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Madeleine Laser

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## **A RUN FOR YOUR MONEY: ARE ABLE ACCOUNTS TRULY AN INNOVATIVE, USER-FRIENDLY FINANCIAL SAVINGS TOOL FOR THE BROAD SPECTRUM OF DISABLED AMERICANS?**

*Madeleine Laser\**

### **I. INTRODUCTION**

There are 8.8 million disabled American wage earners who receive social security disability income benefits.<sup>1</sup> Although these 8.8 million disabled Americans are working, they are constrained to a life savings of no more than two thousand dollars.<sup>2</sup> Disabled Americans, many of whom lobbied for the passage of the Achieving a Better Life Experience (“ABLE”) Act, desire a future where they no longer fear taking a full-time job or promotion.<sup>3</sup> Passage of the ABLE Act, thus,

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\* Madeleine Laser is a Juris Doctor candidate at Touro College Jacob D. Fuchsberg Law Center. She has a bachelor’s degree in Sociology, with a concentration in Human Services from the State University of New York at New Paltz. The author wishes to thank her academic advisor, Professor Rena Sepowitz, for her guidance and feedback throughout the writing process. Additionally, the author credits a great deal of her success to her parents. Their unconditional love, support, and encouragement have provided the roots that have allowed the author to flourish beyond the greatest heights. Finally, this Note is dedicated to the author’s older sister, Arielle. Arielle has Autism Spectrum Disorder, and if it were not for her unique spirit, the author would not have found a home among the extraordinary people of the special needs community. Thank you.

<sup>1</sup> *Disability Statistics*, COUNCIL FOR DISABILITY AWARENESS, [http://www.disabilitycanhappen.org/chances\\_disability/disability\\_stats.asp](http://www.disabilitycanhappen.org/chances_disability/disability_stats.asp) (last updated Mar. 28, 2018).

<sup>2</sup> M&LAdmin4, *The Able Act vs. The Special Needs Trust: Which Financial Tool is Right for Your Family?*, M&L SPECIAL NEEDS PLAN. (Jan. 15, 2015), <http://specialneedsplanning.net/2015/01/the-able-act-vs-the-special-needs-trust-which-financial-tool-is-right-for-your-family/>.

<sup>3</sup> Blake Ellis, *Disabled Americans Fighting for the Right to Save More Money*, CNN MONEY (Mar. 12, 2014, 11:54 AM), <http://money.cnn.com/2014/03/12/pf/disabled-benefits/index.html>.

represents more than a new savings tool that shields a disabled person's assets, but also a growing opportunity for upward socioeconomic mobility and financial stability. Disabled Americans should not fear losing benefits because their benefits are protected in an ABLE account.<sup>4</sup>

Disabled individuals who receive Supplemental Security Income (“SSI”) benefits and Medicaid are legally entitled to have two thousand dollars in savings without being disqualified.<sup>5</sup> Against their better judgment, hard-working disabled individuals constantly spend their money to avoid losing these benefits by surpassing the two thousand dollar savings cap threshold.<sup>6</sup> Disabled individuals are “[shackled] to a life of poverty,” unable to create a financial safety net or prepare for future goals.<sup>7</sup> Recipients of SSI and Medicaid whose disabilities inhibit their ability to earn enough money to pay bills and keep food on their table describe their financial situation as a “constant state of anxiety and fear.”<sup>8</sup> The Social Security Act (“SSA”) strictly limits how a recipient can earn, save, and spend money, which consequently discourages upward economic mobility for fear of losing benefits.<sup>9</sup>

Prior to the enactment of the ABLE Act in 2014 under the Obama Administration, the only way a recipient of SSI and Medicaid benefits could save money without negative consequences was to establish either a special needs trust or pooled trust.<sup>10</sup> However, creating a trust is “costly” and time consuming.<sup>11</sup> Furthermore, when a beneficiary contributes her own money, rather than money from a third-party, the trust must include a Medicaid payback provision – the state becomes a creditor for the cost of benefits used by the beneficiary upon her death – leaving beneficiaries with little motivation to save for

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

<sup>5</sup> *Understanding Supplemental Security Income SSI Resources—2018 Edition*, SOC. SECURITY ADMIN., <https://www.ssa.gov/ssi/text-resources-ussi.htm> (last visited June 17, 2018).

<sup>6</sup> Joseph Pisani, *People with Disabilities Finally Get a Way to Save Money*, USA TODAY (Feb. 4, 2017, 1:02 PM), <https://www.usatoday.com/story/money/personalfinance/2017/02/04/people-disabilities-finally-get-way-save-money/97381332/>.

<sup>7</sup> *Id.*

<sup>8</sup> Ben Steverman, *These Government Rules Trap Millions of Americans in Poverty*, BLOOMBERG (Aug. 2, 2016, 7:00 AM), <https://www.bloomberg.com/news/articles/2016-08-02/these-government-rules-trap-65-million-americans-in-poverty>.

<sup>9</sup> *Id.*

<sup>10</sup> See 42 U.S.C.S. § 1396p(d)(4)(A), (C) (2013).

<sup>11</sup> M&LAdmin4, *supra* note 2.

future generations.<sup>12</sup> “Despite living in the ‘land of the free,’” the paradox in which disabled Americans find themselves stuck when trying to work and save is described as “bereft of basic human freedom in exchange for other-directed human supports/services.”<sup>13</sup>

Congress passed the ABLE Act on December 3, 2014 to address such shortcomings of the SSA regulations and trust exceptions that prevent a recipient of benefits from adequately saving money.<sup>14</sup> The ABLE program was enacted to “encourage and assist individuals and families in saving private funds for the purpose of supporting individuals with disabilities to maintain health, independence, and quality of life.”<sup>15</sup> Ideally, ABLE accounts represent a new, efficient, and easy way for disabled Americans to save money without jeopardizing benefits.<sup>16</sup> However, are ABLE accounts truly the innovative savings tool advocates have been asking for?<sup>17</sup>

Each savings tool carries its own set of advantages and disadvantages, varying in degree based on the disabled individual’s personal abilities, present needs, and future plans. ABLE accounts are intended to be an innovative tool to allow *all* disabled Americans to independently save more money and earn higher salaries without the loss of benefits.<sup>18</sup>

This Note will argue that the ABLE Act provides an innovative savings tool for only a narrow group of high-functioning disabled Americans because the account holders act independently to manage their assets. Lobbyists and advocates of the ABLE Act sought an innovative savings tool that furnishes special needs individuals with self-determination. However, statutory guidelines burden ABLE

<sup>12</sup> M&LAdmin4, *supra* note 2.

<sup>13</sup> Serena Lowe, *Independence, Self-Sufficiency, Freedom: The Collaboration to Promote Self-Determination*, NAT’L FRAGILE X ORG., <http://www.fragilex.org/wp-content/uploads/2012/01/Independence-Self-Sufficiency-Freedom-The-Collaboration-to-Promote-Self-Determination.pdf> (last visited June 15, 2018).

<sup>14</sup> *Achieving a Better Life Experience (ABLE) Act*, NAT’L DOWN SYNDROME SOC., <https://www.ndss.org/advocate/ndss-legislative-agenda/economic-self-sufficiency/achieving-a-better-life-experience-able-act/> (last visited June 15, 2018).

<sup>15</sup> *Achieving a Better Life Experience Act of 2014*, H.R. 647, 113th Cong. § 101 (2014).

<sup>16</sup> Ann Carrns, *529A Accounts Let Disabled Save Without Risk to Government Aid*, N.Y. TIMES (May 6, 2016), <https://www.nytimes.com/2016/05/07/your-money/529a-accounts-let-disabled-save-without-risk-to-government-aid.html?mcubz=0>.

<sup>17</sup> John W. Nadworny, *Incorporating the ABLE Act into Special Needs Planning*, FIN. PLAN. ASS’N: J. FIN. PLAN., <https://www.onefpa.org/journal/pages/may15-incorporating-the-able-act-into-special-needs-planning.aspx> (last visited June 15, 2018).

<sup>18</sup> Ellis, *supra* note 3.

account holders with great responsibility to create, manage, and appropriately use their accounts to prevent the loss of government benefits. Saundra Gumerove, a long-time practicing special needs attorney and mother of a special needs daughter, holds a deep skepticism of ABLE accounts: “Will a disabled person with more severe cognitive or developmental disabilities appreciate the consequences, and more tangibly, the financial penalties that she may incur for buying a candy bar from the local convenience shop?”<sup>19</sup> The ABLE Act was, indeed, a milestone for the special needs community. Yet, this piece of legislation excludes a lower-functioning group of disabled individuals seeking financial security, maintains arbitrary age limitations, and unnecessarily creates pitfalls for those using ABLE accounts by failing to address several major policy problems.

This Note will be divided into six parts. Part II will concentrate on the SSA imposed regulation of government benefits that disabled individuals receive and rely on. Part III will introduce the cycle of dependence created by the SSA’s prohibitive regulations and the reasons why Congress needed to create efficient financial savings tools for disabled individuals striving for economic growth and upward mobility. Part IV of this Note will cover the multiple types of trusts that are available to disabled individuals who desire to save money while maintaining their government benefits. Part IV will address the barriers that trusts present for individuals and their families. Part V will analyze whether the ABLE accounts represent a superior savings tool as compared to the trusts that have been utilized up until this point. Finally, Part VI will briefly conclude with a discussion of proposed legislation and amendments to the ABLE Act. The author will include recommendations that make the ABLE accounts more readily available to a broader spectrum of individuals with disabilities.

## II. WHAT’S AT RISK?

The Social Security Administration is a federal agency that implements the regulations of the SSA.<sup>20</sup> The first generation of the SSA was enacted in 1935 to “offer immediate relief to families”

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<sup>19</sup> Interview with Saundra Gumerove, Esq., Managing Partner, Saundra Gumerove & Associates, in Jericho, N.Y. (Feb. 1, 2018).

