [\*981] of disability rights activists. This Part next describes how Texas's initial interest in **supported decision-making** grew out of the **disability** rights community's efforts to promote self-determination in the face of budget cuts and government restructuring that placed increased importance on "personal responsibility" for people with **disabilities**. It also briefly discusses Texas's 2009 **supported decision-making** pilot project. Part II identifies two issues that put guardianship in general on Texas legislators' agendas in the years leading up to the 2015 84th Legislative Session: the issue of guardianship abuse and concerns about the impact of the aging of the population on probate courts. Part III explains how advocates organized to draft and pass supported decision-making legislation and other guardianship reform bills. Section A describes the legislation that was ultimately passed. Section B focuses on the organization of the Guardianship Reform and Supported Decision-Making Workgroup (GRSDM) and its community-organizing style of work. Section C explains how GRSDM won the support of key,

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United Nations," and argued that signing the treaty "could relinquish U.S. sovereignty to a U.N. committee" and were "particularly worried that the committee could violate the rights of parents who choose to home school their disabled children").

<sup>33</sup> Without specifically discussing Texas, Sean Burke predicted that the so-called "silver tsunami" - the term used to describe the effect the demographic trend would have on the courts - would put pressure on policy makers to adopt supported decision-making. Burke, *supra* note 1, at 884-86; see also *infra* Section II.B (discussing the effects of the silver tsunami on the adoption of supported decision-making in Texas).

<sup>34</sup> See *infra* note 98 and accompanying text.

<sup>35</sup> See *infra* Section III.A.

<sup>36</sup> See, e.g., Michael E. Porter et al., Social Progress Imperative Social Progress Index 2016, at 12, 17 (2016), <http://13i8vn49fubl3go3i12f59gh.wpengine.netdna-cdn.com/wp-content/uploads/2016/06/SPI-2016-Main-Report.pdf> (ranking Canada second, Sweden sixth, and Germany fifteenth on an index that measures "social progress," which looks at a country's ability to meet its residents' basic human needs, to provide the "foundation of wellbeing" by providing services such as access to basic knowledge and healthcare and access to opportunity).

<sup>37</sup> See *infra* notes 50-51 and accompanying text.

<sup>38</sup> See, e.g., Ryan T. Anderson, Conservatives Do Believe in Social Justice. Here's What Our Vision Looks Like., Heritage Found. (Mar. 20, 2017), <https://www.heritage.org/civil-society/commentary/conservatives-do-believe-social-justice-heres-what-our-vision-looks> (describing a worldview in which economic freedom allows for the fulfillment of duties, such as the natural duties that family members owe to each other and the duty to serve one's community, and arguing that government should play a limited role in supporting, rather than running, institutions that provide services of public concern like education and healthcare).

<sup>39</sup> See *infra* notes 59-62 and accompanying text.

influential stakeholders. Section D illustrates how some supporters of the legislation framed it as an autonomy-enhancing piece of civil rights legislation, while others appealed to conservatives by highlighting its ability to save money and draw upon the natural support network of the family. Part IV discusses lessons to be learned from Texas's experiences and provides an overview of Texas's implementation efforts to date.

I

## Supported Decision-Making and "Personal Responsibility"

### A. Guardianship and Supported Decision-Making

Supported decision-making stands in contrast to guardianship, a form of "surrogate" decision-making imposed after a court proceeding.<sup>40</sup> Guardianship is a relationship created by the state that empowers a court-appointed guardian to make decisions for another person who the court finds to be incapable of making decisions for him or herself, oftentimes referred to as the "ward."<sup>41</sup> The past century has seen significant changes in guardianship in the United States, with a move from a model where legal incapacity flowed directly from **[\*982]** a medical diagnosis to a more functional approach.<sup>42</sup> The decision-making norm has moved from the very paternalistic "best interests" standard to the somewhat less paternalistic "substituted judgement" standard, where the preferences and goals of the person under guardianship are supposed to guide the guardian's decisions.<sup>43</sup> In most states today, judges can impose a "tailored," or limited, rather than "plenary" guardianship, where the guardian is empowered to make decisions for the person under guardianship in only certain designated areas.<sup>44</sup> Even in the best of circumstances, though, guardianship is still a sort of "civil death," where the person under guardianship's decisions lack legally binding effect.<sup>45</sup>

Advocates of supported decision-making hope that its adoption will transform society's treatment of people with intellectual and cognitive disabilities by acknowledging their rights to autonomy and self-determination.<sup>46</sup> CRPD Article 12 separates the concept of legal capacity from cognitive decision-making ability.<sup>47</sup> Rather than triggering a loss of legal capacity as in guardianship, as Professor Rebekah Dillar explains, under Article 12's regime "cognitive and other mental disabilities trigger a right to 'support' in decision-making."<sup>48</sup> Though there are many different supported decision-making models,<sup>49</sup> a common theme is that supporters must have a close and trusting

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<sup>40</sup> Dinerstein, *supra* note 2, at 9-10.

<sup>41</sup> *Id.*; see also Brenda K. Uekert & Richard Van Duizend, Nat'l Ctr. for St. Cts., *Adult Guardianships: A "Best Guess" National Estimate and the Momentum for Reform*, 2011 *Future Trends St. Cts.* 106, 106-07 (demonstrating issues that can arise through guardianship).

<sup>42</sup> Glen, *supra* note 2, at 103-15.

<sup>43</sup> See *id.* at 115-19. The National Guardianship Network's Standards of Practice provide definitions for both "best interests" and "substituted judgement." Nat'l Guardianship Ass'n, *Standards of Practice* (4th ed. 2013).

<sup>44</sup> Glen, *supra* note 2, at 103-15.

<sup>45</sup> Dinerstein, *supra* note 2, at 9.

<sup>46</sup> See, e.g., About SDMNY: Transformation, Supported Decision-Making New York, <http://sdmny.org/about-sdmny/transformation/> (last visited July 3, 2018) ("SDM has the potential to transform how we see, understand and treat people with [intellectual and developmental disabilities] ...").

<sup>47</sup> Diller, *supra* note 4, at 496.

<sup>48</sup> *Id.*; see also CRPD, *supra* note 8, art. 12 ("States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.").

<sup>49</sup> See, e.g., Glen, *supra* note 13, at 505-07 (describing pilot projects in Bulgaria, the Czech Republic, Latvia, and Massachusetts that use paid facilitators to provide ongoing support to clients and their chosen supporters, and an Israeli model that used paid supporters); Inclusion Europe, Swedish Personal Ombudsman Service (PO) for People with Mental Health

relationship with the person being supported.<sup>50</sup> **[\*983]** Even models that use paid supporters recognize the centrality of trust. For example, the "personal ombudsmen" model that uses NGO-employed professionals to provide decision-making support to people with mental health challenges in Sweden is structured so that ombudsmen do not work out of offices, have flexible schedules, meet with individuals in their homes, and commit to long-term engagements in order to build mutual, non-hierarchical relationships of trust.<sup>51</sup>

#### B. **Supported Decision-Making**, the **Disability** Rights Movement, and Conservatism

The centrality of independence and the provision of support through trusting, preferably personal, relationships makes supported decision-making particularly appealing to groups and actors operating within the American disability rights movement<sup>52</sup> and to American conservatives and libertarians who favor small government.<sup>53</sup> This is not the first time these groups have had converging interests - indeed, the Americans With Disabilities Act's (ADA) successful passage during the Reagan Era has been attributed in part to advocates' framing of the legislation as a way to move people with disabilities from welfare to work.<sup>54</sup> Focusing on the beginnings of the pan-disability movement in the 1970s and the passage of the ADA in the early 1990s, Professor Samuel Bagenstos has argued that "independence" is the American disability rights movement's most important "collective action frame" - that is, its most important "way[] of interpreting the world" to encourage support for the movement among relevant audiences.<sup>55</sup> Supported decision-making seems to fit the trend.

**Supported decision-making** embodies the complex vision of "decisional" independence that American **disability** rights activists have long embraced, which holds that assistance can promote independence so long as the person receiving assistance directs the services **[\*984]** that he or she receives.<sup>56</sup> The concept of decisional independence is the work of the influential Independent Living Movement of the 1970s,<sup>57</sup> and its influence on supported decision-making is readily apparent. The crux of decisional independence is the ability to make decisions about one's own life, free from the control of paternalistic institutions and actors.<sup>58</sup> In the supported decision-making context, this means the ability to make decisions free from the paternalistic institution of guardianship. The influence of the Independent Living Movement's nuanced, simultaneous embrace of both the concept of self-

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Problems, <http://www.right-to-decide.eu/2014/08/swedish-personal-ombudsman-service-po-for-people-with-mental-health-problems/> (last visited July 3, 2018) (describing a system for people with mental health diagnoses that employs paid supporters who work for NGOs).

<sup>50</sup> See, e.g., The Arc of Tex., *Alternatives to Guardianship: Supported Decision-Making Agreements* (2015), <https://www.thearcoftexas.org/wp-content/uploads/2016/06/Supported-Decision-Making-For-Families-UPDATED-Jan-2016.pdf> ("Using a **supported decision-making** agreement, a person with a **disability** chooses someone they trust to serve as their supporter."); Stainton, *supra* note 10, at 6 ("Supported decision-making requires a network of people who know a person intimately as an individual and whose relationship is based on trust and mutuality rather than a professional or contractual relationship.").

<sup>51</sup> See Inclusion Europe, *supra* note 49.

<sup>52</sup> As Professor Samuel Bagenstos has noted, there is no single disability rights movement with unified goals and tactics; "the" movement is diverse and composed of actors and organizations with varying motivations, goals, and strategies. Samuel R. Bagenstos, *Law and the Contradictions of the Disability Rights Movement* 12 (2009). Support for the concept of "independence," though, has consistently been a source of agreement for diverse movement actors. *Id.* at 30-32.

<sup>53</sup> See Anderson, *supra* note 38.

<sup>54</sup> See Samuel R. Bagenstos, *The Americans With Disabilities Act as Welfare Reform*, *44 Wm. & Mary L. Rev.* 921, 953-75 (2003).

<sup>55</sup> Bagenstos, *supra* note 52, at 27.

<sup>56</sup> *Id.* at 26.

<sup>57</sup> *Id.* at 25.

<sup>58</sup> *Id.* at 25-26.



reliance and the importance of services<sup>59</sup> can also be felt in supported decision-making. For example, supporters of a companion bill to Texas's Supported Decision-Making Agreement Act<sup>60</sup> presented "supports and services" - a term of art in disability rights organizing that refers to formal and informal resources and assistance that help individuals with disabilities meet their personal needs and live independently in the community<sup>61</sup> - as integral to and entirely consistent with independence.<sup>62</sup> Supported decision-making's embrace of decisional independence is of course no coincidence; the emerging supported decision-making paradigm should be understood to be in part an outgrowth of the American disability rights movement's work, rather than an international human rights law concept alone.<sup>63</sup>

**[\*985] Supported decision-making** also shares with the broader American **disability** rights movement an ambivalence towards professionals.<sup>64</sup> As Professor Bagenstos explains, during the 1970s and 1980s disability rights activists developed a critique of professionalism, holding that nondisabled professionals such as doctors, psychiatrists, and caseworkers who worked with people with disabilities were often paternalistic, arbitrary, and oppressive.<sup>65</sup> State-funded disability benefits programs were even worse, with arbitrary rules for compliance dictating the life outcomes of people with disabilities.<sup>66</sup> Yet at the same time, the movement often relied on the assistance and endorsement of professionals,<sup>67</sup> and individuals with disabilities have acknowledged the benefits of and advocated for access to assistance from professionals, so long as the person with the **disability** directs the services he or she receives.<sup>68</sup> While some **supported decision-making** model projects use volunteer<sup>69</sup> or paid professional supporters,<sup>70</sup> the ideal arrangement is widely understood to involve the use of trusted individuals who have personal relationships with the decision-maker as supporters.<sup>71</sup> Self-advocates<sup>72</sup> have expressed concerns

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<sup>59</sup> Id. (noting that actors within the Independent Living Movement saw government benefits as promoting autonomy so long as individuals receiving the benefits could direct them, while also "continually and insistently urging an ethic of self-help and individual responsibility").

