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### Disability Benefits as Poverty Law: Revisiting the "Disabled State"

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## ARTICLE

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### DISABILITY BENEFITS AS POVERTY LAW: REVISITING THE “DISABLED STATE”

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KAREN M. TANI<sup>†</sup>

*This essay uses the history of Sullivan v. Zebley, a famous disability benefits case, to revisit political scientist Deborah Stone’s argument in THE DISABLED STATE (1984). Observing that “[m]edical certification” of disability had “become one of the major paths to public aid in the modern welfare state,” Stone wondered whether policymakers were asking the “concept of disability” to do too much and whether they were sufficiently alert to the concept’s tendency to expand over time.*

*Filed in 1983 and decided by the Supreme Court in 1990, Sullivan v. Zebley is an example of those expansionary pressures and their results. When the Social Security Administration stopped making Supplemental Security Income payments to 5-year-old Brian Zebley, despite his continuing and severe disabilities, lawyers at the legal aid organization Community Legal Services filed a class action. They contended that not only had the Social Security Administration erred in Zebley’s case, but also that the Agency’s overall eligibility determination process for child disability benefit claimants was too restrictive. The plaintiffs’ ultimate victory before the Supreme Court, and the surprising allies it amassed along the way, illustrate how readily many actors and institutions connected disability to deservingness and embraced disability as a distributional device in the late twentieth century. The post-Zebley backlash against child claimants, however, illustrates how closely the public continued to associate disability with deviance and fraud, especially when they observed take-up*

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<sup>†</sup> J.D., Ph.D. (History); Seaman Family University Professor, University of Pennsylvania. Jonathan Stein, Tom Sutton, and Richard Weishaupt generously offered firsthand recollections of the *Zebley* litigation and related context. Conversations with Ruth Colker, Doron Dorfman, Jasmine Harris, Nate Holdren, Daniel Walters, and the faculty of the Michael E. Moritz School of Law enriched my understanding of the stakes. Leticia Salazar and Amanda Smith provided excellent research assistance. Paul Riermaier and Patrick Kerwin supplied invaluable assistance with archival sources and other hard-to-find documents. The careful and thoughtful editors of the *University of Pennsylvania Law Review* made this essay clearer and more persuasive. All errors are my own.

among Black citizens. Negative perceptions contributed to the program's reform in 1996. Congress preserved the new path to eligibility that Zebley created, but also narrowed it. Decisional power, meanwhile, remained in the hands of medical gatekeepers.

*This essay casts the Zebley story as one of triumph and tragedy. It was a triumph for poverty lawyers and their clients, who, under hostile circumstances, pressed for a more generous and life-affirming social welfare system. They saw that the boundaries of disability were malleable and they pushed on them. But it remains a tragedy that the best route to subsistence for so many children has further entangled disability with medicalization, suspicion, and surveillance.*

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## INTRODUCTION

"What seems to us so obvious now—that there is a state of being called 'disabled' which . . . requires special treatment—is a fairly modern perception."<sup>1</sup>

"If disability means anything it means this."<sup>2</sup>

Of all the things President Ronald Reagan wanted to change when he arrived in Washington, D.C., the federal Legal Services Corporation<sup>3</sup> was high on his list. His time as governor of California had convinced him that

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1 DEBORAH STONE, *THE DISABLED STATE* 26 (1984).

2 Interview with Thomas Sutton (July 18, 2019) (on file with author) [hereinafter Sutton Interview]. Sutton was a lawyer in the *Zebley* case. See 493 U.S. 521 (1990).