<sup>20</sup> Patricia P. Martin & David A. Weaver, *Social Security: A Program and Policy History*, 66 SOC. SECURITY BULL. 1 (2005), <https://www.ssa.gov/policy/docs/ssb/v66n1/v66n1p1.html>.

stricken by poverty during the Great Depression.<sup>21</sup> Between the 1930s and 1950s, the social security program was evolving constantly; amendments in 1939 included the addition of child, spouse, and survivor benefits, as well as policy changes that introduced monthly benefits that began in 1940.<sup>22</sup> These federal social welfare programs have grown and changed exponentially since their inception.<sup>23</sup> In 1974, there were approximately five million SSI recipients, compared to the nearly fifty-five million recipients in 2016.<sup>24</sup> More recent statistical analysis conducted in January 2018 found that over thirteen million SSI recipients, out of almost sixty-seven million total recipients, were disabled.<sup>25</sup> Thus, millions of disabled individuals who are recipients of SSI face difficult and unique challenges in securing their monthly benefits.<sup>26</sup>

#### A. Supplemental Security Income under the Social Security Act

Americans with disabilities may qualify to receive SSI under the SSA.<sup>27</sup> The SSA defines “disability” as an

[inability] to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than twelve months.<sup>28</sup>

The severity of an individual’s disability is assessed in light of the “combined effect of all the individual’s impairments,” rather than consideration of each impairment separately when determining

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<sup>21</sup> *Id.*

<sup>22</sup> *Id.* It was toward the end of 1950s when the Social Security Administration introduced disability insurance benefits, a necessity in a post-World War II America; and, furthermore, Congress only established Medicare in 1965, twenty years after the creation of federal social security welfare programs. *Id.*

<sup>23</sup> *Id.*

<sup>24</sup> *SSI Annual Statistical Report, 2016: Federal Benefit Rates, Total Annual Payments, and Total Recipients*, SOC. SECURITY ADMIN., at Table 2, [https://www.ssa.gov/policy/docs/statcomps/ssi\\_asr/2016/sect01.html](https://www.ssa.gov/policy/docs/statcomps/ssi_asr/2016/sect01.html) (last visited June 18, 2018).

<sup>25</sup> *Monthly Statistical Snapshot, January 2018*, SOC. SECURITY ADMIN., at Table 1, [https://www.ssa.gov/policy/docs/quickfacts/stat\\_snapshot/2018-01.pdf](https://www.ssa.gov/policy/docs/quickfacts/stat_snapshot/2018-01.pdf) (last visited June 18, 2018).

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

<sup>27</sup> See 42 U.S.C.S. § 1382(a)(1) (LexisNexis 2018).

<sup>28</sup> § 1382c(a)(3)(A).

eligibility under the meaning of disability defined in the SSA.<sup>29</sup> A person living with multiple impairments faces great disability even if each ailment, when scrutinized separately, does not present a severe handicap.<sup>30</sup> Additionally, an individual's "physical or mental impairment" must be identifiable by qualified medical professionals as an "anatomical, physiological, or psychological abnormalit[y]."<sup>31</sup>

Furthermore, a person's disability must inhibit the individual's ability to engage in "substantial gainful activity" to qualify for SSI.<sup>32</sup> Substantial gainful activity is not an ambiguous term, but rather a precise quantitative value of monthly earnings determined annually by the Social Security Administration and based on the national wage index.<sup>33</sup> For instance, if a person with a disability were earning \$1,175 per month, her application for SSI benefits would be denied in 2017 because substantial gainful activity in 2017 was \$1,170.<sup>34</sup> However, if that same person earning \$1,175 per month reapplied for SSI in 2018, when the substantial gainful activity amount is \$1,180, she could now be found eligible for benefits.<sup>35</sup>

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<sup>29</sup> § 1382c(a)(3)(G).

<sup>30</sup> *See id.*; Anne Fitzpatrick, *Multiple Disabilities: Social Security Must Consider Combined Effects*, DISABILITYSECRETS, <https://www.disabilitysecrets.com/resources/social-security-disability/multiple-disabilities-combined-effects.htm> (last visited June 18, 2018). For example, a person with rheumatoid arthritis who lives with "repeated flareups" but does not have "fever, extreme fatigue, malaise, or weight loss" fails to meet the "listing requirements" to be found severely handicapped by Social Security Administration standards. *Id.* However, if this same person also suffers from a mental illness such as moderate depression or anxiety – two conditions that "can decrease your tolerance for pain" – the Social Security Administration "must consider whether the combined effects" of each medical condition "add up to an impairment that is just as severe as the arthritis as described in the listing." *Id.*

<sup>31</sup> § 1382c(a)(3)(D). The Social Security Administration assesses subjective pain of an alleged disabled individual by considering all symptoms, "including pain, and the extent to which your symptoms can reasonably be accepted as consistent with the objective medical evidence and other evidence." 20 C.F.R. § 404.1529 (2018).

<sup>32</sup> § 1382c(a)(3).

<sup>33</sup> *Substantial Gainful Activity*, SOC. SECURITY ADMIN., <https://www.ssa.gov/oact/cola/sga.html> (last visited June 18, 2018). Because substantial gainful activity amounts "generally change with changes in the national average wage index," the value of substantial gainful activity can change annually. *Id.* In fact, the Social Security Administration website provides the substantial gainful activity values dating back to 1975 and the dollar amount has never decreased from one year to the next. *Id.* Additionally, the historical series of substantial gainful activity amounts shows many years when the amount did not change, but rather remained the same as the previous year. *Id.*

<sup>34</sup> *Id.*

<sup>35</sup> *Substantial Gainful Activity*, *supra* note 33. Although a person who is denied SSI benefits can reapply, individuals may also choose to appeal such denial with representation of a social security disability attorney; "nearly two-thirds of applicants are awarded benefits at their disability hearing," and a person's "chances of winning [an] appeal are significantly increased"

Once the Social Security Administration deems a person eligible for SSI benefits under the statutory regulations, she will be provided monthly payments as long as her disability is unceasing and monthly earnings are below what is considered substantial gainful activity for that year.<sup>36</sup> However, not every SSI recipient will receive the monthly maximum pay out.<sup>37</sup> A person's monthly SSI benefits are reduced by any income that can be used to pay for food and shelter.<sup>38</sup>

### B. Medicaid Under the Social Security Act

Medicaid is a program under the SSA that provides medical insurance to individuals who are receiving, or would be eligible to receive, SSI benefits.<sup>39</sup> Therefore, a disabled person who is eligible for SSI can be eligible for Medicaid if her income and resources do not cover the cost of various medical services required by the individual.<sup>40</sup> In fact, a majority of states use one application for both SSI and Medicaid.<sup>41</sup>

Fortunately, a disabled person who is “disqualified from receiving SSI payments” because of increased income may still receive Medicaid benefits if she is eligible for “special status.”<sup>42</sup> A person who loses SSI benefits may be deemed to have “special status” by the Social Security Administration when (1) a loss in Medicaid benefits “would seriously inhibit his ability to continue his employment,”<sup>43</sup> and (2) the

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when assisted by an attorney. *How to React If Your Social Security Disability Claim or SSI Claim is Denied*, DISABILITY BENEFITS CTR., <https://www.disabilitybenefitscenter.org/how-to/appeal-social-security-disability-denial> (last visited June 18, 2018).

<sup>36</sup> *Substantial Gainful Activity*, *supra* note 33.

<sup>37</sup> *SSI Federal Payment Amounts for 2018*, SOC. SECURITY ADMIN., <https://www.ssa.gov/oact/cola/SSI.html> (last visited June 18, 2018).

<sup>38</sup> *Income Exclusions For SSI Program*, SOC. SECURITY ADMIN., <https://www.ssa.gov/oact/cola/incomexcluded.html> (last visited June 18, 2018). There are some program exclusions, other than trusts or an ABLE account, that allow a disabled person receiving SSI to have money without it counting toward one's monthly benefit payout, but each of these exclusions relates to income that must be used for work-related purposes. *Id.* For example, a disabled person can exclude any income that is being used to pay for vocational assistance, or a program that enables a disabled individual to pursue work. *Plan To Achieve Self-Support (PASS)*, SOC. SECURITY ADMIN., <https://www.ssa.gov/disabilityresearch/wi/pass.htm> (last visited June 18, 2018).

<sup>39</sup> *See* 42 U.S.C.S. § 1396d(a) (LexisNexis 2018).

<sup>40</sup> *See id.*

<sup>41</sup> *Medicaid Information*, SOC. SECURITY ADMIN., <https://www.ssa.gov/disabilityresearch/wi/medicaid.htm> (last visited June 18, 2018).

<sup>42</sup> *Baystate Med. Ctr. v. Leavitt*, 545 F. Supp. 2d 20, 33 (D.D.C. 2008).

<sup>43</sup> § 1382h(b)(1)(C).



income being earned by the disabled individual, although high enough to lose eligibility for SSI benefits, is “not sufficient” to cover medical expenses.<sup>44</sup>

Although SSI payment will cease immediately upon income earnings that equal or surpass substantial gainful activity, Medicaid coverage under special status can last up to at least seven years and nine months beyond termination of SSI benefits.<sup>45</sup> Thus, this status reflects a significant exception as compared to the mostly rigid rules under the SSA, especially considering that disabled individuals are more likely to be self-employed or work in part-time positions that generally do not offer medical benefits.<sup>46</sup>

### III. THE HARD TRUTH OF SAVING MONEY WITHOUT TRUSTS OR THE ABLE ACT

The Medicaid special status exception is uniquely generous as compared to the rest of the SSA rules and regulations that cause disabled individuals great anxiety regarding their ability to save money in the absence of auxiliary financial tools.<sup>47</sup> The Social Security Administration encourages financial independence and “wants you to succeed,” as exemplified by its exclusion of income for self-support programs for disabled individuals.<sup>48</sup> However, the Social Security Administration’s incentivized savings programs substantially limit a person’s spending powers to predominantly only work-related services and expenses.<sup>49</sup> Therefore, when a disabled person receiving SSI benefits begins to earn money through the work she has been

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<sup>44</sup> § 1396h(b)(1)(D).

<sup>45</sup> *2017 Red Book: A Summary Guide to Employment Supports for Persons with Disabilities Under the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) Programs*, SOC. SECURITY ADMIN., at 35, <https://www.ssa.gov/redbook/documents/TheRedBook2017.pdf> (last visited June 18, 2018).

<sup>46</sup> *Persons with a Disability: Labor Force Characteristics Summary*, U.S. DEP’T LAB.: BUREAU LAB. STAT. (June 21, 2017, 10:00 AM), <https://www.bls.gov/news.release/disabl.nr0.htm>.

<sup>47</sup> Steverman, *supra* note 8.

<sup>48</sup> *We Heard You! More about Saving Money While Receiving Supplemental Security Income (SSI)*, SOC. SECURITY ADMIN.: TICKET TO WORK (Aug. 1, 2013), [https://choosework.ssa.gov/blog-archive/blog-post?post\\_id=235](https://choosework.ssa.gov/blog-archive/blog-post?post_id=235).