<sup>60</sup> H.B. 39, 84th Leg., Reg. Sess. (Tex. 2015). This bill is described in detail in Section III.A.

<sup>61</sup> See, e.g., Richard LaVallo, Disability Rights Tex., Supports & Services - Alternatives to Guardianship 8 (2017) (on file with author) (providing examples of informal supports and services, such as family and friends; formal supports and services, such as Medicaid programs and supported decision-making agreements; and other types of supports and services such as free or reduced meals, free or reduced transportation, technology, and daily call and home visiting services); see also In re Guardianship of Dameris L., 956 N.Y.S.3d 848, 856, 875-76 (N.Y. Surrogate's Ct. 2012) (terminating a guardianship upon evidence that the person under guardianship was able to "exercise her legal capacity, to make and act on her own decisions, with the assistance of a support network," which included family, neighbors, agency staff, as well as publicly funded benefits and resources).

<sup>62</sup> See Hearing on H.B. 39 Before the S. Comm. on State Affairs, 2015 Leg., 85th Sess. (Tex. 2015), [http://tlcenate.granicus.com/MediaPlayer.php?view\\_id=30&clip\\_id=10001](http://tlcenate.granicus.com/MediaPlayer.php?view_id=30&clip_id=10001) [hereinafter Hearing on H.B. 39].

<sup>63</sup> See Glen, supra note 2, at 128-31 (explaining how trends in American disability organizing - the integration presumption, "normalization," and person-centered planning - have all contributed to the "paradigm shift" towards supported decision-making).

<sup>64</sup> Bagenstos, supra note 52, at 21-23.

<sup>65</sup> Id. at 21-22.

<sup>66</sup> Id. at 22.

<sup>67</sup> Id.

<sup>68</sup> See id. at 25.

<sup>69</sup> See, e.g., Glen, supra note 13, at 506 (describing an Israeli pilot project that used volunteer supporters to assist with financial decisions only).

<sup>70</sup> See supra notes 11 & 51 and accompanying text (describing the Swedish and German models).

<sup>71</sup> See supra note 50 and accompanying text.

that using paid supporters could turn supported decision-making into "simply another service." <sup>73</sup> And indeed, in order for supported decision-making to operate as an "organic process, ... engrained within the daily process of decision-making," it is important for supporters to be part of an individual's everyday support network. <sup>74</sup>

Yet not all people with disabilities have these types of personal support networks, particularly older people with intellectual disabilities who may have been institutionalized and cut off from their families [**\*986**] and support networks. <sup>75</sup> In some cases, agency-based professionals may be part of an individual with a disability's daily support network, and a trusting, personal relationship may exist. <sup>76</sup> Agency-based professionals may also have a role to play in helping individuals build up their personal support networks. The Canadian Association for Community Living took this approach in a 2014 policy proposal, suggesting that community agencies in Canada be tasked with helping individuals with disabilities create personal networks to assist with decision-making or providing decision-making support directly when necessary. <sup>77</sup> Numerous supported decision-making models also have professionals serve as facilitators who help decision-makers and their supporters enter into a supported decision-making agreement, or provide ongoing, indefinite facilitation. <sup>78</sup> A formal supported decision-making agreement of course need not be the only type of support an individual with a **disability** receives, and many organizations advocating for **supported decision-making** also dedicate significant effort to expanding supports and services more broadly. <sup>79</sup> Nonetheless, supported decision-making's explicit emphasis on trusting, personal relationships as a source of support still has appeal for small-government conservatives who are suspicious of professionals - particularly the state-funded kind.

### C. Early **Supported Decision-Making** in Texas

The themes that have characterized the American **disability** rights movement's complex relationship with small-government, American [**\*987**] conservatism were present in Texas's earliest work on supported decision-making. Texas's interest in supported decision-making predates the CRPD's entrance into force. In fact, its interest grew out of the disability rights community's response to extensive state budget cuts in 2004, which resulted in an overhaul

<sup>72</sup> The self-advocacy movement within disability rights organizing holds that "people with intellectual and/or developmental disabilities have the right to advocate for themselves," and self-advocates have organized groups that provide individuals with support and education about how to effectively advocate on their own behalf. See Self-Advocacy, The Arc, <https://www.thearc.org/who-we-are/position-statements/rights/self-advocacy> (last visited June 23, 2018).

<sup>73</sup> Glen, *supra* note 13, at 508.

<sup>74</sup> Stainton, *supra* note 10, at 6.

<sup>75</sup> *Id.*

<sup>76</sup> See, e.g., Freed From Guardianship: A Kentucky First: Woman Wins Her Rights in Court Using SDM, Exceptional Family KY, Summer/Fall 2017, at 14 (describing how a 22-year-old woman diagnosed with a mild intellectual disability successfully had her rights restored by demonstrating to the court that she was making decisions for herself with the support of a team that consisted of "friends and paid caregivers through Kentucky's intellectual and developmental disability Medicaid waiver called Supports for Community Living").

<sup>77</sup> Canadian Ass'n for Cmty. Living, A Statutory Framework for the Right to Legal Capacity and Supported Decision Making: For Application in Provincial/Territorial Jurisdictions in Canada 6, 12-13 (2014), <http://www.cacl.ca/sites/default/files/Draft%20Statutory%20Fmwk%20-%20Legal%20Capacity%20-%20June%209.pdf>.

<sup>78</sup> See *supra* note 49 and accompanying text.

<sup>79</sup> See, e.g., Long Term Supports and Services, The Arc, <https://www.thearc.org/who-we-are/position-statements/systems/long-term-supports-and-services> (last visited July 2, 2018) (identifying the need for a nationwide system of long-term supports and services and identifying the requirements for that system); State Plan, Tex. Council for Developmental Disabilities, <http://www.tccd.texas.gov/about/state-plan/> (last visited July 3, 2018) (including the goal of "improving and/or expanding community-based systems to better support people with developmental disabilities ..." in its FY 2017-2021 state plan).

of the state's Department of Health and Human Services.<sup>80</sup> With the CRPD being contentiously negotiated in Geneva,<sup>81</sup> representatives from advocacy organizations, state government, and local organizations came together, viewing the restructuring's embrace of personal responsibility as an opportunity to promote self-determination for Texans with disabilities.<sup>82</sup>

The work of the "Texas Self-Determination State Policy Team," as the participants in the convening were termed, embodied the various contradictions and tensions that have characterized so much of American disability rights organizing. The Team hoped to take advantage of the new legislation's emphasis on personal responsibility, including the following in its "purpose" document:

While roles and responsibilities are being redefined within the health and human services system, self-determination requires fundamental changes in roles and responsibilities of people supported by the system. These include increased participation and contribution from people with disabilities and at times, their families - freedom and responsibility go hand in hand.<sup>83</sup>

**[\*988]** On the other hand, the Team recognized that support, particularly in the form of publicly funded services, is often indispensable for self-determination for people with disabilities.<sup>84</sup> And while the document explained that people with disabilities often "count on family or other allies," it acknowledged that "sometimes people lack the personal and family support they need to have control in their lives - yet they are no less entitled to exercise principles of self-determination."<sup>85</sup>

The Team identified guardianship and substitute decision-making as barriers to self-determination in Texas, and created an Alternatives to Guardianship Subcommittee.<sup>86</sup> The Alternatives to Guardianship Subcommittee continued to meet for several years under various leadership configurations,<sup>87</sup> with its work ultimately culminating

<sup>80</sup> See Ian Hill, Case Study: Texas, in John Holahan et al., *Urban Inst., State Responses to Budget Crisis in 2004: An Overview of Ten States* 4 (2004). For a variety of reasons, states across the United States faced enormous budget deficits in 2004. See Iris J. Lav & Nicholas Johnson, *Ctr. on Budget & Policy Priorities, State Budget Deficits for Fiscal Year 2004 Are Huge and Growing* (2003) (including a chart of deficits in each state); *State Budget Crunch Overview*, PBS: NOW (Jan. 10, 2003), <http://www.pbs.org/now/politics/statebudgets.html> (listing a range of possible explanations for the deficit situation). The Texas Legislature rejected proposals to raise taxes and implemented enormous budget cuts instead. Hill, *supra*, at 110.

<sup>81</sup> See Dinerstein, *supra* note 2, at 8 ("Article 12 was one of the most hotly contested articles to be considered during the treaty deliberation process."); Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, United Nations Dep't of Econ. & Soc. Affairs: Division for Inclusive Soc. Dev., <https://www.un.org/development/desa/disabilities/resources/ad-hoc-committee-on-a-comprehensive-and-integral-international-convention-on-the-protection-and-promotion-of-the-rights-and-dignity-of-persons-with-disabilities.html> (last visited July 18, 2018) (noting that an Ad Hoc Committee was established in 2001 to begin work on a comprehensive international convention on the rights of persons with disabilities, and that it continued to work through 2006 when its work culminated in the adoption of the CRPD and its Optional Protocol).

<sup>82</sup> See Tex. Self-Determination State Policy Team, *History and Purpose* (2004) (on file with author).

<sup>83</sup> *Id.* The document also discusses the important role of personal relationships and private income in supporting self-determination, highlighting "relationships that endure and support their community connections" and "abilities to generate personal income that [people] can use to have freedom and control in their lives" as outcomes that a new system of support for people with disabilities should promote. *Id.*

<sup>84</sup> *Id.* ("At the heart of a self-determination-based system is the belief that by designing publicly funded supports as investments in people, the system will enhance and expand its capacity... . The Texas Self-Determination State Policy Team recognizes that many people with disabilities require support to exercise self-determination.").

<sup>85</sup> *Id.*

<sup>86</sup> The subcommittee was co-convened by Susan Murphree of Disability Rights Texas, then known as Advocacy Incorporated, and Cynthia King, of the Arc of Fort Bend. See Memorandum from the Tex. Self-Determination Policy Planning Subcomm. Team 3 (Sept. 13, 2004) (on file with author).

in the passage of H.B. 1454 in 2009, which directed the Texas Health and Human Services Commission to develop a supported decision-making pilot project.<sup>88</sup> This was the first pilot project on supported decision-making in the United States.<sup>89</sup> Though the Texas Council for Developmental Disabilities (TCDD) - a federally funded organization tasked with developing and supporting best practices and policies that promote self-determination for people with developmental disabilities<sup>90</sup> - called for increased funding for programs providing alternatives **[\*989]** to guardianship in their 2006 Biennial Report,<sup>91</sup> H.B. 1454 provided none. As a work-around, the TCDD released a Request for Proposal (RFP) and covered the costs of the project.<sup>92</sup> The grant was ultimately awarded to the Arc of San Angelo,<sup>93</sup> a local chapter of a nationwide, grassroots organization started by "parents who were frustrated at the lack of services and the negative public image for children with intellectual developmental disabilities," in the 1950s.<sup>94</sup> The pilot project aimed to use agency-trained volunteer supporters.<sup>95</sup> Matching volunteers with people in need of support, though, proved to be a barrier to the model's success.<sup>96</sup> Volunteers' time constraints and scheduling conflicts left most of the work of implementing and sustaining services to paid staff, who lacked the organizational capacity to take it on.<sup>97</sup>

## II

### Guardianship Already on the Agenda

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<sup>87</sup> See E-mail from Jessica Ramos, Pub. Policy Dir., Tex. Council for Developmental Disabilities, to Belinda Carlton, Retired Pub. Policy Specialist, Tex. Council for Developmental Disabilities (Sept. 20, 2017, 11:32 AM CST) (on file with author).

<sup>88</sup> H.B. 1454, 81st Leg., Reg. Sess. (Tex. 2009); see also Tex. Council for Developmental Disabilities, TCDD Future Funding Proposal Executive Summary: Volunteer Advocate Pilot Project (2009) (on file with author) (describing H.B. 1454). The bill was sponsored by Texas State Senator Judith Zaffirini, who would go on to sponsor the supported decision-making legislation passed in 2015. See Terri Langford, Guardianship Reform Could Offer New Freedoms, Tex. Trib. (Apr. 26, 2015), <https://www.texastribune.org/2015/04/26/guardianship-reform-could-offer-new-freedoms/>.