3 The Legal Services Corporation was the Nixon-era successor to the War on Poverty's pathbreaking Legal Services Program. ALAN HOUSEMAN & LINDA E. PERLE, *SECURING EQUAL JUSTICE FOR ALL: A BRIEF HISTORY OF CIVIL LEGAL ASSISTANCE IN THE UNITED STATES* 11, 21-22 (2018), [https://www.clasp.org/sites/default/files/publications/2018/05/2018\\_securingequaljustice.pdf](https://www.clasp.org/sites/default/files/publications/2018/05/2018_securingequaljustice.pdf) [<https://perma.cc/68X2-287U>] (describing the creation of the Legal Services Program, the efforts to weaken the program during the Nixon Administration, and the subsequent creation of the Legal Services Corporation, a "private, nonprofit corporation" that receives annual appropriations from Congress but is formally outside of government).

federally funded legal aid lawyers were using lawsuits to advance radical political ideas and to stymie conservative reforms.<sup>4</sup> A related target was the welfare state, which Reagan had long criticized for fostering dependency and wasting taxpayer dollars.<sup>5</sup> He aimed to reduce the number of Americans who relied on federally funded social welfare programs and shift governmental power into the hands of people who shared his views. Other institutions of American government seemed amenable to his plans, including a Republican-dominated Senate and a U.S. Supreme Court that had shifted markedly rightward since Chief Justice Earl Warren's retirement.

It was all the more surprising, then, that through *Sullivan v. Zebley*,<sup>6</sup> a lawsuit filed in 1983, legal aid lawyers managed to significantly expand the welfare state, at least for children. They did so not by attempting to expand Aid to Families with Dependent Children ("AFDC"),<sup>7</sup> the public assistance program that had been so central to legal aid efforts in the 1960s and 1970s.<sup>8</sup> Rather, they sought, and won, a broader legal interpretation of who counted as "disabled." Via that aperture, many more children became legally entitled to government income support.

<sup>4</sup> See, e.g., Stephen Wermiel, *Government-Paid Legal Services for the Poor Stir Local Contention and a Growing National Debate*, WALL ST. J., June 12, 1981, at 42 (quoting an attorney from Reagan's budget office as stating that "[w]hat [the office] dislike[s] is the use of clients as a means of furthering broad political strategies in court" and "that political, public-interest-type lawyering"); Stuart Taylor Jr., *Legal Aid for the Poor: Reagan's Longest Brawl*, N.Y. TIMES, June 8, 1984, at A16 (describing Reagan as "an adversary of liberal activist legal aid lawyers"). Reagan's experiences with California Rural Legal Assistance appear to have been particularly influential in his thinking. See, e.g., James E. Bylin, *Reagan vs. CRLA: Did Both Win?*, WALL ST. J., July 20, 1971, at 10 (describing developments in what became a "long feud" between Reagan and California Rural Legal Assistance); Michael S. Serrill, *An Organization at War with Itself*, TIME, Oct. 3, 1983, at 83 (attributing "Reagan's animosity" toward the Legal Services Corporation to "the late '60s when as Governor of California he was unable to restrict some state social programs because of legal aid lawsuits").

<sup>5</sup> See Mark Neal Aaronson, *Representing the Poor: Legal Advocacy and Welfare Reform During Reagan's Gubernatorial Years*, 64 HASTINGS L.J. 933, 1007-08 (2013) (describing how Reagan framed "welfare reform" in opposition to "tax relief" and how he advocated for "compulsory employment for those capable of working"). Reagan's state-level welfare reform efforts created further tension with legal aid lawyers. *Id.* at 1013-14 (describing the "complicated chess game" between the Reagan administration, which allegedly transformed California's Department of Social Welfare into a powerful vehicle for pursuing Reagan's aims, and legal aid lawyers, who responded in-kind by creating a "law reform unit . . . to oversee welfare advocacy" in California).

<sup>6</sup> The case began as *Zebley v. Heckler*. See 642 F. Supp. 220 (E.D. Pa. 1986), *vacated sub nom. Zebley ex rel. Zebley v. Bowen*, 855 F.2d 67, 69 (3d Cir. 1988), *aff'd sub nom. Sullivan v. Zebley*, 493 U.S. 521, 541 (1990).

<sup>7</sup> Before 1968, the AFDC program was called Aid to Dependent Children ("ADC").