<sup>49</sup> *Id.*

encouraged to obtain, she is limited to spending the money as the Social Security Administration sees fit.<sup>50</sup>

Imagine living in an unfurnished apartment because SSA limitations prevent working recipients from saving enough money to purchase basic necessities like a couch.<sup>51</sup> While non-disabled members of the workforce nervously prepare to ask their bosses for promotions and raises, one disabled American arranged with her employer to limit her raises to no more than seven-hundred dollars per month.<sup>52</sup>

Working disabled people who receive benefits fail to achieve upward mobility because the SSA restrictions, which are intended to “bar freeloaders,” ultimately prevent many well-intentioned earners from saving too much money; money that could be used for “emergencies, retirement, and other life goals.”<sup>53</sup> As previously mentioned, a person receiving SSI can only save up to two thousand dollars in total without affecting monthly payments.<sup>54</sup> The author’s reiteration of the two thousand dollars savings cap is not redundant, but rather intentional, because disabled individuals represent a population that is increasingly vulnerable to medical emergencies and economic challenges, yet fails to have an adequate financial security net.<sup>55</sup>

Moreover, disabled recipients are further disadvantaged when unable to create a financial buffer to cover unanticipated expenses because disabled Americans statistically earn less than their non-disabled peers.<sup>56</sup> The median income for a person with a disability was

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<sup>50</sup> *Id.* The SSA’s incentivized work programs limit a recipient from spending her earnings for products or services that are “impairment-related work expenses”; for example, a wheelchair or a guide dog is deductible as an impairment-related work expense, but “travel expenses related to obtaining medical items or services” are not deductible. *2017 Red Book*, *supra* note 45.

<sup>51</sup> Pisani, *supra* note 6.

<sup>52</sup> Ellis, *supra* note 3.

<sup>53</sup> Steverman, *supra* note 8.

<sup>54</sup> *Understanding Supplemental Security Income*, *supra* note 5.

<sup>55</sup> *Helping American Families Achieve Financial Security While Facing Special Needs and Disabilities Challenges*, VOYA FIN., at 2, <https://professionals.voya.com/stellent/public/6113184.pdf> (last visited June 18, 2018); *Disabled People and Financial Well-being: Savings and Insurance*, SCOPE, at 2 (July 2013), <https://www.scope.org.uk/Scope/media/Documents/Publication%20Directory/Disabled-people-and-financial-well-being-savings-and-insurance.pdf?ext=.pdf>.

<sup>56</sup> Lewis Kraus, *2016 Disability Statistics Annual Report*, UNIV. N.H.: INST. ON DISABILITY/UCED, at 3 (Jan. 2017), [https://disabilitycompendium.org/sites/default/files/user-uploads/2016\\_AnnualReport.pdf](https://disabilitycompendium.org/sites/default/files/user-uploads/2016_AnnualReport.pdf).

twenty-one thousand dollars per year in 2015, ten thousand dollars less than the median income for non-disabled individuals.<sup>57</sup> Additionally, disabled individuals with at least a high school education earn 37% less than their non-disabled coworkers with the same level of education.<sup>58</sup> Thus, the inability of disabled individuals to accrue a substantial savings from the meager income earned perpetuates financial insecurity and dependency on government benefits such as SSI.<sup>59</sup>

The only recipients fortunate enough to save more than two thousand dollars are those who have found a way to hire “pricey” lawyers to create and manage trusts; for instance, some lawyers utilize payment plans for clients who cannot pay the entirety of a bill up front, or people seek financial help from family or friends.<sup>60</sup> Yet, a disabled individual who receives benefits and chooses to deposit her own money into a first-party trust is subject to complicated limitations and regulations that present barriers.<sup>61</sup> These complexities drove activists within the special needs community to lobby for passage of the ABLE Act, which they hoped would provide a financial savings tool to alleviate much of the headache surrounding the establishment of a trust.<sup>62</sup> However, the ABLE program which was created to satisfy the need for a simpler, user-friendly method to saving money is not as worry-free as advocates had anticipated.<sup>63</sup> For this reason, trusts continue to lead the way in reliable financial savings for disabled individuals and their families, despite their intricacies.<sup>64</sup>

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

<sup>58</sup> *Workers with Disabilities Earn Less Than Their Peers; The Pay Gap Widens as Educational Attainment Increases*, AM. INSTS. FOR RES. (Dec. 14, 2014), <https://www.air.org/resource/workers-disabilities-earn-less-their-peers-pay-gap-widens-educational-attainment-increases>.

<sup>59</sup> Steverman, *supra* note 8.

<sup>60</sup> Pisani, *supra* note 6.

<sup>61</sup> Jeffrey Levine, *Special Needs Trusts vs. ABLE Accounts – Which is Better?*, ED SLOTT & COMPANY, LLC (Sept. 16, 2015), <https://www.iraahelp.com/slottreport/special-needs-trusts-vs-able-accounts-which-better>.

<sup>62</sup> Susan Johnston Taylor, *What to Know Before Opening an ABLE Account*, U.S. NEWS (Jan. 11, 2017, 10:43 AM), <https://money.usnews.com/money/personal-finance/articles/2017-01-11/what-to-know-before-opening-an-able-account>; Stuart Spielman, *10 Things to Know About the ABLE Act*, AUTISM SPEAKS (Apr. 1, 2015), <https://www.autismspeaks.org/news/news-item/10-things-know-about-able-act>.

<sup>63</sup> Pisani, *supra* note 6.

<sup>64</sup> David Rephan & Joelle Groshek, *ABLE Act Accounts: Achieving a Better Life Experience for Individuals with Disabilities with Tax-Preferred Savings (and the Old Reliable Special and Supplemental Needs Trusts)*, 42 WM. MITCHELL L. REV. 963, 992 (2016).

#### IV. TRUSTS AS A MEANS OF SAVING MONEY AS A RECIPIENT OF GOVERNMENT BENEFITS

Before the enactment of the ABLE Act, disabled individuals and their families hired lawyers to create trusts when they wanted to build future savings without endangering eligibility for government benefits.<sup>65</sup> Trusts are a statutory exception under the SSA to counting income and resources.<sup>66</sup> Although ABLE accounts present a new, allegedly improved, way for disabled individuals to save money, trusts are a reliable legal tool that families have utilized to plan for the future of their disabled loved ones.<sup>67</sup> However, the trusts that are available to disabled individuals receiving government benefits – third-party special needs trusts, first-party special needs trusts (“SNT”)<sup>68</sup> and pooled special needs trusts (“pooled trust”)<sup>69</sup> – carry complex guidelines and restrictions that “make their use by individuals with disabilities challenging and sometimes inflexible.”<sup>70</sup>

##### A. Trusts as a Resource

A primary concern for disabled individuals who open an SSA qualifying trust is that their assets will be counted as a resource.<sup>71</sup> A trust will be counted as a resource, affecting SSI and Medicaid eligibility, when the disabled individual (1) has an ownership interest in the trust, (2) has the legal right to convert assets in the trust to cash, and (3) is not legally restricted from using the trust assets for her support and maintenance.<sup>72</sup> If a person’s assets are declared a resource, the disabled individual will risk losing government benefits because such assets are regarded as countable income.<sup>73</sup> Thus, the disabled

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<sup>65</sup> *Id.* at 965-66.

<sup>66</sup> 42 U.S.C.S. § 1396p(d)(4) (LexisNexis 2018).

<sup>67</sup> Rephan & Groshek, *supra* note 64, at 965-66.

<sup>68</sup> § 1396p(d)(4)(A).

<sup>69</sup> § 1396p(d)(4)(C)(i)-(iv).

<sup>70</sup> Rephan & Groshek, *supra* note 64, at 968.

<sup>71</sup> Amy O’Hara, *Your Special Needs Trust Explained*, 4 SPECIAL NEEDS ALLIANCE: VOICE NEWSL. 12 (Aug. 2010), <https://www.specialneedsalliance.org/the-voice/your-special-needs-trust-explained-2/>.

<sup>72</sup> *SI 01110.100 Distinction Between Assets and Resources*, PROGRAM OPERATIONS MANUAL SYS. (Jan. 27, 2009), <https://secure.ssa.gov/poms.nsf/lnx/0501110100>.

<sup>73</sup> *SI 01120.203 Exceptions to Counting Trusts Established on or after January 1, 2000*, PROGRAM OPERATIONS MANUAL SYS. (July 30, 2018), <https://secure.ssa.gov/poms.nsf/lnx/0501120203>.

individual must ultimately sacrifice all control over her assets to ensure that the trust qualifies under the SSA exception.<sup>74</sup>

### B. Third-Party Special Needs Trusts

A commonly used trust for disabled individuals who receive government benefits is a third-party special needs trust.<sup>75</sup> A third-party trust differs greatly from first-party SNTs and pooled trusts because someone other than the disabled individual funds the third-party trust.<sup>76</sup> This type of trust, if drafted correctly, will have minimal effect upon a disabled individual's benefits because the money in the third-party trust "never belonged" to the disabled person outright.<sup>77</sup> On the other hand, first-party SNTs and pooled trusts are specifically referenced within the SSA as exceptions because they are both funded with assets directly from the disabled individual.<sup>78</sup>

The source of the trust funds is a crucial distinction with significant legal outcomes.<sup>79</sup> A third-party trust fund for the benefit of a disabled individual is typically established and funded by a parent or grandparent.<sup>80</sup> Thus, the third-party trust has little effect on the disabled beneficiary who receives government benefits because the assets of the trust are not coming out of the disabled person's pocket.<sup>81</sup> For instance, third-party trusts do not require a provision for reimbursement to Medicaid when the beneficiary dies.<sup>82</sup> Instead,

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<sup>74</sup> *SI 01120.200 Information on Trusts, Including Trusts Established Prior to January 01, 2000, Trusts Established with the Assets of Third Parties, and Trusts Not Subject to Section 1613(e) of the Social Security Act*, PROGRAM OPERATIONS MANUAL SYS. (June 7, 2018), <https://secure.ssa.gov/poms.nsf/lnx/0501120200>. A disabled individual relinquishes the power "to revoke or terminate the trust and then use the funds to meet his food or shelter needs," use "the trust principal for his or her support and maintenance under the terms of the trust," or "sell his or her beneficial interest in the trust." *Id.*

<sup>75</sup> *Self-Settled vs. Third-Party Special Needs Trusts*, TR. BUILDERS L. GROUP: HAMPTON ROADS ESTATE PLAN. & ADMIN. L. BLOG (Feb. 28, 2014), [http://trustbuilders.com/lawyer/2014/02/28/Elder-Law/Self-Settled-vs.-Third-Party-Special-Needs-Trusts\\_bl11721.htm](http://trustbuilders.com/lawyer/2014/02/28/Elder-Law/Self-Settled-vs.-Third-Party-Special-Needs-Trusts_bl11721.htm).

<sup>76</sup> 1-1 FUNDAMENTALS OF SPECIAL NEEDS TRUSTS § 1.05[4] (2018).

<sup>77</sup> *What Is a "Third-Party" Special Needs Trust and How Is It Different from Other Kinds of Trusts?*, SPECIAL NEEDS ANSWERS, <https://specialneedsanswers.com/what-is-a-third-party-special-needs-trust-and-how-is-it-different-from-other-kinds-of-trusts-15111> (last modified June 27, 2017).