<sup>89</sup> Glen, *supra* note 13, at 502 n.36.

<sup>90</sup> Each state and United States territory has a federally funded, self-governing Developmental Disabilities Council charged with identifying the most pressing needs of people with developmental disabilities in their state or territory. State Councils on Developmental Disabilities, Admin. for Cmty. Living, <https://www.acl.gov/programs/aging-and-disability-networks/state-councils-developmental-disabilities> (last visited June 3, 2018). TCDD is Texas's Developmental Disabilities Council. Authorization Through the Developmental Disabilities Assistance and Bill of Rights Act, Tex. Council for Developmental Disabilities, [www.tcdd.texas.gov/about/legal-authorization/](http://www.tcdd.texas.gov/about/legal-authorization/) (last visited June 3, 2018).

<sup>91</sup> Tex. Council for Developmental Disabilities & Tex. Office for Prevention of Developmental Disabilities, Working Towards a Better Future: 2006 Texas Biennial Disability Report 15 (2006) (on file with author).

<sup>92</sup> Tex. Council for Developmental Disabilities, *supra* note 88; Tex. Council for Developmental **Disabilities**, Requests for Proposals #2010-6: Alternatives to Guardianship: Volunteer **Supported Decision-Making** Advocate Pilot (2010) (on file with author).

<sup>93</sup> Press Release, Tex. Council for Developmental Disabilities, Grant Awarded to the Arc of San Angelo (Apr. 19, 2011), <http://www.tcdd.texas.gov/tcdd-grant-to-develop-alternative-to-guardianship/>.

<sup>94</sup> About Us, The Arc of San Angelo, <https://www.thearcsofsanangelo.org/about#> history (last visited Apr. 13, 2018); see also Mission & Core Values, The Arc, <https://www.thearc.org/who-we-are/mission-and-values> (last visited Apr. 13, 2018) (listing core values as "people first," "equity," "community," "self determination," and "diversity").

<sup>95</sup> The Arc of San Angelo, Alternatives to Guardianship: Volunteer-Supported Decision-Making Pilot 1-2 (2012), <http://sdmny.org/download/arc-of-san-angelo-evaluation-supplemental-report-ii2012/?wpdmdl=420&ind=NIUZtEXMLUiyt2bgbCYHAqlpZwUp5pxjXs7-knQFCoMNMJlItowvHLjHMC5CqVfU85Rf6uwcx-rLrhYdHQXkd4Jq9-MZymhB-GhMKoF0>.

<sup>96</sup> *Id.* at 4.

<sup>97</sup> *Id.*

The passage of supported decision-making legislation in Texas in 2015 did not simply grow linearly out of the pilot project. Rather, it was the result of concerted organizing efforts in a legislature that was already primed to address guardianship. In the years preceding the 84th Legislature, while the pilot project was getting off the ground, two interconnected issues related to guardianship were on the legislative agenda. First, a coalition of family members of people with disabilities and elderly people were testifying at legislative hearings and [\*990] vociferously criticizing Texas's probate courts and guardianship system as profit driven, abusive, and exploitative.<sup>98</sup> In addition, in Texas and across the country, court administrators were looking to state legislatures for help in bracing for the impending "silver tsunami" of aging baby boomers poised to flood the courts with guardianship cases.<sup>99</sup>

#### A. Judges and Family Members Clash over the Guardianship "Industry"

For several years prior to the 84th Legislative Session, guardianship abuse activists had been making their concerns known to members of the legislature and the media. In 2010, a writer with the Fort Worth Weekly published a series of stories detailing the actions of a "tight-knit network of judges, attorneys, government agencies, banks, professional guardians, and care providers" in Tarrant County, Texas.<sup>100</sup> According to the reports, these people were physically [\*991] removing elderly people from their homes following ex parte hearings, clashing with family members who were being removed as guardians for their loved ones, and making money off of the arrangement.<sup>101</sup>

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<sup>98</sup> See infra Section II.A. In recent years, similar allegations have been made about guardianship systems and probate courts across the country, and the issue has been receiving increased media attention. See, e.g., 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> (describing the case of an elderly Nevada couple who were forcibly removed from their home and placed in an assisted living facility after a private, for-profit guardianship company filed an ex parte petition); Susan B. Garland, Calls for Court Reform as Legal Guardians Abuse Older Adults, *N.Y. Times* (July 28, 2017), <https://www.nytimes.com/2017/07/28/business/calls-for-court-reform-as-legal-guardians-abuse-older-adults.html> (describing a case of guardianship abuse in Nevada and the inability of courts across the country to adequately monitor guardianship cases to prevent abuse).

<sup>99</sup> See Tex. Office of Court Admin., Texas Guardianship Cases: Improving Court Processes and Monitoring Practices in Texas Courts 2 (2014), [http://www.txcourts.gov/media/700159/GUARDIANSHIP-STUDY\\_11-12-14-Final.pdf](http://www.txcourts.gov/media/700159/GUARDIANSHIP-STUDY_11-12-14-Final.pdf). [hereinafter Texas 2014 Guardianship Report] (noting that "guardianship has become a topic of growing importance in the court community in recent years as courts grapple with how best to handle the increase in cases requiring the appointment of a guardian" in light of the "'Silver Tsunami' - the term coined to describe the demographic trend suggesting that as the Baby Boomer generation ages, the need for guardianships will increase dramatically"); Letter from Hon. Gerald W. VandeWalle & Hon. Janice K. Walker, Co-Chairs of the Conference of Chief Justices/Conference of State Court Adm'rs, to Hon. Jonathan Lippman, Chief Judge, N.Y. State Unified Court Sys., & Hon. A. Gail Prudenti, Chief Admin. Judge, Office of Court Admin. (Nov. 28, 2012), [https://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2012\\_NGN\\_WING\\_project\\_ltr\\_with\\_RFP\\_11-12.authcheckdam.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/2012_NGN_WING_project_ltr_with_RFP_11-12.authcheckdam.pdf) (noting, in a letter explaining the need for the establishment of a working group on guardianship issues, that there are a "growing number of elders and those with disabilities who need decision-making support," and that "the older population is expected to increase by 36% between 2010 and 2020, with an especially rapid rise in the 85+ group").

<sup>100</sup> Jeff Prince, In Whose Best Interest?, *Fort Worth Wkly.* (Sept. 8, 2010), <https://www.fweeky.com/2010/09/08/in-whose-best-interest/> [hereinafter Prince, In Whose Best Interest?]; Jeff Prince, Rethinking Guardianship, *Fort Worth Wkly.* (May 19, 2010), <https://www.fweeky.com/2010/05/19/rethinking-guardianship/> [hereinafter Prince, Rethinking Guardianship]. For more coverage of the issue, see Michael Barajas, How Judges, Probate Attorneys and Guardianship Orgs Abuse the Vulnerable, *San Antonio Current* (Sept. 4, 2012), <https://www.sacurrent.com/sanantonio/how-judges-probate-attorneys-and-guardianship-orgs-abuse-the-vulnerable/Content?oid=2243812>. Media coverage of guardianship abuse has continued since the passage of the reforms as well. See, e.g., Patrick Michels, Out of Reach, *Tex. Observer* (Apr. 3, 2017), <https://www.texasobserver.org/texas-guardianship-neglect/>; Patrick Michels, Who Guards the Guardians, *Tex. Observer* (July 6, 2016), <https://www.texasobserver.org/texas-guardianship-abuse/>.

<sup>101</sup> See infra Section II.A.

Local activists, such as Debby Salinas Valdez of G.R.A.D.E. - Guardianship Reform Advocates for the Disabled and Elderly <sup>102</sup> - were calling out the system as profit-oriented and abusive. <sup>103</sup> "The bottom line is that constitutional rights are being trampled," Valdez told the Texas Tribune. <sup>104</sup> Activists showed up outside court proceedings. <sup>105</sup> Local news stations covered the issue. <sup>106</sup> Activists got the attention of Travis County Probate Judge Guy Herman, who viewed them with suspicion. <sup>107</sup> "The Legislature has said we're out here to protect the individual, not to protect the guardian," he told the Texas Tribune. <sup>108</sup> "What you have going on here," said Herman, "is people who have done something wrong coming down to the Legislature, [\*992] going to the newspaper, instead of trying their case in a court of law. In essence, they're trying to intimidate judges." <sup>109</sup>

By 2015, things had come to a head between Judge Herman and the G.R.A.D.E. activists. During the 2015 session, as the supported decision-making legislation was moving out of committee towards a vote, G.R.A.D.E. activists were testifying against a number of guardianship bills sponsored by the Texas Real Estate, Probate, and Trust section of the bar association (REPTL). <sup>110</sup> Several provisions of an omnibus guardianship bill were in fact a response to what Judge Herman saw as abusive tactics used by some of the activists and others to thwart the probate courts' work. <sup>111</sup> For example, one provision required that a motion be filed and a hearing be held before a new party could intervene in a guardianship proceeding. <sup>112</sup> This was due to a growing practice - among the G.R.A.D.E. activists and others <sup>113</sup> - of delaying guardianship proceedings by getting additional attorneys to

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<sup>102</sup> G.R.A.D.E., <http://www.guardianshipreform.org/> (last visited July 4, 2018).

<sup>103</sup> See Prince, *In Whose Best Interest?*, supra note 100 (quoting Valdez discussing the case of an elderly woman who became subject to a court-initiated guardianship proceeding after the president of Guardianship Inc. called Adult Protective Services: "These are the tactics we've seen used in other cases - they intimidate and isolate. They've got her cash, and so she can't even hire an attorney without the court's approval" (internal quotation marks omitted)); Prince, *Rethinking Guardianship*, supra note 100 ("When it becomes a business, it's no longer about the ward, it's about the money." (internal quotation marks omitted) (quoting Valdez)).

<sup>104</sup> Emily Ramshaw, *The Fight for Ceci*, Tex. Trib. (Sept. 15, 2010), <https://www.texastribune.org/2010/09/15/families-lose-guardianship-in-secret-hearings/>.

<sup>105</sup> See Prince, *In Whose Best Interest?*, supra note 100 (noting that a group of ten people gathered outside a court proceeding to support a woman who was the subject of a court-initiated guardianship proceeding, "including several local residents who had watched their own families [be] torn apart by court-appointed guardians, attorneys, and caretakers").

<sup>106</sup> Jeff Prince, *The 33 News on Guardianship "Gestapo," Fort Worth Wkly.* (Oct. 7, 2010), <https://www.fweek.com/2010/10/07/guardianships-gestapo-tactics-on-the-33-news/>.

<sup>107</sup> Ramshaw, supra note 104.

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

<sup>109</sup> *Id.*

<sup>110</sup> See Hearing on S.B. 1438 Before the S. Comm. on State Affairs, 2015 Leg., 85th Sess. (Tex. 2015), [http://tlcenate.granicus.com/MediaPlayer.php?view\\_id=30&clip\\_id=10291](http://tlcenate.granicus.com/MediaPlayer.php?view_id=30&clip_id=10291) [hereinafter Hearing on S.B. 1438] (statement of Guy Herman); see also Hearing on S.B. 1923 Before the S. Comm. on State Affairs, 2015 Leg., 85th Sess. (Tex. 2015) (relating to a bill that would allow retired probate court judges to serve as special judges); William D. Pargaman, *Estate, Guardianship, and Trust Law*, 78 *Tex. B.J.* 649, 650 (2015) (listing and discussing bills sponsored by REPTL during the 84th Legislative Session).

<sup>111</sup> Hearing on S.B. 1438, supra note 110 (statement of Guy Herman) (claiming violence and the threat of a lawsuit had been used against him and the Texas Senate to stop the bill from passing).

<sup>112</sup> Pargaman, supra note 110, at 650 (noting that HB 1438 requires "an interested person wishing to intervene in a guardianship proceeding [to] file a timely motion, serve all parties, state the grounds for intervention, and attach a pleading setting forth the purpose").