<sup>8</sup> See MARTHA F. DAVIS, *BRUTAL NEED: LAWYERS AND THE WELFARE RIGHTS MOVEMENT, 1960-1973* at 20-21 (1993) (describing efforts by legal aid lawyers to make the ADC/AFDC program more generous and its administration more fair); KAREN M. TANI, *STATES OF DEPENDENCY: WELFARE, RIGHTS, AND AMERICAN GOVERNANCE, 1935-1972* at 200-02 (2016) (reviewing some of the lawsuits that legal aid lawyers pursued on behalf of ADC/AFDC recipients).

The program at the heart of that case, Supplemental Security Income (“SSI”), is often misunderstood. Public commentators tend to conflate it with Social Security Disability Insurance (“SSDI”) and to refer to recipients of either program as being “on disability.”<sup>9</sup> But whereas SSDI is a contribution-based program, akin to what is popularly known as Social Security (Old-Age Insurance), SSI is a need-based program of income support.<sup>10</sup> It benefits people who are very poor and whom the government deems exempt from the obligation of labor—namely, people with serious, long-term disabilities, and people over the age of 65.<sup>11</sup> It is the federally funded, federally administered<sup>12</sup> successor to federal-state programs of Old-Age Assistance, Aid to the Blind, and Aid to the Permanently and Totally Disabled. Phrased differently, when Congress created SSI in 1972, it replaced all the major New Deal-era “welfare” programs other than the then-embattled AFDC program (now called Temporary Aid to Needy Families, or TANF).<sup>13</sup>

But SSI also subtly expanded one of those programs—the one aimed at “the permanently and totally disabled.”<sup>14</sup> Historically, policymakers and the broader public considered AFDC *the* income support program for children;

<sup>9</sup> See, e.g., Terrence McCoy, *Disabled, or Just Desperate?*, WASH. POST (Mar. 30, 2017), <https://www.washingtonpost.com/sf/local/2017/03/30/disabled-or-just-desperate/> [<https://perma.cc/DXP5-3LUQ>] (using the term “on disability” to refer to individuals who receive benefits through the SSI program, the SSDI program, or both).

<sup>10</sup> Compare Mark Duggan, Melissa S. Kearney, & Stephanie Rennane, *The Supplemental Security Income Program*, in 2 ECONOMICS OF MEANS-TESTED TRANSFER PROGRAMS IN THE UNITED STATES 50 (Robert A. Moffitt ed., 2016) (noting that SSDI eligibility is based on work history and that the SSDI program is “financed by payroll taxes and the Social Security trust fund”), with *id.* at 1 (“Supplemental Security Income (SSI) is a federally administered, means-tested program that provides . . . benefits to low-income individuals who meet a categorical eligibility requirement.”). For further illustration of the differences between programs, see also SSA, ANNUAL STATISTICAL SUPPLEMENT TO THE SOCIAL SECURITY BULLETIN 7-10 (2021), <https://www.ssa.gov/policy/docs/statcomps/supplement/2021/supplement21.pdf> [<https://perma.cc/CZT2-R9W4>], which notes that eligibility for and payments from the Old-Age, Survivors, and Disability Insurance program depend on the covered worker’s contributions to the program.

<sup>11</sup> See DUGGAN ET AL., *supra* note 10, at 32 (“The SSI eligibility is based in part on an applicant’s successful demonstration of a disability that renders the individual unable to perform adequately in the labor market.”).

<sup>12</sup> State administrators play a role in evaluating eligibility, but apply federally created standards. See *id.* at 6-7 (describing the “team” of “state disability examiner[s]” responsible for evaluating eligibility).

<sup>13</sup> *Id.* at 5 (“The federal Supplemental Security Income program . . . replaced a combination of approximately 1,350 different state and local programs that provided benefits to low-income aged, blind, and disabled individuals.”); see also *id.* at 18, 43-44 (describing the interaction between the SSI and AFDC/TANF programs).