<sup>78</sup> FUNDAMENTALS OF SPECIAL NEEDS TRUSTS, *supra* note 76, § 1.05[2].

<sup>79</sup> *See* FUNDAMENTALS OF SPECIAL NEEDS TRUSTS, *supra* note 76, § 1.05[1].

<sup>80</sup> FUNDAMENTALS OF SPECIAL NEEDS TRUSTS, *supra* note 76, § 1.05[4].

<sup>81</sup> *See* FUNDAMENTALS OF SPECIAL NEEDS TRUSTS, *supra* note 76, § 1.05[4].

<sup>82</sup> *See* FUNDAMENTALS OF SPECIAL NEEDS TRUSTS, *supra* note 76, § 1.05[4].

accumulated wealth left in the third-party trust can go to the disabled individual's family without first passing through the hands of Medicaid as a creditor.<sup>83</sup>

Unlike a first-party SNT, a third-party trust provides a disabled individual neither the opportunity to contribute her own earnings to the trust nor the independence to create the trust.<sup>84</sup> Yet, the third-party trust is a reliable savings tool for people wanting to provide for a disabled family member without jeopardizing eligibility for government benefits.<sup>85</sup> However, this type of trust is not appropriate for a disabled individual who seeks economic independence and a desire to build her own future savings beyond the two thousand dollars savings cap.<sup>86</sup> On the other hand, a self-settled trust – first-party SNT or a pooled trust – makes it possible for disabled individuals to build their own savings with their own money.<sup>87</sup>

### C. First-Party Special Needs Trusts

A self-settled first-party SNT is advantageous compared to third-party trusts because a disabled individual funds the SNT with her own assets.<sup>88</sup> Nevertheless, problems arise as to whether the money in the trust should be counted as a resource affecting SSI and Medicaid eligibility when the disabled individual, a recipient of benefits, directly transfers money to the trust.<sup>89</sup> For this reason, the SSA contains an exception for self-settled trusts.<sup>90</sup>

The trust exception under the SSA provides that assets in a first-party SNT do not count as a resource toward SSI and Medicaid eligibility, allowing disabled individuals to save an unlimited amount of their own money for future planning so long as certain requirements are met.<sup>91</sup> For an SNT to qualify under this exception, the trust must be irrevocable and meet the following criteria: (1) contain the assets of a disabled individual under sixty-five years of age; (2) be established through the actions of a parent, grandparent, legal guardian or a court;

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<sup>83</sup> See FUNDAMENTALS OF SPECIAL NEEDS TRUSTS, *supra* note 76, § 1.05[4].

<sup>84</sup> See FUNDAMENTALS OF SPECIAL NEEDS TRUSTS, *supra* note 76, § 1.05[4].

<sup>85</sup> See FUNDAMENTALS OF SPECIAL NEEDS TRUSTS, *supra* note 76, § 1.05[4].

<sup>86</sup> See FUNDAMENTALS OF SPECIAL NEEDS TRUSTS, *supra* note 76, § 1.05[4].

<sup>87</sup> *Self-Settled vs. Third-Party*, *supra* note 75.

<sup>88</sup> FUNDAMENTALS OF SPECIAL NEEDS TRUSTS, *supra* note 76, § 1.05[2].

<sup>89</sup> FUNDAMENTALS OF SPECIAL NEEDS TRUSTS, *supra* note 76, § 1.05[2].

<sup>90</sup> See 42 U.S.C.S. § 1396p(d)(4)(A) (LexisNexis 2018).

<sup>91</sup> See *id.*

and (3) be used for the sole benefit of the disabled individual.<sup>92</sup> The State will receive the remaining assets in the trust upon the death of the beneficiary equal to the amount of Medicaid benefits paid to the disabled individual throughout her lifetime.<sup>93</sup>

### 1. *Disabled and Under 65-Years-Old*

The first requirement to open a qualified SNT is that the individual must be disabled and under sixty-five years old.<sup>94</sup> A person who meets the definition of “disabled” for SSI benefits pursuant to the SSA,<sup>95</sup> thus, qualifies as disabled for the purposes of opening an SNT.<sup>96</sup> Additionally, the SNT will not be counted as a resource if the disabled individual is less than sixty-five years old when the trust is opened, and the exception continues to apply after the individual reaches age sixty-five.<sup>97</sup>

### 2. *Established and Managed by a Third-Party*

An SNT cannot be set up through the actions of the disabled individual, but rather through the actions of the disabled person’s parents, grandparents, legal guardian, or a court.<sup>98</sup> Placing such responsibility on a third-party is reasonable considering that establishing an SNT pursuant to SSA guidelines is a time-consuming and complex process and, if done incorrectly, places the disabled individual’s benefits at risk.<sup>99</sup> Even legally competent, disabled adults may have a parent or grandparent establish the SNT.<sup>100</sup> However, such third-party requirement perpetuates a cycle of dependence of disabled individuals on other persons.<sup>101</sup> Thus, SSA policy should reflect the abilities of mentally competent, disabled adults who can navigate the nuances of creating their own SNTs.

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<sup>92</sup> See *id.*; see also *SI 01120.203*, *supra* note 73.

<sup>93</sup> § 1396p(d)(4)(A); *SI 01120.203*, *supra* note 73.

<sup>94</sup> § 1396p(d)(4)(A).

<sup>95</sup> See § 1382c(a)(3).

<sup>96</sup> *SI 01120.203*, *supra* note 73.

<sup>97</sup> *SI 01120.203*, *supra* note 73.

<sup>98</sup> *SI 01120.203*, *supra* note 73.

<sup>99</sup> Paul Sullivan, *Exploring Trusts for the Disabled*, N.Y. TIMES (Nov. 5, 2010), <http://www.nytimes.com/2010/11/06/your-money/06wealth.html>.

<sup>100</sup> *SI 01120.203*, *supra* note 73.

<sup>101</sup> See *SI 01120.203*, *supra* note 73.

Moreover, the third-party who creates the trust for the benefit of the disabled individual must hold legal authority to manage the assets of the disabled individual.<sup>102</sup> A third-party may establish legal authority in two ways: (1) independent legal authority as the disabled individual's appointed guardian or conservator; or (2) establishment of the SNT as a "seed-trust" initially funded with a nominal amount of the third-party's own property.<sup>103</sup>

### 3. "Sole Benefit" Rule

For the trust to qualify as an exception to counting as a resource under the SSA, the trust must be established and used only for the benefit of the disabled individual; this is commonly referred to as the Sole Benefit Rule.<sup>104</sup> However, exceptions to this rule include payments to a third-party for services or payment of an administrative expense.<sup>105</sup> Yet, all expenses ultimately benefit, or provide services to, the disabled individual.<sup>106</sup> For instance, qualified exceptions under the Sole Benefit Rule include (1) the disbursement of trust assets to a third-party for "receipt of goods or services" for the disabled individual and (2) payment for necessary travel expenses to allow the disabled individual to receive medical treatment.<sup>107</sup>

However, an advantage of establishing a seemingly restrictive and complex SNT is the freedom of determining how to spend the funds.<sup>108</sup> The trustee can purchase practically anything for the disabled individual as long as the funds are not used for food or shelter.<sup>109</sup> This spending restriction is in place because SSI benefits should ideally fulfill all food and shelter expenses, despite this not always being the

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<sup>102</sup> *SI 01120.203*, *supra* note 73.

<sup>103</sup> Kristen M. Lewis, *Special Needs Trust: The Cornerstone of Planning for Beneficiaries with Disabilities*, SPECIAL NEEDS TR. PANEL, at 16, [https://www.americanbar.org/content/dam/aba/publishing/rpteereport/te\\_lewis.authcheckdam.pdf](https://www.americanbar.org/content/dam/aba/publishing/rpteereport/te_lewis.authcheckdam.pdf) (last visited June 18, 2018).

<sup>104</sup> *SI 01120.201 Trusts Established with the Assets of an Individual on or after 01/01/00*, PROGRAM OPERATIONS MANUAL SYS. (May 22, 2018), <https://secure.ssa.gov/poms.nsf/lnx/0501120201>.

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

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

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

<sup>108</sup> See Betsy Simmons Hannibal, *How Special Needs Trust Funds Can Be Used*, NOLO, <https://www.nolo.com/legal-encyclopedia/how-special-needs-trust-funds-can-be-used.html> (last visited June 18, 2018).

<sup>109</sup> *See id.*



case.<sup>110</sup> If trust fund assets are used to pay for either of these necessities, SSI benefits may be reduced.<sup>111</sup> For this reason, among others, trust fund assets are typically used for travel, education, caregiving, and medical services not provided by Medicaid.<sup>112</sup>

#### 4. *Medicaid Payback Requirement*

Finally, the trust must include a specific provision that gives the remaining funds in the trust to Medicaid upon the death of the disabled individual.<sup>113</sup> Essentially, the state from which the disabled individual collects Medicaid will receive trust assets up to the total amount of medical assistance paid to the disabled individual upon the beneficiary's death.<sup>114</sup> This Medicaid payback is not limited to the period after the trust's creation.<sup>115</sup> Instead, the payback includes all Medicaid payments made to the beneficiary during her lifetime.<sup>116</sup> Thus, a disabled individual's freedom of disposition of property is instantly reduced by the value of assets immediately owed to the State.<sup>117</sup> However, this Medicaid payback provision is not unique to first-party SNTs, but is also required in pooled trusts and ABLE accounts.<sup>118</sup>

#### D. **Pooled Special Needs Trusts (Master Trust)**

In addition to the Medicaid payback requirement, pooled trusts are similar to first-party SNTs because both types of trusts are directly funded by the disabled individual's personal assets and require the beneficiary to fall within SSA's definition of disabled.<sup>119</sup> Yet, the pooled trust differs greatly in administration and management from the

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<sup>110</sup> See Betsy Simmons Hannibal, *Can a Special Needs Trust Pay for Food and Shelter?*, NOLO, <https://www.nolo.com/legal-encyclopedia/can-special-needs-trust-pay-food-shelter.html> (last visited June 18, 2018).

<sup>111</sup> *Id.*

<sup>112</sup> Hannibal, *supra* note 108.

<sup>113</sup> *SI 01120.203*, *supra* note 73.

<sup>114</sup> See *SI 01120.203*, *supra* note 73.

<sup>115</sup> *SI 01120.203*, *supra* note 73.

<sup>116</sup> *SI 01120.203*, *supra* note 73.

<sup>117</sup> See *SI 01120.203*, *supra* note 73.

<sup>118</sup> *ABLE Accounts and SNTs: How to Choose?*, SPECIAL NEEDS ALLIANCE, <https://www.specialneedsalliance.org/able-accounts-and-snts-how-to-choose/> (last visited June 18, 2018).