<sup>113</sup> Hearing on S.B. 1438, supra note 110 (statement of Sherry Johnston, an activist with G.R.A.D.E., noting that she had engaged in this practice).

intervene to file more recusals, because each party is allotted just two. <sup>114</sup> "These people are out of control who are opposing this bill, and it is not right," <sup>115</sup> Judge Herman exclaimed, citing the fees the state and county were incurring to defend him and others in lawsuits brought by those opposing the bill. <sup>116</sup> The advocates had a different take. "We are informing the committee that Probate Judge Guy Herman and other judges that never give anybody in guardianship the opportunity to have a simple trial by jury or due process is behind these bills," G.R.A.D.E. member Sherry Johnston stated. <sup>117</sup>

**[\*993]** The problems with Texas's guardianship system also came to the attention of someone who held more clout with Texas judges and legislators: Tom Suehs. Suehs is the former Commissioner of Health and Human Services for Texas and a principal with the Texas Star Alliance, <sup>118</sup> a heavy-hitting Texas lobbying firm. <sup>119</sup> Suehs's elderly mother-in-law, Sophie Paulos, spent three months and about \$ 100,000 opposing a guardianship proceeding that was initiated after two of her daughters called adult protective services with concerns that Suehs and his wife were exploiting Paulos. <sup>120</sup> Judge Herman presided over the case, and Paulos had to foot the bill for the court-appointed guardian ad litem who served as an investigator at the court-approved rate of \$ 300 per hour. <sup>121</sup> To stop her civil rights from being taken away, Paulos also had to hire her own attorney. <sup>122</sup> The case was ultimately settled through mediation, with Paulos retaining her rights. <sup>123</sup> Before Paulos died, Suehs promised her that he would advocate for guardianship reform in Texas. <sup>124</sup> By 2013, he was testifying about pending guardianship bills. <sup>125</sup> By 2015, the state legislature was **[\*994]** primed to do something to reform guardianship,

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<sup>114</sup> Id.

<sup>115</sup> Id.

<sup>116</sup> Id. ("They've trashed me, they've trashed the lawyers, and they've trashed you all, and it's just inappropriate, and I want you to pass this bill, it's a good bill, there's nothing wrong with it.").

<sup>117</sup> Id. (statement of Sherry Johnston).

<sup>118</sup> See Meet Thomas M. Suehs, Principal, Tex. Star All., <http://www.texasstaralliance.com/tsateam/thomas-suehs/> (last visited Feb. 4, 2018).

<sup>119</sup> See Our Story, Tex. Star All., <http://www.texasstaralliance.com/about/> (last visited Feb. 4, 2018) (describing itself as an Austin-based "results-driven, bipartisan government affairs firm backed by a trusted reputation and a track record of success"); Texas Star Alliance Shines Again!, Tex. Star All. (Feb. 20, 2017), [www.texasstaralliance.com/texas-star-alliance-shines-again/](http://www.texasstaralliance.com/texas-star-alliance-shines-again/) (announcing the firm's high rankings in Capital Inside 2017 Texas Lobby Power Rankings); Telephone Interview with Richard LaVallo, Legal Dir., Disability Rights Tex. (Sept. 7, 2017).

<sup>120</sup> Andrea Ball, Woman's Costly Court Battle Prompts Call for Reform of Guardianship System, Austin Am.-Statesman (May 12, 2013, 3:44 PM), <http://www.mystatesman.com/news/woman-costly-court-battle-prompts-call-for-reform-guardianship-system/ot00UWJGLoR48W6WiOjRI/>.

<sup>121</sup> Id. (noting that a potential ward cannot "immediately refuse to have a guardian ad litem," and that "guardians ad litem have access to the potential ward's financial, medical, and personal records"). Guardians ad litem are appointed by the court during proceedings to establish guardianship over a proposed ward, and are charged with representing "the best interests of an incapacitated person in a guardianship proceeding." Tex. Est. Code Ann. § 1002.013 (West 2017).

<sup>122</sup> Ball, *supra* note 120. Attorneys ad litem, on the other hand, are charged with representing a proposed ward's legal interests in a guardianship proceeding. Tex. Est. Code Ann. § 1054.001 (West 2017). An attorney ad litem has an attorney-client relationship with the proposed ward. See *Coleson v. Bethan*, 931 S.W.2d 706, 712 (Tex. App. 1996). A proposed ward who has the capacity to contract may also retain an attorney other than an appointed attorney ad litem to represent his or her interests. § 1054.006.

<sup>123</sup> Ball, *supra* note 120.

<sup>124</sup> Tom Suehs, Guardianship Reforms to Bring Peace of Mind to Elderly, Disabled, Hous. Chron. (July 15, 2015), <http://www.houstonchronicle.com/opinion/outlook/article/Suehs-Guardianship-reforms-to-bring-peace-of-6387057.php>.

and, as will be discussed later on, GRSDM - an ad hoc coalition led by experienced policy specialists, but inclusive of several activists concerned about guardianship abuse - was the perfect partner.<sup>126</sup>

## B. Bracing for the "Silver Tsunami"

During these same years, state court administrators across the country were scrambling to brace for the "silver tsunami."<sup>127</sup> The number of seniors across the country was set to balloon, with the largest jump among the "old old" - those eighty-five and over.<sup>128</sup> As it was, many probate courts could barely handle their current guardianship caseloads, and they expected an influx.<sup>129</sup> In 2013, the Texas Office of Court Administration applied for a grant from the National Guardianship Network to develop solutions,<sup>130</sup> and published a comprehensive report on guardianship in 2014.<sup>131</sup> Prior to the introduction of the Supported Decision-Making Agreement Act, Chief Justice Nathan Hecht identified guardianship reform as a priority in his February 2015 State of the Judiciary Speech before the Texas legislature.<sup>132</sup> Hecht noted both that the "silver tsunami" would bring an **[\*995]** increased need for guardianships, and also that people under guardianship "lose[] important rights" and that "unfortunately, guardians can also take unfair advantage."<sup>133</sup> Interest in guardianship went beyond GRSDM's bills during the 84th Legislature: Texas also passed legislation to fund a two-year pilot project to audit compliance with guardianship reporting requirements.<sup>134</sup> The legislature's concern with guardianship continued into the 85th Legislature, with both houses voting to continue to fund the audit program,<sup>135</sup> though Governor Greg Abbot vetoed the audit bill

<sup>125</sup> See, e.g., Hearing on S.B. 647 Before the S. Comm. on Jurisprudence, 2013 Leg., 83rd Sess. (Tex. 2013) (statement of Tom Suehs), <http://tlcSENATE.granicus.com/MediaPlayer.php?viewid=9&clipid=676>.

<sup>126</sup> See infra Part III.

<sup>127</sup> The issue was taken up by professional organizations such as the National Center for State Courts, the American Bar Association, and the Conference of State Court Administrators, among others. See, e.g., Conference of State Court Adm'rs., *The Demographic Imperative: Guardianships and Conservatorships* (2010), <http://cosca.ncsc.org/media/Microsites/Files/COSCA/Policy%20Papers/COSCA%20White%20Paper%20-2010.ashx>; Naomi Karp & Erica Wood, AARP Pub. Policy Inst. & ABA Comm'n on Law & Aging, *Guarding the Guardians: Promising Practices for Court Monitoring* 5 (2007), [https://assets.aarp.org/rqcenter/il/2007\\_21\\_guardians.pdf](https://assets.aarp.org/rqcenter/il/2007_21_guardians.pdf); Uekert & Duizend, *supra* note 41, at 107 (arguing for improved data collection on guardianships and conservatorships in state courts in light of the "projection of active pending adult-guardianship cases nationwide"); see also *supra* note 99 and accompanying text.

<sup>128</sup> Karp & Wood, *supra* note 127.

<sup>129</sup> See David Slayton, *Tex. Office of Court Admin., Texas Guardianship Reform Efforts 1*, <https://nvcourts.gov/AOC/Committees> and *Commissions/Guardianship/Study/Documents/Texas Guardianship Presentation/* (noting that only ten out of 254 Texas counties have probate courts with resources necessary to adequately prevent guardianship abuse).

<sup>130</sup> See David Slayton, *Tex. Office of Court Admin., Texas Working Interdisciplinary Networks of Guardianship Stakeholders (WINGS) Project Application 2* (2013) [hereinafter *WINGS Project Application*], <http://www.txcourts.gov/media/414324/TexasWINGS-Grant-Application-Packet.pdf> (discussing an increased need for guardianship due to the aging of the population in the application's statement of need section).

<sup>131</sup> *Texas 2014 Guardianship Report*, *supra* note 99.

<sup>132</sup> Nathan L. Hecht, Chief Justice, Supreme Court of Tex., *Address to the 84th Texas Legislature: The State of the Judiciary in Texas* (Feb. 18, 2015), <http://www.txcourts.gov/media/857636/state-of-the-judiciary-2015.pdf>.

<sup>133</sup> *Id.* at 6.

<sup>134</sup> *Tex. Office of Court Admin., Guardianship Compliance Project Performance Report 1*, 4-6 (2016) <http://www.txcourts.gov/media/1436796/guardianshipcomplianceprojectfinal.pdf>.



citing "unnecessary bureaucracy and unnecessary spending."<sup>136</sup> The passage of the Supported Decision-Making Agreement Act and GRSDM's other bills was thus part of the legislature's larger effort to address the issues facing the Texas guardianship system at the urging of the Office of Court Administration and Chief Justice Hecht.

### III

#### GRSDM Effectively Organizes and Passes a Package of Bills

With guardianship already a hot topic for Texas legislators, by the 84th Legislature, advocates in the disability rights community in Texas - who had long taken issue with guardianship - decided it was a good time to act. They formed GRSDM, an ad hoc coalition of organizations whose constituencies could benefit from supported decision-making, and came up with a package of bills, including the Supported Decision-Making Agreement Act.

#### A. The Legislation

During its 84th Legislative Session in 2015, Texas ultimately passed three pieces of legislation promoted by GRSDM: The Supported Decision-Making Agreement Act,<sup>137</sup> the Texas Judicial [\*996] Council Guardianship Reforms,<sup>138</sup> and the Ward's Bill of Rights.<sup>139</sup> These pieces of legislation are meant to work in tandem to prevent unnecessary guardianships by providing due process protections and alternatives like supported decision-making, and to protect the rights of individuals who are under guardianship. The Supported Decision-Making Agreement Act describes the scope of a supported decision-making agreement,<sup>140</sup> the authority of the supporter,<sup>141</sup> and the term of the agreement.<sup>142</sup> It also provides a model agreement and lays out the requirements for entering into it.<sup>143</sup> Finally, it states that people receiving copies of an agreement "shall rely" on it and shall not be held liable for actions taken in good faith when doing so.<sup>144</sup> The Act does not provide for publicly or agency-funded supporters or facilitators, though nothing in its language precludes agencies from stepping in and providing these services if a

<sup>135</sup> See S.B. 667, 85th Leg. Res. Sess. (Tex. 2017), Tex. Legis. Online, <https://capitol.texas.gov/BiillLookup/History.aspx?LegSess=85R&Bill=SB667> (last visited May 14, 2018).

<sup>136</sup> Patrick Michels, Abbot Veto Is a Major Setback for Oversight of Troubled Adult Guardianship System, Tex. Observer (June 14, 2017), <https://www.texasobserver.org/guardianship-veto/>; Letter from Gregory S. Davidson, Exec. Clerk to the Governor, to Rolando B. Pablos, Sec'y of State (June 12, 2017), <https://gov.texas.gov/uploads/files/press/06122017BudgetAndLinItemVetos.pdf> (providing Governor Abbott's 2017 line item vetoes).

<sup>137</sup> S.B. 1881, 84th Leg., Reg. Sess. (Tex. 2015) (codified at Tex. Est. Code § 1357 (West 2017)).

<sup>138</sup> H.B. 39, 84th Leg., Reg. Sess. (Tex. 2015) (codified in scattered sections of Tex. Est. Code tit. 3 (West 2017)).

<sup>139</sup> S.B. 1882, 84th Leg., Reg. Sess. (Tex. 2015) (codified at Tex. Est. Code § 1151.351 (West 2017)).

<sup>140</sup> Tex. Est. Code § 1357.051 (West 2017).

<sup>141</sup> Id. § 1357.052.

<sup>142</sup> Id. § 1357.053.