<sup>14</sup> Social Security Amendments of 1972, Pub. L. No. 92-603, 86 Stat. 1329 (repealing Title XIV of the Social Security Act, which had provided for “Grants to States for Aid to the Permanently and Totally Disabled,” and explaining that an individual who met previous state definitions of “permanently and totally disabled” would automatically meet the new SSI program’s definition of “disabled”).

when they thought of disability-based income support, they imagined adults as the beneficiaries.<sup>15</sup> But from the start, SSI did cover some children. The law provided that a child claimant should receive benefits if the child's medical impairment was comparable in severity to that of a qualifying adult.<sup>16</sup> The *Zebley* case, filed on behalf of five-year-old Brian Zebley and similarly situated children, challenged federal administrative rules for implementing this child-focused language. Zebley's lawyers argued that an administrative misinterpretation of the governing statute (an amendment to the Social Security Act) had denied thousands of children their legal entitlements.<sup>17</sup>

The case eventually made it all the way to the U.S. Supreme Court, where, by a 7-to-2 vote, the Court sided with the plaintiffs.<sup>18</sup> At the time, it appeared to be the largest class action ever won against the Social Security Administration (SSA).<sup>19</sup> And it had a stunning effect on the landscape of public benefits. As a result of *Zebley*, the SSA reviewed hundreds of thousands of previous application denials and benefit termination decisions and issued billions of dollars in back payments.<sup>20</sup> While one of Zebley's attorney's acted as "de facto supervisor" of the children's disability program,<sup>21</sup> the SSA also collaborated with the plaintiffs' legal team to rewrite its policies for evaluating child claimants.<sup>22</sup> In 1989, the year before the Court decided *Zebley*, 264,000 children were receiving SSI benefits. By 1996, that number

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<sup>15</sup> Policymakers in fact routinely referred to SSI's predecessor programs as "the adult categories." See SSA, ANNUAL REPORT OF THE SUPPLEMENTARY SECURITY INCOME PROGRAM 2 (2013) (explaining how SSI replaced programs for "needy aged, blind, or disabled individuals," groups collectively called the "adult categories").

<sup>16</sup> 42 U.S.C. § 1382(c)(a)(3)(A) (1988).

<sup>17</sup> See *Zebley v. Heckler*, 642 F. Supp. 220, 221 (E.D. Pa. 1986). For a more precise explanation of the argument, see discussion *infra* Section I.

<sup>18</sup> *Sullivan v. Zebley*, 493 U.S. 521, 541 (1990).

<sup>19</sup> See Jack Borden, *Unequal Justice*, CITY PAPER, May 8, 1992, Box 548, Harry A. Blackmun Papers, MSS84430 (on file with Library of Congress). The case also broke records for legal services. See Allen Redlich, *Who Will Litigate Constitutional Issues for the Poor?*, 19 HASTINGS CONST. L.Q. 745, 774 (1992) (noting that *Sullivan v. Zebley* "involved more money than any case in legal services' history" (citations omitted)).

<sup>20</sup> See Bob Woodward & Benjamin Weiser, *Costs Soar for Children's Disability Program*, WASH. POST, Feb. 4, 1994, at A13 (stating that the ruling in *Zebley* cost "billions" in "new entitlement payments").

<sup>21</sup> See *id.* ("[Jonathan] Stein's legal victory gave him enormous leverage over the children's disability program. According to federal and state officials, he became the program's de facto supervisor.").

<sup>22</sup> See E-mail from Jonathan Stein to Karen Tani (Dec. 9, 2021, 11:06 PM) (on file with author) (explaining that after the Supreme Court's decision, as part of reaching a final settlement, the plaintiffs' legal team negotiated with the Agency over "an interim final regulation that would be the new governing law"); see also Stipulation and Order at 4, *Zebley v. Sullivan*, 493 U.S. 521 (1990) (No. 83-3314) (memorializing the Social Security Administration's commitment to revise the children's disability standard and to "consult with" and solicit comments from plaintiffs' counsel as part of that revision process).

had risen to 955,000, and many observers credited *Zebley* (although as this essay shows, other factors mattered, too).<sup>23</sup>