<sup>119</sup> See *SI 01120.203*, *supra* note 73.

first-party SNT.<sup>120</sup> Pooled trusts function in a similar manner as banks, in which an organization or agency holds the assets of many individuals simultaneously while each individual's assets are in separate accounts.<sup>121</sup> In practice, an account in a pooled trust is “established for each individual,” but the nonprofit organization where the account is held combines all assets “to maximize the return on investment and at the same time reduce the cost of administration and management,” similar to that of a mutual trust fund.<sup>122</sup>

Members of the National Academy of Elder Law Attorneys regard pooled trusts as a special needs planning tool for “families of modest means” because interested parties do not need to hire an attorney to draft a new trust.<sup>123</sup> In some cases, establishing an account only requires signing a contract that agrees to membership in the pooled trust.<sup>124</sup> Furthermore, the elements which differentiate pooled trusts from SNTs, as well as qualify pooled trusts as an exception to counting, include (1) establishment and maintenance by a nonprofit association and (2) separate accounts for each disabled individual, created through actions of the disabled individual or a third-party with legal authority.<sup>125</sup>

### 1. *Nonprofit Associations*

A nonprofit, or tax-exempt, organization establishes and manages a pooled trust, in which the disabled individuals can create their own subaccount.<sup>126</sup> An advantage to having a nonprofit organization managing such a trust is that the disabled individual does not need to find another person to manage the trust as trustee.<sup>127</sup> The nonprofit organization acts as the trustee for all of the subaccounts that

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<sup>120</sup> Mary Browning, *Pooled Trusts vs. Special Needs Trusts*, COLE SCHOTZ, P.C. (Sept. 6, 2011), <https://www.csspecialneedsblog.com/2011/09/articles/special-needs-trusts/pooled-trusts-vs-special-needs-trusts/>.

<sup>121</sup> *SI 01120.203*, *supra* note 73.

<sup>122</sup> Michele P. Fuller & Kevin P. Urbatsch, *Pooled Trusts: An Approach to Special Needs Planning for Families of Modest Means*, 34 BIFOCAL 79, 84 (2013).

<sup>123</sup> *Id.* at 86.

<sup>124</sup> *Id.*

<sup>125</sup> *SI 01120.203*, *supra* note 73.

<sup>126</sup> Sandra L. Smith, *What is a Pooled Trust, and When Should You Use One?*, LEXISNEXIS LEGAL NEWS ROOM EST. & ELDER L. (Oct. 21, 2011, 12:18 PM), <https://www.lexisnexis.com/legalnewsroom/estate-elder/b/estate-elder-blog/archive/2011/10/21/what-is-a-pooled-trust-and-when-should-you-use-one.aspx>.

<sup>127</sup> *See id.*

are pooled for investment and management purposes, which frequently lowers the administrative costs of maintaining the trust.<sup>128</sup> Nonetheless, families and individuals interested in opening a subaccount in a pooled trust are encouraged to meet with an attorney because each nonprofit organization has its own requirements for membership in the trust; for example, some pooled trusts are limited by region while other such organizations base eligibility on classification of disability or source of assets.<sup>129</sup>

## 2. *Subaccounts for Each Individual, Created by the Individual*

Similar to the administration of a bank, a nonprofit organization establishes a pooled trust that holds assets for a person who may request an individual accounting of her trust assets.<sup>130</sup> However, because the funds by definition may be pooled for investment and management purposes, the assets of the trust are not invested for the unique benefit of a sole beneficiary with a subaccount.<sup>131</sup> Thus, a pooled trust is beneficial to a disabled individual who prefers to leave the management of the trust assets in the hands of an experienced organization, although it does not promote individualized future planning as provided in an SNT.<sup>132</sup> Yet, unlike the SNT, a disabled individual may establish a subaccount in a pooled trust herself and without the need of a third-party.<sup>133</sup>

## E. SNTs Versus Pooled Trusts

SNTs and pooled trusts share many of the same requirements, such as the Medicaid payback provision and application of the Sole Benefit Rule.<sup>134</sup> However, the differences between the SNT and

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

<sup>129</sup> Fuller & Urbatsch, *supra* note 122. An attorney with experience in special needs planning can help steer a disabled individual to a pooled trust that is suitable for her specific needs; “[s]ome pooled special needs trusts only accept those with developmental disabilities, while others specialize in managing proceeds from litigation recoveries.” Fuller & Urbatsch, *supra* note 122.

<sup>130</sup> *SI 01120.203*, *supra* note 73.

<sup>131</sup> Robert Kulas, *The Pros and Cons of a Pooled Trust*, HG.ORG LEGAL RESOURCES, <https://www.hg.org/article.asp?id=26758> (last visited June 18, 2018).

<sup>132</sup> *See id.*

<sup>133</sup> *See id.*

<sup>134</sup> FUNDAMENTALS OF SPECIAL NEEDS TRUSTS, *supra* note 76, § 1.05.

pooled trust reflect the purposes and advantages of each trust.<sup>135</sup> A disabled individual who desires a savings plan that is uniquely tailored to her own needs and future plans will find greater advantages in establishing an SNT.<sup>136</sup> On the other hand, a pooled trust provides a disabled individual with a more financially prudent option to investing her money and eliminates the burden of finding a responsible party to act as trustee and third-party with legal authority to establish the trust.<sup>137</sup> Nonetheless, both of these trusts inevitably strip the disabled individual of her autonomy.<sup>138</sup> Such loss of independence does not wholly discount the great benefits of an SNT or pooled trust but rather reflects the traditional and overgeneralized belief that most disabled individuals are reliant and incapable.

When choosing a trust option, the disabled individual must decide between placing assets in a trust ultimately controlled by a third-party trustee or a nonprofit organization.<sup>139</sup> Each of these trusts places investment and management control in the hands of anyone other than the disabled individual.<sup>140</sup> However, adoption of the ABLE Act demonstrates a progressive policy change that encourages independence for a group of persons previously treated as dependent and needy; such legislation represents a gradual shift in societal awareness toward understanding the needs and desires of income-earning disabled Americans.<sup>141</sup>

Pervasive belief that disabled individuals are not as capable as their nondisabled counterparts largely stems from government programs, such as SSI and Medicaid, which create “counterproductive” cycles of poverty.<sup>142</sup> Those who attain some form of self-sufficiency are penalized because of inflexible regulations that produce and maintain dependency on government assistance.<sup>143</sup> For these reasons, passage of the ABLE Act represents a significant feat

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<sup>135</sup> FUNDAMENTALS OF SPECIAL NEEDS TRUSTS, *supra* note 76, § 1.05; *see* Kulas, *supra* note 131.

<sup>136</sup> *See* Kulas, *supra* note 131.

<sup>137</sup> Kulas, *supra* note 131.

<sup>138</sup> *See* Kulas, *supra* note 131.

<sup>139</sup> *See* Kulas, *supra* note 131.

<sup>140</sup> *See* Kulas, *supra* note 131.

<sup>141</sup> *See* *What are ABLE Accounts?*, NAT’L RESOURCE CTR.: ACHIEVING BETTER LIFE EXPERIENCE ACT, <http://ablenrc.org/about/what-are-able-accounts> (last visited June 18, 2018).

<sup>142</sup> Lowe, *supra* note 13.

<sup>143</sup> Lowe, *supra* note 13.

for disabled individuals in America, a “meaningful pathway into the middle class for people with disabilities.”<sup>144</sup>

However, some critical flaws in the ABLE Act make its use more challenging than lobbyists and advocates of the financial savings tool anticipated.<sup>145</sup> Trusts are complicated; they are reliable savings devices that can protect a disabled beneficiary’s benefits at a cost of independence and simplicity.<sup>146</sup> The special needs community increasingly pressured legislative bodies to adopt a less legally driven, accessible financial planning program for disabled individuals.<sup>147</sup> Yet, significant policies of the ABLE Act at issue include the age restriction placed on onset of an individual’s disability, lack of clarity regarding qualified disability expenses, and presence of misinformation or absence of guidance for families seeking establishment of an ABLE account for a disabled family member.<sup>148</sup> These regulations further isolate individuals based on their disabilities instead of inviting the whole community, and its spectrum of varying capacities, to take part in future savings alongside their nondisabled peers.

## V. THE ABLE ACT AND ABLE ACCOUNTS

The idea of creating an innovative money-saving program such as the one authorized by the ABLE Act originated with frustrated parents who wanted to easily save money for their disabled children.<sup>149</sup> Parents of special needs children, “struggling with a herculean work-life challenge,” juggle enormous responsibilities that have consequences for their entire family; “careers are cut short, finances are put in disarray, life is chaotic.”<sup>150</sup>

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<sup>144</sup> *ASAN Praises Congressional Passage of the ABLE Act*, AUTISTIC SELF ADVOC. NETWORK (Dec. 18, 2014), <http://autisticadvocacy.org/2014/12/asan-praises-congressional-passage-of-the-able-act/>.

<sup>145</sup> See Kathryn Flynn, *Should You Open an ABLE Account for a Child With a Disability?*, FORBES (Feb. 6, 2018), <https://www.forbes.com/sites/katiepf/2018/02/06/should-you-open-an-able-account-for-a-child-with-a-disability/#15f0ef2259d9>.

<sup>146</sup> See M&LAdmin4, *supra* note 2.

<sup>147</sup> Mari-Jane Williams, *How the Proposed ABLE Act Will Help Parents of Children With Disabilities*, WASH. POST (Mar. 6, 2014), [https://www.washingtonpost.com/news/parenting/wp/2014/03/06/how-the-proposed-able-act-will-help-parents-of-children-with-disabilities/?utm\\_term=.f805f26e1188](https://www.washingtonpost.com/news/parenting/wp/2014/03/06/how-the-proposed-able-act-will-help-parents-of-children-with-disabilities/?utm_term=.f805f26e1188).

<sup>148</sup> See Flynn, *supra* note 145.

<sup>149</sup> Pisani, *supra* note 6.

<sup>150</sup> Maggie Jackson, *A Parental Juggling Job*, BOSTON.COM (Dec. 14, 2008), [http://archive.boston.com/jobs/news/articles/2008/12/14/a\\_parental\\_juggling\\_job/](http://archive.boston.com/jobs/news/articles/2008/12/14/a_parental_juggling_job/).