<sup>143</sup> Id. §§1357.055-.056.

<sup>144</sup> Id. § 1357.101. In his testimony in support of the bill, Richard LaVallo, the Legal Director of Disability Rights Texas and principal drafter of the Bill, stated that supported decision-making agreements would not override a doctor's independent obligation to determine whether a person has the capacity to consent to medical care. Hearing on S.B. 1881 Before the S. Comm. on Health & Human Servs., 2015 Leg., 85th Sess. (Tex. 2015), <http://tlcsenate.granicus.com/MediaPlayer.php?viewid=30&clipid=9607> (testimony of Richard LaVallo) [hereinafter Hearing on S.B. 1881]. This position was based on Disability Rights Texas's understanding of the law governing capacity to consent to medical decisions in Texas. Telephone Interview with Richard LaVallo, supra note 119. Not all disability rights attorneys practicing in Texas agree with this reading of the laws, and of course the text, not the legislative history, governs first and foremost. Id.

decision-maker wants them.<sup>145</sup> The legislature also did not provide funding for training on how to enter into and implement supported decision-making agreements.<sup>146</sup>

H.B. 39, known as the Texas Judicial Council Guardianship Reforms, provides the "teeth" for implementing supported decision- [\*997] making in Texas.<sup>147</sup> The bill strengthens due process rights for allegedly incapacitated people in guardianship proceedings by requiring that attorneys ad litem and judges consider whether available supports, services, and other alternatives can be used instead of guardianship.<sup>148</sup> Importantly, the bill also requires that before ordering a guardianship, judges must find by clear and convincing evidence that alternatives to guardianship and available supports and services have been considered and determined to be infeasible.<sup>149</sup> The law also mandates that one of the four hours of training required for court-appointed attorneys in guardianship proceedings be dedicated exclusively to alternatives to guardianship and supports and services, and extends this training requirement to all attorneys representing parties in guardianship proceedings.<sup>150</sup> The bill also makes one of the guardian ad litem's statutory duties to evaluate alternatives to guardianship and available supports and services that would avoid the need for the appointment of a guardian.<sup>151</sup> Importantly, these provisions apply to all people in guardianship proceedings, not just those who have or who wish to enter into formal supported decision-making agreements.

The Texas Judicial Council Guardianship Reforms Bill also strategically lists in one place all of the alternatives to guardianship that were previously scattered throughout the Estates Code.<sup>152</sup> These alternatives include not only supported decision-making agreements but also powers of attorney, representative payee agreements, and the creation of management and special needs trusts, among others.<sup>153</sup> This was done because most people in guardianship proceedings are not represented by experienced disability rights attorneys, but rather [\*998] by attorneys ad litem who are often unfamiliar with alternatives.<sup>154</sup> Judges, too, are often unfamiliar with the various alternatives available, particularly because not all judges presiding over guardianship hearings in Texas are specialized probate judges, and some are not even lawyers.<sup>155</sup> With the simplified Estates Code, improved

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<sup>145</sup> See Tex. Est. Code Ann. § 1357.002(5) ("Supporter" means an adult who has entered into a **supported decision-making** agreement with an adult with a **disability**"); Id. § 1357.052 (outlining the scope of the supporter's authority and not requiring that the supporter have a wholly personal relationship, but rather specifying that the relationship must be "one of trust and confidence" and "not undermine the decision-making authority of the adult").

<sup>146</sup> See Ursula Parks, Legislative Budget Bd., Fiscal Note, S.B. 1881, 84th Leg. Reg. Sess. (Apr. 3, 2015), <https://capitol.texas.gov/tlodocs/84R/fiscalnotes/pdf/SB018811.pdf#navpanes=0> ("No significant fiscal implication to the State is anticipated."). See infra Part IV for a discussion of the training being provided in Texas.

<sup>147</sup> Hearing on H.B. 39, supra note 62 (testimony of Richard LaVallo).

<sup>148</sup> H.B. 39§§4-5, 84th Leg., Reg. Sess. (Tex. 2015), codified at Tex. Est. Code Ann. § 1054.004 (West 2017).

<sup>149</sup> Tex. Est. Code Ann. §§1101.101(a)(1)(D)-(E) (West 2017). Prior to the passage of H.B. 39, court investigators in Texas were required to "determine whether a less restrictive alternative than guardianship" might be appropriate, but the old probate code did not require a judicial determination supported by evidence in the record, so it was not enforceable. See [Tex. Probate Code Ann. § 648A\(a\)](#) (West 2013) (listing duties of a court investigator); id. § 684 (listing judicial findings required before the imposition of a guardianship). The old probate code also provided that the Department of Aging and Disability Services could be appointed a successor guardian upon the death, resignation, or removal of a prior guardian if "there is no less restrictive alternative to continuation of the guardianship," but did not require that the court make a finding. Id. § 695.

<sup>150</sup> Tex. Est. Code Ann. § 1054.201 (West 2017).

<sup>151</sup> Id. § 1054.054.

<sup>152</sup> Id. § 1002.0015.

<sup>153</sup> Id.

<sup>154</sup> See Hearing on H.B. 39, supra note 62 (testimony of Richard LaVallo) (stating "a critical component of this bill is training" because "often lawyers default to guardianship").

mandatory trainings, and heightened evidentiary standards, the infrastructure is in place to keep many people out of guardianship; how this plays out in practice remains to be seen.

The Ward's Bill of Rights specifies that a ward "retains all legal and civil rights and powers except" for those specifically limited by guardianship.<sup>156</sup> In twenty-four paragraphs, it details many of these rights, which range from rights related to access to the courts; to the right to have contact information for Disability Rights Texas, the local independent living center, and other similar agencies; to the right to live in the most integrated setting guaranteed by the ADA; and the right to have one's preferences considered and to exercise self-determination in a variety of aspects of life.<sup>157</sup> Similar to the Texas Judicial Council Guardianship Reforms Bill, the Ward's Bill of Rights consolidated in the Estates Code rights that were already held by people under guardianship, to facilitate access to this information.

## B. Building a Coalition

GRSDM was convened in June 2013 by representatives of several leading disability rights organizations with significant policy experience. These repeat policy players brought community organizing and negotiating skills to the table, as well as working relationships with legislators and key stakeholders, such as Judge Herman and members of the probate bar.<sup>158</sup> Belinda Carlton, a Policy Specialist with TCDD, which awarded the 2009 pilot grant, acted as lead organizer.<sup>159</sup> Bob Kafka, an organizer with ADAPT of Texas - the state chapter of a national, grassroots group that organizes disability rights activists to **[\*999]** engage in nonviolent, direct action<sup>160</sup> - chaired the meetings, which were held at ADAPT's offices.<sup>161</sup> Richard LaVallo, the Legal Director at Disability Rights Texas, was the "legal mind" behind the project.<sup>162</sup> A diverse range of organizations were part of the ad hoc coalition, which operated by the consensus vote of all representatives present at meetings: the Arc of Texas, the Autistic Self-Advocate Network, the Coalition of Texans with Disabilities, G.R.A.D.E., Texas Parent to Parent, the Texas Association of Centers for Independent Living, the Texas Chapter of the National Association of Social Workers, the Mental Health Association of Texas, and AARP, among others.<sup>163</sup> Tom Suehs was also involved and advocated for the bills as a pro bono lobbying assignment. Suehs's clout in the legislature was key to the bills' passages.<sup>164</sup>

The coalition, of course, did not come together without work, and organizing the coalition should be understood as the beginning of the implementation of supported decision-making in Texas. The lead organizers carefully recruited

<sup>155</sup> See *id.* (testimony of Nathan Hecht, C.J.); see Tex. Est. Code Ann. § 1022.002(a) (West 2017) (providing that a county court has original jurisdiction over guardianship proceedings in a county in which there is no statutory probate court or county court at law exercising original probate jurisdiction); Tex. Judicial Branch, Judge Qualifications and Selection in the State of Texas, <http://www.txcourts.gov/media/48745/Judge-Qualifications-6> 26 14.pdf (last visited Feb. 3, 2017) (noting that a law license is not required to become a constitutional county court judge).

<sup>156</sup> Tex. Est. Code Ann. § 1151.001 (West 2017).

<sup>157</sup> See *id.* § 1151.351.

<sup>158</sup> Telephone Interview with Belinda Carlton, Retired Pub. Policy Specialist, Tex. Council for Developmental Disabilities (Sept. 13, 2017).

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

<sup>160</sup> Welcome to ADAPT!, ADAPT, <http://adapt.org/> (last visited May 14, 2018).

<sup>161</sup> Telephone Interview with Belinda Carlton, *supra* note 159.

<sup>162</sup> *Id.*

<sup>163</sup> See GRSDM Policy Supporters, GRSDM, <https://grsdm.wordpress.com/supporters/> (last visited Feb. 3, 2018) (listing supporters).

<sup>164</sup> Telephone Interview with Richard LaVallo, *supra* note 119.

key allies whose constituencies could benefit from supported decision-making, and who would hold sway in the legislature, but did not already have supported decision-making on their radars.<sup>165</sup> Community organizing through one-on-one conversations was crucial to bringing in supporters; people needed to understand how supported decision-making aligned with the interests of their organizations.<sup>166</sup> While some coalition members were very familiar with disability rights concepts like self-determination, these concepts were new for others.<sup>167</sup> Getting the support of AARP, a lobbying powerhouse,<sup>168</sup> for example, took several meetings between Carlton and Bob Jackson, the Texas AARP State Director, as well as a plane trip to D.C. to get the approval of national.<sup>169</sup> This organizing work in Texas also put supported decision-making on the map for some organizations that have a national presence. For example, since [\*1000] 2013, AARP has taken up supported decision-making more broadly and is pursuing efforts in other states.<sup>170</sup>

GRSDM ultimately came up with a list of seven legislative proposals that taken together took an expansive approach to promoting alternatives to guardianship, protecting the due process rights of people in guardianship proceedings, and protecting the rights of those who are under guardianship. In addition to the three bills that ultimately passed, GRSDM also promoted legislation that would have spelled out the duties of a guardian,<sup>171</sup> legislation that would have protected the due process rights of alleged incapacitated persons subject to court-initiated guardianship proceedings,<sup>172</sup> and a proposal to change the term "ward," which many felt was dehumanizing, to "person under guardianship."<sup>173</sup> The legislation that GRSDM ultimately proposed represented

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<sup>165</sup> Telephone Interview with Belinda Carlton, *supra* note 158.

<sup>166</sup> *Id.*

<sup>167</sup> *Id.*

<sup>168</sup> See Megan R. Wilson, Lobbying's Top 50: Who's Spending Big, Hill (Feb. 7, 2017, 6:00 AM), <http://thehill.com/business-a-lobbying/business-a-lobbying/318177-lobbyings-top-50-whos-spending-big> (listing AARP's 2016 lobbying expenditures at \$ 8.71 million).

<sup>169</sup> Telephone Interview with Belinda Carlton, *supra* note 158.

<sup>170</sup> In 2015, for example, AARP Virginia hosted a discussion on supported decision-making, featuring Jonathan Martinis, the Legal Director of Quality Trust for Individuals with Disabilities, one of the groups that endorsed GRSDM's platform. Britney Jubert, Virginia Elder Rights Coalition to Host Discussion on Supported Decision-Making, AARP Va. (Aug. 12, 2015), <https://states.aarp.org/supported-decision-making/>. AARP also co-published a guide for supporters. AARP & Tex. Appleseed, Help for Supporters Under a Supported Decision-Making Agreement (2d ed. n.d.), <http://protecttheirmoneytx.org/sites/default/files/pdfs/supporters> under a supported decision-making agreement.pdf.

<sup>171</sup> H.B. 3930, 84th Leg., Reg. Sess. (Tex. 2015). GRSDM's original proposal required guardians to visit wards in residential care facilities at least once per month, and to return all calls and emails regarding the ward within one week, among other requirements. GRSDM, Relating to Duties of a Guardian: A Policy Paper in Bill Format (2014), <https://grsdm.files.wordpress.com/2014/10/duties-of-guardians.pdf>. The introduced bill relaxed the requirements, but still required monthly visits. See Tex. H.B. 3930. The bill faced stiff opposition from a parents' group who voiced concerns about how these burdens would undermine their ability to continue to serve as guardians for their children, some of whom lived in institutions far distances away. Telephone Interview with Belinda Carlton, *supra* note 158.