Eventually, backlash arose, but not before an array of “strange bedfellows” had lined up behind the idea that *disability*, understood in an individualized, medical manner, was the right way to think about one of the era’s most urgent social and political questions: who deserved government assistance? Poverty alone was not a workable criterion—not in a country that had historically associated poverty with moral failure and that had just witnessed an allegedly disastrous “war on poverty.”<sup>24</sup> The concept of disability, however, appealed to a range of people, especially once it became clear that the federal government (as opposed to state and local governments) would foot the bill for people who fell into this category.<sup>25</sup> In the words of political scientist Deborah Stone, from her landmark 1984 book *The Disabled State*, Americans turned to the concept of disability “to resolve the issue of distributive justice.”<sup>26</sup>

This essay recounts the history of the *Zebley* litigation, with an emphasis on the coalition that legal aid lawyers catalyzed and the broader definition of disability that they helped embed in U.S. law and policy. Part I briskly reviews the history of the SSI kids program and explains the origins of the *Zebley* litigation. Part II explains how and why the *Zebley* litigation attracted a renowned group of poverty lawyers. Part III documents the interests that coalesced around the plaintiff class as *Zebley* headed to the Supreme Court and also summarizes the Court’s decision. Part IV analyzes *Zebley*’s aftermath: the SSI kids program expanded significantly, resulting in backlash and retrenchment—but not a return to the status quo ante.

A concluding section, Part V, connects this history to an unresolved tension in American law, and in American society more generally: the tension between reducing human beings to their economic value (in pursuit of goals like economic health and productivity) and fostering a climate that is genuinely inclusive, in which belonging does not turn on skin color, biological sex, inherited wealth, or other nonvolitional traits. From a pragmatic

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<sup>23</sup> Mary C. Daly & Mark Duggan, *When One Size Does Not Fit All: Modernizing the Supplemental Security Income Program*, 686 ANNALS AM. ACAD. POL. & SOC. SCI. 229, 235-36 (2019).

<sup>24</sup> The War on Poverty was heavily criticized during its time and immediately after. See THE WAR ON POVERTY: A NEW GRASSROOTS HISTORY, 1964-1980 at 6-7 (Annelise Orleck & Lisa Gayle Hazirjian eds., 2011) (describing conservative critiques of the program and complaints by local officials, as well as disappointment that the program had failed to quell urban unrest). Twenty-first century scholars have provided more nuanced assessments and noted important successes. See, e.g., *id.* at 6, 23 (acknowledging “negative and positive” legacies and noting that among the positive was cutting in half the “number of Americans living in poverty”).

<sup>25</sup> See *infra* Section III for a discussion of how the legal team in *Zebley* enlisted medical professionals, anti-abortion advocates, and state attorneys general, among others, to write amicus briefs to the Supreme Court in support of their position.

<sup>26</sup> STONE, *supra* note 1, at 13.

perspective, the SSI kids programs carved a path towards inclusion: by providing the bare means of survival, this program increased the chances that a particularly vulnerable class of children would thrive in American society. As Part IV explains, the *Zebley* litigation also subtly tugged the SSI program away from its touchstone, the labor requirements of the capitalist economy, and thereby suggested that “deservingness” need not be tethered so closely to work-specific impairments. In these ways, the *Zebley* story underscores the emancipatory possibilities of what Stone provocatively labeled “the disabled state.”<sup>27</sup>

At the same time, however, this history offers a powerful reminder of two points that the disability community has long voiced and that scholars, including Stone, have underscored. First, the SSI program has always embraced medicalized understandings of disability and thereby empowered medical gatekeepers, reinforcing the view that people who claim disability are inexpert and untrustworthy.<sup>28</sup> Government reliance on these medical gatekeepers also perpetuates the notion that only a fraction of people who claim disability are “medically worthy”; others, by extension, are unworthy and yet are nonetheless claiming public support.<sup>29</sup>

Second, the expansion of SSI, in the context of a non-universal social welfare system, has reinforced the public impression that to have a disability is to be favored, because it appears to unlock state-created privileges that nondisabled people struggle to obtain.<sup>30</sup> Yet for many people with disabilities, disability has in fact correlated with hardship and exclusion, which is why antidiscrimination laws like the Americans with Disabilities Act and Section 504 of the Rehabilitation Act exist. The link between disability and cash benefits may reinforce the unfortunate and misplaced notion that civil rights

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<sup>27</sup> *Id.* at 12-13.