Stephen Beck, Jr. was among these drained, overextended parents who tirelessly advocated and lobbied for any form of legislation that would bring a glimmer of financial ease to disabled individuals and their families.<sup>151</sup> To honor Beck's fight for the passage of the ABLE Act and in recognition of his death only weeks before President Barack Obama signed the bill, the law was officially named The Stephen Beck Jr. Achieving a Better Life Experience Act, also known as the ABLE Act.<sup>152</sup>

The ABLE Act is an amendment to the Internal Revenue Code of 1986 and enacted "to provide for the tax treatment of ABLE accounts established under State programs for the care of family members with disabilities."<sup>153</sup> The congressional bill text of the ABLE Act sets forth two purposes of ABLE accounts: (1) to "encourage and assist" disabled individuals and their family to save money for the disabled individual's "health, independence, and quality of life," and (2) to provide disabled individuals with a way to secure such funds that "supplement, but not supplant," benefits received under the SSA.<sup>154</sup> However, a disabled individual, who desires to open an ABLE account and reap the benefits proffered by the new legislation, must meet a number of requirements under the ABLE Act.<sup>155</sup>

### A. Eligibility to Open an ABLE Account

An individual who is disabled, as defined in the SSA, is eligible to open an ABLE account whether or not she is receiving SSI or Medicaid benefits, so long as she was disabled before turning twenty-six years old.<sup>156</sup> A qualifying disabled individual may open one account for herself, in which she then becomes the "designated

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<sup>151</sup> Pisani, *supra* note 6.

<sup>152</sup> Pisani, *supra* note 6.

<sup>153</sup> Tax Increase Prevention Act of 2014, 113 Pub. L. No. 295, 128 Stat. 4010 (2014).

<sup>154</sup> Tax Increase Prevention Act § 1.

<sup>155</sup> See *What are ABLE Accounts?*, *supra* note 141.

<sup>156</sup> See 26 U.S.C.S. § 529A(e)(1) (LexisNexis 2018). If the disabled individual is not receiving government benefits under the SSA, but nonetheless falls within the SSA's definition of disabled, the disabled individual may receive a "disability certification," which is filed with the Secretary of the State, which certifies that the individual is in fact disabled, as defined by the SSA, and "includes a copy the individual's diagnosis . . ." § 529A(e)(1)(B), (2)(A). The Nebraska State Treasury interprets the twenty-six year old age restriction as a "need to minimize the impact on tax losses due to the tax-advantaged nature of an ABLE account." Rachel Biar, *ABLE Legislation—Raising Age*, ENABLE SAVINGS PLAN (May 3, 2016), <https://www.enablesavings.com/home/blog-list/article-post/blog/able-legislation—raising-age-1.html>.

beneficiary” of her account.<sup>157</sup> As a “designated beneficiary,” she is the owner of her ABLE account;<sup>158</sup> the owner may make personal contributions, maintain her account independently, and is entitled to a separate accounting.<sup>159</sup> Thus, an ABLE account owner can act similarly to other nondisabled individuals because she can manage her own personal savings account.<sup>160</sup> Although seemingly banal, the ability to open and own a substantial savings account as a disabled person who receives government benefits is new and progressive.<sup>161</sup> At the end of the day, the ABLE program encourages “greater autonomy and dignity” for eligible individuals.<sup>162</sup>

### B. The ABLE Account Assets

The purpose of an ABLE account is to provide disabled individuals, especially those who receive government benefits, with the opportunity to grow their own future savings in a way that greater supports their unique needs as a person with a disability.<sup>163</sup> Under the ABLE program, a contribution to an ABLE account represents a “down payment on freedom” because disabled individuals are now able to allocate income to meet “financial savings goals” and engage in decision-making conversations regarding their investment options.<sup>164</sup>

The annual contribution an ABLE account owner is entitled to deposit is fifteen thousand dollars free from taxation; an annual contribution that is over seven times greater than the amount of *total* life savings permitted under the SSA.<sup>165</sup> The ABLE program invites

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<sup>157</sup> § 529A(e)(3).

<sup>158</sup> *Id.*

<sup>159</sup> § 529A(b)(3), (e)(6).

<sup>160</sup> *See id.*

<sup>161</sup> *See* Rephan & Groshek, *supra* note 64, at 975-76.

<sup>162</sup> Rephan & Groshek, *supra* note 64, at 976.

<sup>163</sup> *See* Megan Leonhardt, *ABLE Savings Accounts: An Updated, State-by-State List of Programs*, TIME (May 10, 2017, 4:06 PM), <http://time.com/money/4618317/529-able-savings-account-states/>.

<sup>164</sup> *The Achieving A Better Life Experience (ABLE) Act*, FLA. DEVELOPMENTAL DISABILITIES COUNCIL, <https://www.fddc.org/sites/default/files/The%20Achieving%20a%20Better%20Life%20Experience%20%28ABLE%29%20Act%20Article%205-25-16.pdf> (last visited June 18, 2018).

<sup>165</sup> *See* Tax Cuts and Job Act, H.R. 1, 115th Cong. (2017) (emphasis added); *New Tax Law Makes Changes to ABLE Accounts*, SPECIAL NEEDS ANSWERS, <https://specialneedsanswers.com/new-tax-law-makes-changes-to-able-accounts-16488> (last modified Dec. 29, 2017). Prior to the enactment of the Tax Cuts and Jobs Act in December

vocational achievements and opportunities for economic growth.<sup>166</sup> Disabled individuals with ABLE accounts should no longer need to turn down promotions, raises, and bonuses in an effort to restrict their total savings to two thousand dollars.<sup>167</sup> In addition to the advantage of a savings account that produces interest and holds money for unanticipated emergencies, the ABLE account assets can cover qualified disability expenses that cannot be purchased with SSI or Medicaid benefits.<sup>168</sup>

### 1. *Qualified Disability Expenses*

The assets of an ABLE account are invested and used only for the benefit of the designated beneficiary.<sup>169</sup> The assets can be withdrawn tax-free when used to pay for “qualified disability expenses” (“QDE”).<sup>170</sup> The ABLE Act provides an expansive, but not comprehensive, list of QDE:

[E]ducation, housing, transportation, employment training and support, assistive technology and personal support services, health, prevention and wellness, financial management and administrative services, legal fees, expenses for oversight and monitoring, funeral and burial expenses, and other expenses, which are approved by the Secretary under regulations and consistent with the purposes of this section.<sup>171</sup>

While this list may cover a host of different purchases that are authorized as QDE, the language included at the end of this provision leaves room for interpretation and flexibility.<sup>172</sup> Such open-endedness

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2017, ABLE account holders were only permitted to contribute fourteen thousand dollars annually into their savings accounts. *Id.*

<sup>166</sup> See Williams, *supra* note 147.

<sup>167</sup> See Leonhardt, *supra* note 163.

<sup>168</sup> See Rephan & Groshek, *supra* note 64, at 980.

<sup>169</sup> 26 U.S.C.S. § 529A(e)(5) (LexisNexis 2018).

<sup>170</sup> *Qualified Disability Expenses*, ABLE UNITED, <http://www.ableunited.com/learn/qualified-disability-expenses/> (last visited June 18, 2018).

<sup>171</sup> § 529A(e)(5).

<sup>172</sup> See Eric Kroh, *IRS Advises Broad Definition of Disability Account Expenses*, LAW360 (June 19, 2015, 2:22 PM), <https://www.law360.com/articles/670090/irs-advises-broad-definition-of-disability-account-expenses>.



is not the result of laziness or an oversight in drafting, but rather reflects a much greater purpose.<sup>173</sup>

In 2015, shortly after the passage of the ABLE Act, the Treasury Department and Internal Revenue Service released a notice concerning the ABLE program, which stated that both of these federal agencies will broadly construe QDE as including “basic living expenses.”<sup>174</sup> For instance, the purchase of a smartphone may qualify as a QDE if such device provides the disabled individual with an effective means for communication or navigation.<sup>175</sup> ABLE account holders are not limited to medically necessary expenses related to their disability, but rather enjoy a freedom to spend their money on items or services that will be used to generally maintain or improve their “health, independence, or quality of life.”<sup>176</sup> However, this vague definition of QDE creates dangerous consequences for ABLE account holders who ultimately risk a financial penalty for spending money in a manner that does not comport with both agencies’ understanding of a QDE.<sup>177</sup> Disabled individuals who live with varying cognitive abilities face greater uncertainty and difficulty in understanding how to spend their money, gambling the risk of penalties, because this current policy is imprecise and ill-defined.<sup>178</sup>

It is important for a disbursement to fall within the definition of QDE because such purchases will not qualify as a resource or income against an ABLE account holder who receives SSI or Medicaid benefits.<sup>179</sup> In addition to the broad, yet indistinct, interpretation of QDE, the ABLE Act strictly regulates spending account funds on housing-related expenses, similar to the limitation of spending SNT or

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<sup>173</sup> See *id.*

<sup>174</sup> Terri Harris & Sean Barnett, *Section 529A Interim Guidance Regarding Certain Provisions of Proposes Regulations Relating to Qualified ABLE Programs*, INTERNAL REVENUE SERV., <https://www.irs.gov/pub/irs-drop/n-15-81.pdf> (last visited June 18, 2018).

<sup>175</sup> Kroh, *supra* note 172.

<sup>176</sup> Harris & Barnett, *supra* note 174.

<sup>177</sup> See Harris & Barnett, *supra* note 174.

<sup>178</sup> See *Week #3: What Can Funds Be Used For?*, ABLE NAT’L RESOURCE CTR., <http://ablenrc.org/week-3-what-can-funds-be-used> (last visited June 18, 2018). The ABLE National Resource Center recommends ABLE account holders save purchase receipts or keep a “record of how [a] particular expense is related to your disability”; such precise recordkeeping and management of funds can present challenges to a disabled individual who is developmentally or cognitively delayed, considering that many non-disabled individuals, too, fail to organize their finances. *Id.*

<sup>179</sup> See 26 U.S.C.S § 529A(c)(1)(B) (LexisNexis 2018); see also *Qualified Disability Expenses*, *supra* note 170.

pooled trust assets for housing.<sup>180</sup> When account holders spend their account funds for a housing-related purpose, or are otherwise unable to justify a purchase, such expenses will be included in their gross income and, thus, they will be subject to federal income tax “plus an additional 10 percent penalty” for the calendar year.<sup>181</sup>

## 2. *ABLE Account Funds and Government Assistance Programs*

The foremost benefit of the ABLE program is that disabled individuals receiving SSI or Medicaid benefits can save more than two thousand dollars without losing eligibility for federal assistance programs.<sup>182</sup> Although ABLE account holders collecting SSA benefits are still subject to a two thousand dollar asset limit, money saved in an ABLE account will not be counted toward that asset limit as long as that money is spent on QDE.<sup>183</sup> However, an ABLE account must not exceed a total amount of one hundred thousand dollars to maintain such dual eligibility under both the ABLE program and federal assistance programs.<sup>184</sup>

If ABLE account funds ever exceed one hundred thousand dollars, the disabled individual will not automatically be disqualified from the federal government assistance programs or the ABLE program, but her SSI benefits will be suspended until the account funds drop below the stated limit.<sup>185</sup> Fortunately, if SSI benefits are suspended due to an excess of funds in an ABLE account, the disabled individual will continue to receive coverage under Medicaid as if there was no suspension of SSI.<sup>186</sup>

## C. *Comparing ABLE Accounts to Trusts: Where the ABLE Act Falls Short*

Self-settled trusts and ABLE accounts have distinct advantages and disadvantages, making one superior over another based on

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<sup>180</sup> Tax Increase Prevention Act of 2014, 113 Pub. L. No. 295, § 103(a)(1), 128 Stat. 4010 (2014).