<sup>172</sup> H.B. 3914, 84th Leg., Reg. Sess. (Tex. 2015).

<sup>173</sup> GRSDM, Legislative Leave-Behind (2015), <https://grsdm.files.wordpress.com/2015/02/guardianship.pdf> [hereinafter GRSDM Legislative Leave-Behind]; GRSDM Policy Proposals, GRSDM, <https://grsdm.wordpress.com/grsdm-policy-proposals/> (last visited Feb. 3, 2018). Though changing the terminology was a very important goal for advocates and might, to the outside observer, seem like a less controversial ask, this proposal faced significant pushback. Telephone Interview with Jessica Ramos, Pub. Policy Dir., Tex. Council for Developmental Disabilities (Aug. 18, 2017). A change in terminology would mean a change in all of the court forms, and the Texas Probate Code had just been completely revamped and replaced with the Texas Estates Code. *Id.*; see also T. Aaron Dobbs, Ford + Bergner LLP, It's Going to Be OK: Transition to the New Estates Code A-5-6 (2013) (describing the transition from the Texas Probate Code to the Estates Code). Judges also voiced concern about the possible

over a year of negotiation, discussion, [\*1001] and consensus building between GRSDM members and other stakeholders, discussed further in the next section.

### C. Bringing in Allies

In 2014, with GRSDM holding regular meetings and the San Angelo supported decision-making pilot project wrapping up, the Texas Office of Court Administration was awarded a grant from the National Guardianship Network to establish a "Working Interdisciplinary Network of Guardianship Stakeholders," or "WINGS" Committee.<sup>174</sup> Though the Office of the Court Administration understood the WINGS project to be primarily about aging issues,<sup>175</sup> the RFP required that either the state Protection and Advocacy Organization - tasked by federal law with providing legal representation and other advocacy services to people with disabilities<sup>176</sup> - or the State Council for Developmental Disabilities be included as a stakeholder.<sup>177</sup> Roger Webb, then Executive Director of TCDD had submitted a letter of support for Texas's WINGS application, which mentioned the San Angelo pilot project.<sup>178</sup> After Texas was awarded the grant, the Developmental Disabilities Council came on board.<sup>179</sup>

[\*1002] The WINGS working group provided an opportunity for the TCDD and GRSDM to bring supported decision-making to the attention of a broad range of stakeholders whose support would carry significant sway with the legislature, including the Texas Guardianship Association and the Office of Court Administration.<sup>180</sup> The WINGS stakeholders asked for language explaining the limits of a supporter's authority to access private medical and educational information protected by HIPPA and FERPA, and they wanted supported decision-making agreements to be witnessed or notarized.<sup>181</sup> GRSDM agreed.<sup>182</sup> WINGS threw its weight behind H.B. 39 - the Texas Judicial Council Guardianship Reforms - in particular.<sup>183</sup> The Texas Office of Court Administration

acronym that could result from such a change: "PUGS," for "person under a guardianship." Telephone Interview with Richard LaVallo, *supra* note 119; see also GRSDM, Relating to Changing the Term Ward to Person Under a Guardianship: A Policy Proposal in Bill Format (2014), <https://grsdm.files.wordpress.com/2014/12/person-under-guardianship-grsdm-final.pdf>.

<sup>174</sup> See Nat'l Ctr. for State Courts, Trends in State Courts: 2014, at 85-86 (2014), <http://www.ncsc.org/media/Microsites/Files/Future%20Trends%202014/Wings-Court%20Community%20Partnerships%20Wood.ashx>. Other grantees included the New York State Unified Court System, the Oregon State Unit on Aging, and the Utah Administrative Office of the Courts. *Id.* at 86. The WINGS program grew out of the recommendations of the 2011 Third National Guardianship Summit. Third National Guardianship Summit Standards and Recommendations, [2012 Utah L. Rev. 1191, 1199](http://www.ncsc.org/media/Microsites/Files/Future%20Trends%202014/Wings-Court%20Community%20Partnerships%20Wood.ashx) (recommendation 1.2). Several other WINGS grantees also focused on supported decision-making. See Erica Wood, Guardianship & Capacity, 36 *Bifocal* 44 (Nov.-Dec. 2014).

<sup>175</sup> See WINGS Project Application, *supra* note 130. A report on guardianship subsequently produced by the Texas Office of Court Administration identified that, in fiscal year 2013, the majority of guardianship appointments in Texas were made due to the ward's intellectual capacity, and that half of the cases involved a ward turning eighteen. Texas 2014 Guardianship Report, *supra* note 99. In the 2014 National Center for State Court's report on the WINGS projects, the need for "more focus on alternatives to guardianship" was identified as a top overall issue by the Texas WINGS group. Nat'l Ctr. for State Courts, *supra* note 174, at 88.

<sup>176</sup> See Protection and Advocacy (P&A) System and Client Assistance Program (CAP), Nat'l Disability Rights Network, <http://www.ndrn.org/about/paacap-network.html> (last visited July 1, 2018).

<sup>177</sup> Nat'l Guardianship Network, Working Interdisciplinary Networks of Guardianship Stakeholders (WINGS) - Requests for Proposals from State Courts (2012).

<sup>178</sup> Letter of Support from Roger A. Webb, Exec. Dir., Tex. Council for Developmental Disabilities, to Erica Wood, Nat'l Guardianship Network, (Jan. 25, 2013), <http://www.txcourts.gov/media/414324/TexasWINGS-Grant-Application-Packet.pdf>.

<sup>179</sup> Telephone Interview with Jessica Ramos, *supra* note 174.

<sup>180</sup> *Id.*; see also Slayton, *supra* note 129, at 2 (listing WINGS participants).

<sup>181</sup> Telephone Interview with Belinda Carlton, *supra* note 158.

<sup>182</sup> *Id.*; see also Tex. Est. Code Ann. §§1357.054-1357.055 (West 2017).

Executive Director David Slayton became a major advocate for the package of legislation, testifying in favor of the bills and working to get the buy-in of other WINGS stakeholders.<sup>184</sup>

Through continuous tactics of education, relationship building, and compromise, GRSDM was able to garner support from several additional key players, including the Texas Judicial Council, members of REPTL, and Judge Herman. Carlton also testified before the Texas Judicial Council Elders Committee.<sup>185</sup> The Elders Committee ultimately endorsed several of GRSDM's proposals<sup>186</sup> and helped obtain the support of the entire Texas Judicial Council, with an endorsing resolution signed by Chief Judge Nathan Hecht.<sup>187</sup> Meanwhile, members of GRSDM were sending draft legislation to Judge Herman for feedback, hashing out the details during two-minute phone calls and early-morning meetings in the capital building.<sup>188</sup> When Hecht and Slayton ultimately testified in favor of the bills, they presented supported decision-making and the Texas Judicial Council Guardianship **[\*1003]** Reforms as part of the slate of reforms identified by the WINGS committee as steps towards addressing the "silver tsunami."<sup>189</sup>

While one might have expected the probate bar to have pushed back significantly, GRSDM's "moderate" position on supported decision-making and willingness to work cooperatively with REPTL staved off serious opposition during the 84th Legislative Session.<sup>190</sup> The UN Committee on the Rights of Persons with Disabilities, the independent body tasked with monitoring states parties' implementation of the CRPD,<sup>191</sup> takes the position that Article 12 forbids all forms of substitute decision-making, including guardianship.<sup>192</sup> This position would put many REPTL lawyers out of business. GRSDM and their allies, however, do not agree with the Committee, instead taking the position that, in order to use a supported decision-making agreement, the individual entering into the agreement must be able to understand the nature and consequences of the agreement.<sup>193</sup> REPTL did push back somewhat

<sup>183</sup> GRSDM Legislative Leave-Behind, *supra* note 173. See *supra* Section III.A for a discussion of the bill.

<sup>184</sup> Hearing on S.B. 1881, *supra* note 144 (testimony of David Slayton); Telephone Interview with Richard LaVallo, *supra* note 119.

<sup>185</sup> See Public Comment of Belinda Carlton, Pub. Policy Specialist, Tex. Council for Developmental Disabilities, to the Tex. Judicial Council - Elders Comm. (Jan. 30, 2014), <http://www.t added in 2014/public-comment-elders-committee-jan3014/>.

<sup>186</sup> Tex. Judicial Council, Elders Committee Report - August 22, 2014 (2014), <http://www.txcourts.gov/media/410657/Elders-Committee-Update-for-TJC-August-2014.pdf>.

<sup>187</sup> Tex. Judicial Council, Resolution Adopting the Elders Committee Recommendations (2014), <http://www.txcourts.gov/media/709998/EldersCommitteeRecommendations.pdf>; Telephone Interview with Belinda Carlton, *supra* note 158.

<sup>188</sup> Telephone Interview with Belinda Carlton, *supra* note 158.

<sup>189</sup> Hearing on S.B. 1881, *supra* note 144 (testimony of David Slayton & Nathan Hecht); Hearing on H.B. 39, *supra* note 62 (testimony of Nathan Hecht).

<sup>190</sup> Telephone Interview with Richard LaVallo, *supra* note 119.

<sup>191</sup> Committee on the Rights of Persons with Disabilities, United Nations Human Rights Office of the High Comm'r, <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx> (last visited July 1, 2018).

<sup>192</sup> U.N., Comm. on the Rights of Persons with Disabilities, General Comment No. 1, art. 12, PP 7, 13, 15, U.N. Doc CRPD/C/GC/1 (Apr. 11, 2014) ("Substitute decision-making regimes such as guardianship, conservatorship and mental health laws that permit forced treatment ... must be abolished in order to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others."); see also Diller, *supra* note 4, at 512-15 (explaining that there was debate regarding whether Article 12 permitted guardianship when it was adopted, but noting that the Committee's General Comment No. 1 resolved the debate, and discussing implications for the United States).

during the next session, securing the introduction [\*1004] of language about fiduciary duties into the agreements, though the final language was designed collaboratively with GRSDM.<sup>194</sup>

In addition, REPTL's cooperation was likely due in part to the fact that GRSDM did not push back against REPTL's guardianship bills that guardianship abuse activists were opposing in public hearings.<sup>195</sup> GRSDM members' effective working relationships with other stakeholders like Judge Herman, Chief Justice Hecht, and members of the REPTL bar; their willingness to negotiate; and their experience hashing out the details of disability rights policy in a conservative legislative body all contributed to GRSDM's ability to unanimously pass these bills during the same session in which they were first introduced.

#### D. Independence, Self-Determination, and Saving Money

Different actors used a number of different narratives to characterize the Supported Decision-Making Agreement Act during its public legislative hearings.<sup>196</sup> Some portrayed the legislation purely as a civil rights law that would promote the autonomy of those who could benefit from it, while others emphasized supported decision-making's ability to save money and its use of the "natural" safety net of the family. These arguments are not incongruous, but rather highlight how the model of **supported decision-making** adopted in Texas can be very appealing to both **disability** rights activists and conservative lawmakers.

1.

"They Help Me, but They Do Not Make the Decision for Me"

Proponents of supported decision-making did not invoke the language of international human rights during legislative hearings. Civil rights, decisional autonomy, and self-determination, however, figured [\*1005] prominently. A long-time champion of disability rights, bill sponsor Senator Judith Zaffirini referenced the ADA's integration mandate and framed the bill in terms of its ability to promote the "self-reliance and independence" of

<sup>193</sup> See, e.g., Hearing on S.B. 1881, supra note 144 (testimony of Nathan Hecht); id. (testimony of Richard LaVallo) ("**Supported decision-making** isn't for all people with **disabilities**. The person has to have the capacity to understand what they're entering into, the agreement. So it's not for people with significant disabilities who can't consent."). Many advocates in the United States are also reluctant to fully embrace the Committee's position. See, e.g., Jonathan Martinis, Supported Decision-Making: From Justice for Jenny to Justice for All! 17 (2015), <https://ilny.us/downloads/category/37-2015-conference?download=436:supported-decision-making-from-justice-for-jenny-to-justice-for-all> (noting that guardianship may be needed in emergency situations and to support people who have "no interest in or ability to make decisions" and people who "need immediate protection from exploitation or abuse"); Robert D. Dinerstein, Tales from a Supportive Guardianship, 53 Ct. Rev. 74 (2017) (urging advocates to still consider guardianship reform and describing the supportive guardianship arrangement the author has with his adult sister with intellectual **disabilities**). Michael Bach and others, though, argue that **supported decision-making** should extend to those with significant **disabilities** who may not be able to demonstrate capacity as traditionally measured in order for those individuals to be treated as full citizens. See Michael Bach, Inclusive Citizenship: Refusing the Construction of "Cognitive Foreigners" in Neo-Liberal Times, 4 Res. & Prac. Intell. & Developmental Disabilities 4, 10-14 (2017).