<sup>181</sup> *Qualified Disability Expenses*, *supra* note 170. See § 529A(c)(3)(A).

<sup>182</sup> See Tax Increase Prevention Act of 2014 § 103 (a).

<sup>183</sup> *Id.*

<sup>184</sup> § 103(a)(2).

<sup>185</sup> § 103(b)(1).

<sup>186</sup> § 103(b)(2).

individual need.<sup>187</sup> Identifying a disabled individual's priorities and purpose for building her own savings is important when determining the best financial tool under the circumstances.<sup>188</sup> For instance, some people may prioritize independence over high asset value, whereas others desire assistance with asset management.<sup>189</sup> The ABLE accounts undoubtedly represent a form of freedom that has never been available to disabled individuals, but, nevertheless, the ABLE program may not be the perfect tool for everyone's specific needs and abilities.<sup>190</sup>

The ABLE account is similar to self-settled trusts in that assets in both can be spent on broad types of expenses that benefit the disabled individual and relate to the individual's disability.<sup>191</sup> Additionally, the ABLE program similarly places limitations on an account holder's expenditure of money on housing.<sup>192</sup> Such spending for housing purposes may be counted as a resource and, thus, puts the disabled individual at risk of losing SSI benefits, whether she is saving money in a self-settled trust or ABLE account.<sup>193</sup> Moreover, both of these savings tools give the disabled individual great discretion when spending her assets while also implementing a comparable restriction on purchases using SSI and Medicaid benefits.<sup>194</sup>

However, the ABLE accounts hold a considerable advantage over self-settled trusts in the realm of taxation.<sup>195</sup> The income of a self-settled trust is taxed because the disabled individual contributes her own funds to the trust.<sup>196</sup> When the trust assets are modest, the disabled

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<sup>187</sup> See *The Pros and Cons of ABLE Accounts*, SPECIAL NEED ANSWERS, <https://specialneedsanswers.com/the-pros-and-cons-of-able-accounts-15004> (last modified Mar. 30, 2016).

<sup>188</sup> See *id.*

<sup>189</sup> See *id.*

<sup>190</sup> See *id.*

<sup>191</sup> See discussion of qualified disability expenses in Section V.B.1 Qualified Disability Expenses.

<sup>192</sup> See discussion of qualified disability expenses in Section V.B.1 Qualified Disability Expenses.

<sup>193</sup> See discussion of qualified disability expenses in Section V.B.1 Qualified Disability Expenses.

<sup>194</sup> See discussion of qualified disability expenses in Section V.B.1 Qualified Disability Expenses.

<sup>195</sup> M&LAdmin4, *supra* note 2.

<sup>196</sup> Dennis Sandoval, *Taxation of Special Needs Trust*, SPECIAL NEEDS ALLIANCE, <https://www.specialneedsalliance.org/wp-content/uploads/2016/04/Taxation-of-Special-Needs-Trust.pdf> (last visited June 18, 2018). Although "[f]or income tax purposes, the self-settled pooled special needs trust share simply doesn't exist," the disabled individual may still

individual will generally incur a small income tax liability.<sup>197</sup> On the other hand, the ABLE Act practically eliminates taxation issues.<sup>198</sup> At its core, the ABLE program is an advantaged savings tool because the account can “grow tax-free.”<sup>199</sup> ABLE account holders can, thus, contribute to or draw money from the account without concern about taxation, a benefit to disabled individuals’ building a future financial security net.<sup>200</sup>

The ABLE account’s tax exemption is not free from exceptions.<sup>201</sup> An ABLE account holder who plans to retain the tax advantage is limited to an annual contribution of fifteen thousand dollars.<sup>202</sup> This annual contribution cap may make a self-settled trust a more desirable savings option for a disabled individual who intends to deposit more than fifteen thousand dollars per year.<sup>203</sup> That same individual might opt for opening a self-settled trust if she has, or expects to have, a savings greater than one hundred thousand dollars in total.<sup>204</sup> Because an ABLE account in excess of one hundred thousand dollars results in a suspension of SSI benefits, a self-settled trust for larger amounts would be advisable.<sup>205</sup>

Bi-partisan lawmakers in the United States Senate and United States House of Representatives introduced ABLE 2.0 on April 4, 2017, which is a “package of bills” that intend to ease some of the limitations of the ABLE Act of 2014.<sup>206</sup> Among these bills is the ABLE to Work Act of 2017, which would allow ABLE account

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need to file taxes individually, “including any income and deductible expenses.” Robert Fleming, *Taxation of Pooled Special Needs Trusts*, FLEMING & CURTI, P.L.C. (Sept. 22, 2013), <https://www.elder-law.com/taxation-of-pooled-special-needs-trusts/>.

<sup>197</sup> See Sandoval, *supra* note 196. In such an instance, the disabled individual may advantageously qualify for further income tax deductions when she may “have large medical expenses.” Sandoval, *supra* note 196.

<sup>198</sup> *The Pros and Cons of ABLE Accounts*, *supra* note 187.

<sup>199</sup> See *The Pros and Cons of ABLE Accounts*, *supra* note 187.

<sup>200</sup> See Levine, *supra* note 61.

<sup>201</sup> See *SI 01130.740 Achieving a Better Life Experience (ABLE) Accounts*, PROGRAM OPERATIONS MANUAL SYS. (Apr. 2, 2018), <https://secure.ssa.gov/poms.nsf/lnx/0501130740>.

<sup>202</sup> *Id.*

<sup>203</sup> See *The Pros and Cons of ABLE Accounts*, *supra* note 187.

<sup>204</sup> See *The Pros and Cons of ABLE Accounts*, *supra* note 187.

<sup>205</sup> *SI 01130.740*, *supra* note 201. Medicaid coverage will continue while an ABLE account holder is on suspension due to an excess of funds in the account, and the individual’s eligibility for SSI will not terminate after 12 months of continuous suspension. *SI 01130.740*, *supra* note 201.

<sup>206</sup> Michelle Diamant, *Congress Weighs Expanding ABLE Act*, DISABILITY SCOOP (Apr. 10, 2017), <https://www.disabilityscoop.com/2017/04/10/congress-weighs-expanding-able-act/23557/>.

holders who “work and earn income, but do not participate in an employer’s retirement plan,” to save more than the restricted contribution limit per year as motivation to seek employment.<sup>207</sup> Although the bill is still in committee, if enacted, ABLE account holders would have the opportunity to contribute fifteen thousand dollars plus “an amount equal to the poverty line for a one-person household” per year.<sup>208</sup>

Although the ABLE 2.0 package of bills awaits legislative passage, President Trump’s Tax Cuts and Jobs Act of 2017 introduced some positive changes to the ABLE Act.<sup>209</sup> Primarily, the Act increased the ABLE account contribution limit from fourteen thousand to fifteen thousand dollars; in 2017, and when the ABLE Act was first enacted, the contribution threshold of an ABLE account was fourteen thousand dollars.<sup>210</sup> Additionally, two of the bills included in ABLE 2.0 provide for “enhancements and added flexibility” to the ABLE program.<sup>211</sup> As of 2018, the ABLE to Work Act, the first bill in ABLE 2.0, provides that an ABLE account holder who works would enjoy an “increased contribution limit” if she puts at least part of her earnings in her ABLE account.<sup>212</sup> The second ABLE bill found in the tax legislation, the ABLE Financial Planning Act, qualifies the transfer of money between a 529A college savings account and an ABLE account; this improvement reflects a slow growth in flexibility of the ABLE program, in which such rollover funds between these disparate savings accounts would not result in a penalty.<sup>213</sup>

Passage of ABLE 2.0 would encourage increased growth in ABLE accounts through hard-earned money and financial planning.<sup>214</sup> Thus, the ABLE account is preferable to self-settled trusts for disabled individuals who desire the opportunity to gain greater independence

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<sup>207</sup> See *Achieving A Better Life Experience (ABLE) Act Overview*, NAT’L DOWN SYNDROME SOC’Y, <http://www.ndss.org/advocate/national-advocacy-public-policy/achieving-a-better-life-act-experienceable-act/> (last visited Aug. 13, 2018).

<sup>208</sup> ABLE to Work Act of 2017, H.R. 1896, 115th Cong. (2017).

<sup>209</sup> See *How Does the New Tax Bill (H.R.1) Impact ABLE Accounts?*, ABLENOW (Jan. 2, 2018), <https://www.able-now.com/resources/news/how-does-the-new-tax-bill-hr-1-impact-able-accounts>.

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

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

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

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

<sup>214</sup> See Michelle Diamant, *Tax Law Brings ABLE Changes, Future Worries*, DISABILITY SCOOP (Jan. 9, 2018), <https://www.disabilityscoop.com/2018/01/09/tax-law-able-future-worries/24560/>.

managing personal finances despite ever-present pecuniary limitations.<sup>215</sup> Self-settled trusts that fall within the SSA exception, thus, protecting benefit eligibility, prevent the disabled individual from having any power over the trust assets.<sup>216</sup> Although the disabled individual is the beneficiary of the self-settled trust and can request a distribution of trust assets to use for her benefit, the trustee ultimately holds the legal title and control.<sup>217</sup> The disabled individual who has an ABLÉ account “calls the shots” as legal owner of the account.<sup>218</sup> However, this kind of control over finances may not be for everyone, especially given the lack of clarity of what a QDE is and the desire to avoid a ten-percent penalty.<sup>219</sup> Some disabled individuals can greatly benefit from, and may also prefer, the support and reliance on a third-party to help manage personal finances in a self-settled trust.<sup>220</sup>

In addition to having legal authority over the assets, a disabled individual, in theory, can more easily establish an ABLÉ account which can be “set up with a local financial institution.”<sup>221</sup> Self-settled trusts require careful planning with an attorney who is experienced and knowledgeable in drafting the complex and precise self-settled trust within the parameters of the SSA.<sup>222</sup> Therefore, it is advisable that disabled individuals and their family seek the guidance of an attorney in deciding which savings tool is best suited for personal needs.<sup>223</sup> A disabled individual is not bound to one savings tool over the other; the disabled individual may open her own ABLÉ account while parents and grandparents contribute their own funds to a third-party trust for the benefit of their disabled family member.<sup>224</sup>

Although it has been four years since the ABLÉ Act’s passage, failure to seek an attorney regarding the multitude of financial savings options continues to lead families astray. Gumerove frequently finds families and disabled individuals misusing ABLÉ accounts because of

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<sup>215</sup> *The Pros and Cons of ABLÉ Accounts*, *supra* note 187.

<sup>216</sup> See discussion of pooled trusts *supra* notes 119-25 and accompanying text.

<sup>217</sup> See discussion of pooled trusts *supra* notes 119-25 and accompanying text. See also *supra* note 86 and accompanying text.

<sup>218</sup> See *The Pros and Cons of ABLÉ Accounts*, *supra* note 187.

<sup>219</sup> See discussion of qualified disability expenses *supra* note 174 and accompanying text.

<sup>220</sup> See *The Pros and Cons of ABLÉ Accounts*, *supra* note 187.

<sup>221</sup> Rephan & Groshek, *supra* note 64, at 991.

<sup>222</sup> *ABLE Accounts and SNTs*, *supra* note 118.

<sup>223</sup> See *ABLE Accounts and SNTs*, *supra* note 118.

<sup>224</sup> See *ABLE Accounts and SNTs*, *supra* note 118.

an absence of information provided by legislators and policymakers.<sup>225</sup> A common error Gumerove sees within her practice is the use of ABLE accounts as a third-party savings account, in which a parent or other family member places her own money in an ABLE account for use by the special needs individual.<sup>226</sup> This is a detrimental practice because the remaining money in the ABLE account will go back to the State, under the Medicaid payback provision, upon the death of the disabled individual.<sup>227</sup> Thus, seeking advice from an attorney while in the midst of future financial planning with a disabled individual can aid in preventing the spread of misinformation and erroneous use of ABLE accounts.<sup>228</sup>

Receiving counsel from a specialized attorney is highly encouraged, though not required, when organizing a disabled individual's finances because not all persons with disabilities are entitled to open an ABLE account.<sup>229</sup> Unfortunately, a disabled individual will lose the option of opening an ABLE account if the onset of her disability was after her twenty-sixth birthday, whereas self-settled trusts have no such age restriction.<sup>230</sup> The Arc<sup>231</sup> specifically supports the passage of the ABLE Age Adjustment Act because of the apparent lack of a "philosophical basis for limiting the program to those disabled before the age of 26."<sup>232</sup> Many disabled individuals "who advocated for the law" are consequently ineligible for the ABLE program due to the age restriction.<sup>233</sup> Although this limitation arguably minimizes the "fiscal impact" of passing such a tax-exempt savings

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<sup>225</sup> Interview with Sandra Gumerove, Esq., *supra* note 19.

<sup>226</sup> Interview with Sandra Gumerove, Esq., *supra* note 19.

<sup>227</sup> See Tax Increase Prevention Act § 529A(f).

<sup>228</sup> See *National Policy Matters: ABLE Accounts for People with Disabilities*, ARC, at 13 (Dec. 2016), [https://www.thearc.org/file/documents\\_publications/National-Policy-Matters-ABLE-Act.pdf](https://www.thearc.org/file/documents_publications/National-Policy-Matters-ABLE-Act.pdf).

<sup>229</sup> See *supra* note 6 and accompanying text.

<sup>230</sup> See 26 U.S.C.S. § 529A(e)(1)(A) (LexisNexis 2018); see also *The Pros and Cons of ABLE Accounts*, *supra* note 187.

<sup>231</sup> The Arc, based out of Washington, D.C., is a widely known nonprofit organization that has spent over sixty-five years protecting and advocating for "people with intellectual and developmental disabilities, as well their parents and siblings." *History of the Arc: The Power of Parents*, ARC, <https://www.thearc.org/who-we-are/history> (last visited June 18, 2018).

<sup>232</sup> Mike Nagel, *The Arc Blog: The Arc on the Reintroduction of ABLE Act Improvement Bills*, ARC (Apr. 24, 2017), <https://blog.thearc.org/2017/04/24/arc-reintroduction-able-act-improvement-bills/>.

<sup>233</sup> *Id.*

program, congressional leaders have expressed commitment to correcting the eligibility age through passage of the Adjustment Act.<sup>234</sup>

Among the several bills included in the ABLE 2.0 legislation, the Adjustment Act raises the age of disability onset from twenty-six to forty-six.<sup>235</sup> The ABLE National Resource Center, another renowned disability advocacy organization, also supports the passage of this bill because of the unfavorable impact of the ABLE Act's age restriction on a majority of disabled Americans.<sup>236</sup> For example, individuals who live with debilitating conditions like multiple sclerosis and Lou Gehrig's disease, as well as many injured military veterans, are typically not qualified to open an ABLE account because onset typically occurs later in life after twenty-six years of age.<sup>237</sup> Administrators at the ABLE National Resource Center believe that this raise-the-age bill "has the greatest potential" to "strengthen the ABLE program" because it will broaden the program's application and reach, allowing many who were disqualified because of an arbitrary age restriction to "cover the costs of short, medium and long-term disability-related expenses."<sup>238</sup> Senior Public Policy Advisor at the National Disability Institute and Co-Chair of the Consortium for Citizens with Disabilities Task Force on Financial Security, Chris Rodriguez, regretfully reflects on the "last-minute-addition of the age criteria" because it was understood to be a temporary "concession" by lawmakers to disability advocacy groups for passage of the Act, one which would quickly be changed upon the Act's passage.<sup>239</sup> However, this fiscally conservative compromise led to the ineligibility of many disability rights advocates, as well as other disabled Americans, "who championed the ABLE Act."<sup>240</sup> Furthermore, raising the age of

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<sup>234</sup> *Id.*

<sup>235</sup> See ABLE Age Adjustment Act, H.R. 1874, 115th Cong. (2017). The third proposed bill in ABLE 2.0 is the ABLE Financial Planning Act which would also reduce the age restriction of disability onset, allowing individuals and families who already established a 529 college savings account, prior to any disability, to transfer assets into an ABLE account upon diagnosis of a disability later in life. See ABLE Financial Planning Act, H.R. 1897, 115th Cong. (2017).

<sup>236</sup> See *The ABLE Act: A Progress Report*, ABLE NAT'L RESOURCE CTR. (Dec. 4, 2017), <http://www.ablenrc.org/sites/default/files/docs/resource/ABLE%20Briefing%20Master%20%28Final%20Final%29.pdf>.

<sup>237</sup> *Id.*

<sup>238</sup> *Id.*

<sup>239</sup> Michelle Diamant, *Proposed Changes to ABLE Act Draw Opposition*, DISABILITY SCOOP (Oct. 6, 2016), <https://www.disabilityscoop.com/2016/10/06/proposed-changes-able-opposition/22843/>.

<sup>240</sup> *Id.*



eligibility from twenty-six to forty-six years of age is a primary motivation for continued advocacy for reform of the fairly new ABLE program; unless the program's sustainability is at risk, and without an explicit showing of the fiscal benefits, maintaining the program's age restriction remains arbitrary and unjust.<sup>241</sup>

In addition to the age restriction of the ABLE program, ABLE accounts are increasingly limited given that they can only be funded with cash, and the account assets cannot be used to secure a loan; each of these limitations gives self-settled trusts the appearance of being the more flexible savings tool.<sup>242</sup> A disabled individual is advised to use a trust if she wants a more complex savings plan or to invest in stocks, real estate, or other forms of property.<sup>243</sup> Thus, the ABLE Act, similar to most pieces of legislation that promote public policy, is advantageous for some and impractical for others.<sup>244</sup>

## VI. CONCLUSION

The ABLE Act provides not merely an innovative savings tool for disabled individuals, but also demonstrates greater public understanding of the financial needs of this population of Americans.<sup>245</sup> The ABLE National Resource Center describes the ABLE Act as recognizing “the extra and significant costs of living with a disability” that are not adequately met by government assistance programs.<sup>246</sup> If a disabled individual does not have the means to hire an estate planning attorney to establish a self-settled trust, she must essentially stay poor to remain eligible for SSI and Medicaid benefits.<sup>247</sup>

The ABLE Act provides a disabled individual with a more cost efficient and uncomplicated method to save money for her future.<sup>248</sup> It is a mechanism to help disabled individuals achieve their own American dream, whether that encompasses “more choices about where to live” or “[i]mproved physical and mental health as a result of

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<sup>241</sup> See Nagel, *supra* note 232.

<sup>242</sup> See 26 U.S.C.S. § 529A(b)(2)(A), (5) (LexisNexis 2018).

<sup>243</sup> See *ABLE Accounts and SNTs*, *supra* note 118.

<sup>244</sup> See *The Pros and Cons of ABLE Accounts*, *supra* note 187.

<sup>245</sup> See *What are ABLE Accounts?*, *supra* note 141.

<sup>246</sup> *What are ABLE Accounts?*, *supra* note 141.

<sup>247</sup> See *What are ABLE Accounts?*, *supra* note 141.

<sup>248</sup> See Levine, *supra* note 61.

reduced financial stress.”<sup>249</sup> Overall, ABLE accounts represent a stepping-stone to financial success and independence for thousands of disabled Americans.<sup>250</sup>

Nevertheless, the ABLE account is not the quintessential savings tool for everyone, nor is the ABLE Act a perfect piece of legislation.<sup>251</sup> Disability advocates, as well as community members and families, should remain hopeful regarding the passage of the ABLE 2.0 bills that would increase both the participation of ABLE account holders through raise-the-age legislation and flexibility in use of ABLE account funds.<sup>252</sup> Disabled individuals who rely more heavily on community support systems or have greater assets may prefer a trust.<sup>253</sup> Additionally, through a growth in use of ABLE accounts and development of a body of case law, lawyers, financial planners, and account holders will achieve a better understanding of the types of expenses which qualify as a QDE.<sup>254</sup> Despite its limitations and restrictions, the ABLE program provides what no previous legislation has yet offered, including new opportunities of independence for disabled individuals through personal financial management.<sup>255</sup>

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<sup>249</sup> *Achieving Financial Independence with Ticket to Work and an ABLE Account*, SOC. SECURITY ADMIN. (Oct. 25, 2017, 3:00 PM), <https://choosework.ssa.gov/Assets/uploads/webinars/2017/2017-10-25-WISE-Achieving-Financial-Independence-Presentation.pdf>.

<sup>250</sup> *See id.*

<sup>251</sup> *The Pros and Cons of ABLE Accounts*, *supra* note 187.

<sup>252</sup> Amelis Long, *An Update on ABLE 2.0: Bipartisan Legislation to Enhance ABLE Accounts*, ENABLE SAVINGS PLAN (Apr. 25, 2017), <https://www.enablesavings.com/home/blog-list/article-post/blog/an-update-on-able-20-bipartisan.html>.

<sup>253</sup> *See* Levine, *supra* note 61.

<sup>254</sup> *See* Harris & Barnett, *supra* note 174, at 3.

<sup>255</sup> *Achieving Financial Independence*, *supra* note 249.