<sup>194</sup> GRSDM was concerned that inserting this language could deter people from using supported decision-making agreements for fear of potential liability. Telephone Interview with Belinda Carlton, supra note 158; Telephone Interview with Richard LaVallo, supra note 119. Through legal research, GRSDM determined that under Texas agency law, supporters would very likely be found to owe a fiduciary duty regardless of the statute's text. Telephone Interview with Richard LaVallo, supra note 119; see, e.g., *Noell v. Crow-Billingsley Air Park Ltd. P'ship*, 233 S.W.3d 408, 414 (Tex. App. 2007) ("The term 'fiduciary' generally applies 'to any person who occupies a position of peculiar confidence towards another' ... ."). After several GRSDM meetings and negotiating sessions with REPTL lawyers which resulted in the term "fiduciary duty" appearing only once in the statute, GRSDM agreed not to oppose the bill, which was ultimately passed. Telephone Interview with Belinda Carlton, supra note 158; see also Tex. Est. Code Ann. § 1357.052 (West 2017).

<sup>195</sup> See supra Section II.A. They neither endorsed nor opposed the bills. See, e.g., Hearing on S.B. 1438, supra note 110.

<sup>196</sup> See Hearing on S.B. 1881, supra note 144.

people with intellectual disabilities. <sup>197</sup> "Since a guardian makes decisions for another person, that person can lose all self-determination and the right to make life choices, which are key elements of a meaningful life," Senator Zaffirini explained. <sup>198</sup> "**Supported decision-making** would allow persons with **disabilities** the opportunity to make individual choices regarding their own lives, take responsibility for those choices, and have the opportunity to achieve their dreams," Senator Zaffirini continued. <sup>199</sup> Senator Zaffirini made no mention of supported decision-making's ability to save money.

Similarly, testimony by Jessica Bond, a self-advocate representing the Arc of Texas emphasized the rights of people with intellectual disabilities and the significance of the individual with a disability having the final say over important decisions in his or her life. "My parents support me in making my own choices. They help me make decisions on things like my medical care, where to live, purchases to make, transportation, and working and volunteering in my community," Bond explained. <sup>200</sup> "They help me, but they do not make the decision for me. I have the ability and the right to make my own decisions, with support from people that I trust," Bond continued. <sup>201</sup>

Richard LaVallo of **Disability Rights Texas** seemed to know his audience and framed **supported decision-making** as civil rights legislation, but did so in a way that would be particularly appealing to conservative lawmakers. LaVallo noted that the current generation of young adults with disabilities had grown up with the ADA and expected and deserved equal rights and equal treatment. <sup>202</sup> In a move with clear appeal to Tea Party Republicans with libertarian tendencies, [\*1006] as well as more traditional, small-government Republicans, <sup>203</sup> LaVallo explained that **supported decision-making** "recognizes the natural support systems for people with **disabilities**, where family, relatives, and friends help them make decisions ... ." <sup>204</sup> **Supported decision-making** was framed as advancing civil rights as "freedom from government."

## 2. Supported Decision-Making as a Cost-Saving Mechanism

Others testifying in favor of the Supported Decision-Making Agreement Act emphasized its ability to save courts and families money, in addition to its ability to promote autonomy. Chief Justice Nathan Hecht, in particular, took this approach. <sup>205</sup> He framed supported decision-making as a common-sense, partial solution to both the problem of guardianship abuse and the court system's need to prepare for the "silver tsunami," with more emphasis placed on the latter. <sup>206</sup> Importantly, he presented supported decision-making as one response among several to address the impact of the aging population on the courts identified by the WINGS committee. <sup>207</sup> Per Chief Justice Hecht,

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<sup>197</sup> Id. (introductory statement of Sen. Zaffirini).

<sup>198</sup> Id.

<sup>199</sup> Id. This language also echoes the independent living movement's focus on self-reliance and the "dignity of risk." The "dignity of risk" is a key concept in disability rights activism, first coined by activists during the 1970s' Independent Living Movement. See Bagenstos, *supra* note 54, 997-98. As Gerbon DeJong put it, "The dignity of risk is the heart of the [independent living] movement. Without the possibility of failure, the disabled person lacks true independence and the ultimate mark of humanity, the right to choose for good or evil." Id. (quoting Gerbon DeJong, *Defining and Implementing the Independent Living Concept*, in *Independent Living for Physically Disabled People* 4, 20 (Nancy M. Crewe & Irving Kenneth Zola eds., 1983)).

<sup>200</sup> Hearing on S.B. 1881, *supra* note 144 (testimony of Jessica Bond).

<sup>201</sup> Id.

<sup>202</sup> Id. (testimony of Richard LaVallo).

<sup>203</sup> See Royce Poinsett, The 84th Legislative Session, [78 Tex. B.J. 613, 640 \(2015\)](#) (noting that the 84th Texas Legislature was characterized by a "deepening fault line" between the "Traditional Republicans" and the "Movement Conservative Republicans"); see also Anderson, *supra* note 38.

<sup>204</sup> Hearing on S.B. 1881, *supra* note 144 (testimony of Richard LaVallo).

<sup>205</sup> Id. (statement of Judge Nathan Hecht).

<sup>206</sup> Id.



supported decision-making is a "kind of power of attorney lite ... a way to informally try to arrange for support in various decisions of life, without the formality of a guardianship, without the expense, without having to go to court ... ." <sup>208</sup> Richard LaVallo reiterated the cost-savings argument as well. <sup>209</sup> Much like in the case of the ADA, arguments about civil rights, independence, autonomy, and saving money were all deployed by different actors to pass legislation in a politically conservative legislature.

#### IV

##### Lessons from the Lone-Star State

GRSDM's work can provide a useful roadmap for advocates across the country seeking to pass supported decision-making legislation, **[\*1007]** particularly in conservative states. The story of Texas's experience can help advocates in other states identify key players whose support is likely to be important in passing supported decision-making legislation, and GRSDM's work illustrates the effectiveness of community organizing and coalition building before legislation is introduced. Texas's success is further evidence that the "paradigm shift" is underway, and that the concept of self-determination for people with disabilities is resonating broadly, even when the UN and international community's stamp of approval is not emphasized. Indeed, Texas's experience shows that supported decision-making has particular appeal for small-government conservatives who may be skeptical of the UN and international human rights.

Other states seem to be following Texas's lead in passing legislation that formally recognizes supported decision-making agreements but does not set up any type of infrastructure for facilitation or paid supporters. Delaware passed legislation in 2016, <sup>210</sup> and Wisconsin and Washington, D.C., passed laws in 2018. <sup>211</sup> Like Texas's Supported Decision-Making Agreement Act, these laws do not create or charge any agencies or organizations with directly providing supporters or facilitators. <sup>212</sup> Unlike Texas's law, both the Delaware law and a bill awaiting the governor's signature in Alaska explicitly anticipate the possibility of the use of paid supporters, but prohibit people who are paid to provide direct support services from serving as supporters, unless those people are paid specifically to serve as supporters. <sup>213</sup> The D.C. law has similar provisions. <sup>214</sup> It seems likely that these provisions were included to avoid abuse and undue influence, but also in recognition of the strong preference for personal friends and family, rather than professionals, to serve as supporters.

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<sup>207</sup> Id. ("Judge Spencer and her committee studied this for a couple of years, and concluded that it was beneficial to just tackle this on every front, and so this bill is another way of doing that.").

<sup>208</sup> Id. (testimony of Judge Nathan Hecht).

<sup>209</sup> Id. (testimony of Richard LaVallo) ("First of all, Texas cannot afford to provide guardians for all people with disabilities who need support and assistance in making major life decisions.").

<sup>210</sup> Del. Code Ann. tit. 16, §§9401A-9410A (West 2018). Both houses of the Alaska legislature also passed a bill very similar to Delaware's in 2018, but as of the time of printing it had not yet been signed by the governor. See H.B. 336, 30th Leg., 2d Sess. (Alaska 2018); HB 336 Bill History/Action for Legislature, Alaska State Legislatures, <http://www.akleg.gov/basis/Bill/Detail/30?Root=HB%20336> (last visited July 2, 2018).

<sup>211</sup> See [D.C. Code §§7-2131-2134](#) (2018); A.B. 655, 2017-18 Leg. (Wis. 2017) (codified at Wis. Stat. §§53-54 (2018)).

<sup>212</sup> See sources cited *supra* notes 210-11.

<sup>213</sup> [Del. Code Ann. tit. 16, § 9406A\(b\)\(2\)](#); H.B. 336, § 13.56.020(2), 30th Leg., 2d Sess. (Alaska 2018).

<sup>214</sup> [D.C. Code § 7-2132\(a\)](#).

Even though the Texas legislature did not provide funding for the implementation of the Supported Decision-Making Agreement Act, with a training grant from the Texas Council for Developmental Disabilities,<sup>215</sup> Disability Rights Texas had trained approximately 6000 [\*1008] people with disabilities, family members, service providers, and educators as of April 2018.<sup>216</sup> Disability Rights Texas had also assisted 158 people with **disabilities** in entering into **supported decision-making** agreements as of April 2018.<sup>217</sup> And as of May 2018, the University of Texas School of Law's INCLUDE pro bono clinic, which focuses on helping transition-aged special education students enter into supported decision-making agreements,<sup>218</sup> had also counseled and assisted almost 400 transition-aged youth in entering into agreements.<sup>219</sup> Legal services providers across the state have also helped people enter into agreements.<sup>220</sup> It is likely that at least some private attorneys are also helping to execute the agreements, as there have been trainings conducted by and for private attorneys.<sup>221</sup>

Even though the "silver tsunami" was the focus of a great deal of attention during the fight for the Supported Decision-Making Agreement Act's passage, the vast majority of implementation work in Texas has focused on youth transitioning out of special education services.<sup>222</sup> It makes sense to focus on this group for a number of reasons. As Texas's guardianship commission learned while researching strategies in preparation for the "silver tsunami," most guardianships are imposed on transition-aged youth rather than elderly people.<sup>223</sup> This is in part because state regulations implementing the Federal Individuals with Disabilities Education Act often require that parents of children receiving special education services be notified that their child's special education rights will transfer from the parents to the [\*1009] child when the child turns eighteen.<sup>224</sup> In practice, transition counselors at schools often erroneously tell parents they must obtain guardianship in order to stay involved in their child's education planning.<sup>225</sup>

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<sup>215</sup> See Trainings: **Supported Decision-Making** and Alternatives to Guardianship, Tex. Council for Developmental **Disabilities** (Sept. 27, 2017), <http://www.tcdd.texas.gov/supported-decision-making-trainings-drt/>. The training presentation slides are available online. See **Disability** Rights Tex., **Supported Decision-Making: A New Alternative to Guardianship** (2016), [https://www.disabilityrightstx.org/files/Supported Decision Making Training Power Point mar 24 2016.pdf](https://www.disabilityrightstx.org/files/Supported%20Decision%20Making%20Training%20Power%20Point%20mar%2024%202016.pdf).

<sup>216</sup> Telephone Interview with Helen A. Gaebler, Senior Research Attorney & Lecturer, Univ. of Tex. Sch. of Law (Apr. 10, 2018) (on file with author).

<sup>217</sup> E-mail from Richard LaVallo, Legal Dir., Disability Rights Tex., to Author (Apr. 4, 2018) (on file with author).

<sup>218</sup> See Texas Law INCLUDE Project, Univ. of Tex. Sch. of Law, <https://law.utexas.edu/probono/opportunities/texas-law-include-project/> (last visited July 2, 2018).

<sup>219</sup> Telephone Interview with Helen A. Gaebler, *supra* note 216.

<sup>220</sup> *Id.*

<sup>221</sup> See, e.g., Tresi Weeks, Representing Parties in **Supported Decision-Making** Agreements (2017), [https://www.disabilityrightstx.org/files/Representing Parties in Supported Decision-Making Agreements.pdf](https://www.disabilityrightstx.org/files/Representing%20Parties%20in%20Supported%20Decision-Making%20Agreements.pdf) (presented at the 13th Annual Changes and Trends Affecting Special Needs Trust Conference).

<sup>222</sup> This has been an area of focus in several pilot projects across the country as well. See, e.g., Glen, *supra* note 13, at 513-15 (New York); Massachusetts SDM Pilot, Ctr. for Pub. Representation, <http://supporteddecisions.org/current-sdm-pilot/> (last visited July 2, 2018) (Massachusetts).

<sup>223</sup> See Texas 2014 Guardianship Report, *supra* note 99, at 5.

<sup>224</sup> See, e.g., *Tex. Educ. Code Ann. § 29.017(c)* (West 2015) (implementing the notification provisions of Individuals with Disabilities Education Act, as currently codified at *34 C.F.R. §§300.320(c), 300.520(a) (2017)*).

<sup>225</sup> Telephone Interview with Belinda Carlton, *supra* note 158; see also Diller, *supra* note 4, at 521 ("Parents of [young adults] with intellectual disabilities often commence guardianships ... because service providers suggest it as a routine step to take when the child turns eighteen. Standard advice given to parents is that they need guardianships ... to continue being involved in assisting their child in obtaining benefits and services."); Glen, *supra* note 13, at 513-14 (describing this experience in New York).

During Texas's 85th Legislative Session in 2017, advocates passed legislation requiring schools to incorporate **supported decision-making** into the transition planning process for students with **disabilities**.<sup>226</sup> Starting with the 2018-19 school year, when school districts provide notice about the transfer of educational rights, they must also include information and resources about guardianship, alternatives to guardianship including supported decision-making, and other supports and services that may enable students to live independently.<sup>227</sup> The law also requires that school districts provide information and referrals for obtaining public benefits.<sup>228</sup> Starting that same year, the committee reviewing a student's annual individualized education plan must also consider and discuss opportunities for the student to develop his or her decision-making skills.<sup>229</sup> Additionally, this committee must contemplate the use and availability of appropriate supports and services to foster independence and self-determination, including a supported decision-making agreement.<sup>230</sup> If implemented successfully, these changes have the potential to have an extremely broad reach and help divert many students with disabilities from unnecessary guardianships.

Outside of the transition process, though, facilitation in entering supported decision-making agreements in Texas is largely being provided by attorneys.<sup>231</sup> This is in contrast to the pilot projects in New York and Nonatuck, Massachusetts, for example, where social work students, agency-based personnel, and volunteers are serving as facilitators.<sup>232</sup> Though there is no provision for systemic, ongoing facilitation, **[\*1010]** some ongoing support and facilitation is being provided. Staff from Disability Rights Texas routinely attend transition conferences to advocate on behalf of students and can provide assistance to people using supported decision-making agreements if requested.<sup>233</sup> While the INCLUDE clinic sometimes has families attend an initial training and counseling session before returning to enter into an agreement, the clinic has also moved toward a one-day signing clinic where appropriate.<sup>234</sup> The clinic does not have the capacity to provide formal ongoing facilitation to students and their families who have signed agreements in place.<sup>235</sup> Disability Rights Texas has created a series of videos that model the principles of supported decision-making and self-determination that anyone can access.<sup>236</sup> The New York pilot project is looking into using Medicaid waiver funds - which allow states to "waive" certain requirements of the Social Security Act and provide services like habilitation services, case management, and many others in the community rather than in institutional settings<sup>237</sup> - to pay for supported decision-making facilitation.<sup>238</sup> Absent a

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<sup>226</sup> S.B. 748, 85th Leg., Reg. Sess. (Tex. 2017).

<sup>227</sup> 19 Tex. Admin. Code § 89.1049(c) (2017).

<sup>228</sup> Id. § 89.1055(j)(9).

<sup>229</sup> Id. § 89.1055(j)(10)(A).

<sup>230</sup> Id. § 89.1055(j)(10)(B).

<sup>231</sup> See supra notes 221-22 and accompanying text.

<sup>232</sup> See Elizabeth Pell & Virginia Mulkern, Human Servs. Research Inst., Supported Decision Making Pilot: A Collaborative Approach: Pilot Evaluation Year 1 Report 5 (2015), <http://supporteddecisions.org/wp-content/uploads/2015/04/SDM-Evaluation-Report-Year-1-HSRI-2015.pdf> (Massachusetts); Glen, supra note 13, at 511-12 (New York).

<sup>233</sup> To make supported decision-making available to more people than its staff alone can serve, Disability Rights Texas has held clinics in Houston and Dallas (with one being planned in Lubbock), typically hosted by law firms, to train attorneys to provide pro bono legal services to transition-aged youth to enter into **supported decision-making** agreements. **Disability** Rights Texas then schedules appointments with the trained attorneys and their clients to enter into agreements, but the attorneys do not provide ongoing facilitation. E-mail from Richard LaVallo, Legal Dir., Disability Rights Tex., to Author (Apr. 9, 2018).

<sup>234</sup> Telephone Interview with Helen A. Gaebler, Senior Research Attorney & Lecturer, Univ. of Tex. Sch. of Law (May 30, 2018) (on file with author).

<sup>235</sup> Telephone Interview with Helen A. Gaebler, supra note 216.

<sup>236</sup> See, e.g., DisabilityRightsTx, supra note 5.

major change in Texas's political climate and a major expansion of optional community-based waiver services, the use of Medicaid waiver services for anything related to supported decision-making seems very unlikely in Texas. In 2016 Texas had more people on waiting lists for Medicaid Home and Community-Based Services than any other state in the country: 232,068 people in Texas, compared to 73,929 in Louisiana, the state with the next-highest number on waiting lists. <sup>239</sup> Making supported **[\*1011]** decision-making accessible to all, in Texas and across the country, will be challenging. <sup>240</sup>

The Texas experience provides several strategies that should be adopted across the country. Incorporating supported decision-making into the transition process for students receiving special education services is an excellent way to reach a broad and diverse group of younger people with disabilities, and there is evidence that other states are already taking this approach. <sup>241</sup> To further reduce guardianship appointments and promote the autonomy of people with disabilities, states should also consider adopting laws similar to the Texas Judicial Council Guardianship Reform Bill, which requires that judges find by clear and convincing evidence that alternatives to guardianship and available supports and services cannot be used to avoid the need for guardianship. <sup>242</sup> Laws modeled after the Texas Judicial Council Guardianship Reform Bill can help keep people out of guardianship who may not have entered into a formal supported decision-making agreement but are nonetheless providing for their needs with assistance from friends, family, and service providers. The law's consolidation of all alternatives to guardianship in the Estates Code and its requirement that all attorneys representing those in guardianship proceedings be trained on supports and services are additional ways of facilitating access to information about supported decision-making. <sup>243</sup> Hopefully, these requirements will leave attorneys with a better understanding of how supports and services work, and greater comfort in recommending that no guardianship be imposed.

As the Texas Judicial Council Guardianship Reform Bill recognizes, a formal supported decision-making agreement is one way **[\*1012]** among many to promote the ability of people with disabilities to live independently in the community and direct the courses of their own lives. Other supports and services, both informal and formal, are also crucial. Continuing to advocate for the expansion of available community-based formal supports and services for people with disabilities is a key part of ensuring people with disabilities are able to direct and live the lives that they want to live. While supported decision-making looks to personal, trusting relationships for decision-making support, formal supports, like case planning, direct care attendants, free or reduced meals, supported employment or job search assistance, can all be crucial to enabling elderly people and people with disabilities to live a full life in the

<sup>237</sup> See Amie Lulinski et al., *Rebalancing of Long-Term Supports and Services for Individuals with Intellectual and Developmental Disabilities in the United States 1-2* (2018), [http://www.stateofthestates.org/images/documents/SOS-Brief-2018\\_2\\_Rebalancing.pdf](http://www.stateofthestates.org/images/documents/SOS-Brief-2018_2_Rebalancing.pdf).

<sup>238</sup> Glen, *supra* note 13, at 512.

<sup>239</sup> *Waiting List Enrollment for Medicaid Section 1915(c) Home and Community-Based Services Waivers*, Kaiser Family Found., <https://www.kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers/> (last visited July 2, 2018). Comparatively, New York had no people on waiting lists. *Id.*

<sup>240</sup> This challenge is in no way unique to Texas. Indeed, the Massachusetts pilot project made a choice to begin by working only with individuals whose families were supportive of supported decision-making. Pell & Mulkern, *supra* note 232, at 9.

<sup>241</sup> See, e.g., Family Voices of Wis., *Supported Decision Making for Transition Age Youth* (2015), [http://www.familyvoicesofwisconsin.com/wp-content/uploads/2015/04/FVSupported\\_Decision\\_Making\\_Fact\\_sheet\\_NEW1.pdf](http://www.familyvoicesofwisconsin.com/wp-content/uploads/2015/04/FVSupported_Decision_Making_Fact_sheet_NEW1.pdf) (providing a guide for incorporating supported decision-making into the transition planning process in Wisconsin); Glen, *supra* note 13, at 513-15 (discussing the New York pilot project's work with transition-age youth); see also Mike Krings, KU Researchers Land Grant to Apply Self-Determination Model in Schools, Univ. of Kan. (Aug. 30, 2017), <https://news.ku.edu/2017/07/28/ku-researchers-land-grant-implement-self-determination-model-schools-study-how-best-train> (announcing the award of a \$ 3.3 million grant to study the implementation of a learning model for students with disabilities focused on transition and decision-making in Maryland).

<sup>242</sup> See Tex. Est. Code Ann. § 1101.101(a)(1)(D) (West 2017).

<sup>243</sup> H.B. 39, 84th Leg., Reg. Sess. (Tex. 2015) (codified in scattered sections of Tex. Est. Code tit. 3 (West 2017)).

community, so long as they make the decision about whether and how to accept and direct these services. Advocates should continue to push for expansion of these services, even though they may be more politically challenging to obtain.

## Conclusion

The passage of supported decision-making legislation in Texas adds a caveat to the understanding that the CRPD is driving the "paradigm shift" towards supported decision-making. Though supported decision-making has been enshrined in human rights law, and the CRPD is often cited as the source of the current "paradigm shift," the experience in Texas shows that at least some forms of supported decision-making can have broad appeal in conservative legislatures where lawmakers may be skeptical of the UN and international human rights. The passage of supported decision-making legislation in Texas also illuminates how other factors at play in this historical moment are contributing to the salience of supported decision-making: specifically, increased attention to guardianship abuse, and concerns about the impact of the aging of the population on the court system.

Texas's experience also shows that the paradigm shift is not some sort of cosmic event floating across the universe changing people's minds about legal capacity. Rather, changes are the result of a confluence of different, often idiosyncratic factors and hard organizing work. In Texas, the less-traditional advocacy efforts of the G.R.A.D.E. guardianship abuse activists, the fact that politically connected Tom Suehs had a personal experience with guardianship, the fact that Texas received a WINGS grant while GRSDM was separately organizing, and the tireless work and organizing skills of GRSDM all contributed to the ultimate passage of the Supported Decision-Making Agreement Act in 2015. Efforts to pass supported decision-making legislation in **[\*1013]** other jurisdictions will no doubt be shaped by the idiosyncrasies and constituencies in those jurisdictions. Yet there is much to learn from Texas: Texas's unique emphasis on supports and services, and separate legislation incorporating the consideration of supports and services into guardianship decisions should serve as a model for other states seeking to recognize the support networks that people with disabilities are already using, and to help promote them in living independent and self-directed lives in the community.