<sup>28</sup> See JENNIFER L. ERKULWATER, *DISABILITY RIGHTS AND THE AMERICAN SOCIAL SAFETY NET* 225 (2006) (explaining that, under the “medical model,” “experts in medical science, not necessarily the disabled or poor themselves, [are] empowered to speak on the issue of disability determination”).

<sup>29</sup> See Rabia Belt & Doron Dorfman, *Reweighing Medical Civil Rights*, 72 *STAN. L. REV. ONLINE* 176, 178-79 (2020) (expressing concern about a tendency in American social policy to award benefits to “medically worthy individuals,” while deeming “people unable to use medical claiming” as “lazy, dependent, and shiftless”); see also STONE, *supra* note 1, at 91 (explaining how policymakers turned to clinical medicine for “a model of illness that gave legitimacy to claims for social aid” and also a method for “distinguish[ing] between genuine disability . . . and feigned disability”).

<sup>30</sup> See Emily R.D. Murphy, *Brains Without Money: Poverty as Disabling*, 54 *CONN. L. REV.* 699, 702 (2022) (observing the “divergence” between the law’s treatment of people with disabilities and people “who are merely poor,” with disability appearing to trigger rights ranging from income support to accommodations in voting and employment, while “mere poverty” appears to generate “few positive rights or negative rights”).



laws for people with disabilities are also simply a government subsidy, which therefore must be carefully policed.<sup>31</sup>

Ultimately, then, the *Zebley* story is one of “triumph and tragedy,” to borrow historian John Witt’s phrase.<sup>32</sup> It was a triumph for poverty lawyers and their clients, who, under hostile circumstances, continued to press for a more generous and life-affirming social welfare system. But it remains a tragedy that the best route to subsistence for so many children has further entangled disability with medicalization, suspicion, and surveillance.

### I. SSI FOR KIDS AND THE ORIGINS OF *SULLIVAN V. ZEBLEY*

In retrospect, it is not surprising that there was a legal dispute over the boundaries of children’s SSI. When Congress created the program via the Social Security Amendments of 1972, legislators only minimally engaged with the child-focused provision of the law. According to lore, the decision to include children among the law’s beneficiaries originated not with any legislator or political constituency, but rather with a civil servant named Tom Joe. Joe worked as an assistant to the undersecretary of the Department of Health, Education, and Welfare (“HEW”) and thus had access to the House Committee on Ways and Means.<sup>33</sup> He also knew something about children

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<sup>31</sup> For examples of discussions of the “special rights” or subsidy perception of disability civil rights, see Doron Dorfman, *Fear of the Disability Con: Perceptions of Fraud and Special Rights Discourse*, 53 L. & SOC. REV. 1051, 1054 (2019), which documents “people’s suspicions that others fake disabilities to enjoy rights and accommodations perceived as perks or special rights”, and Doron Dorfman, *[Un]Usual Suspects: Deservingness, Scarcity, and Disability Rights*, 10 U.C. IRVINE L. REV. 557, 584-85 (2020), which identifies the “special rights” perception of disability at work in the negative public response to a program at Disney theme parks that allowed disabled guests to “skip lines.”

<sup>32</sup> See John Fabian Witt, Yale L. Sch., *Garland’s Million: The Tragedy and Triumph of Legal History*, Plenary Address Before the American Society for Legal History (Nov. 17, 2021), in *Am. Soc’y Legal Hist.*, at 53:24 (observing that “[t]he law’s history records moral successes . . . and it simultaneously records tragedy,” and that historians’ “stories of compromised triumphs” help “hold at bay the specter of paralyzing disillusionment”).

<sup>33</sup> Edward D. Berkowitz & Larry DeWitt, *The Other Welfare: Supplemental Security Income and U.S. Social Policy* 34 (2013). There is a fascinating parallel here to the history of Section 504 of the 1973 amendments to the Rehabilitation Act. A forerunner to the Americans with Disabilities Act of 1990, Section 504 was essentially the disability equivalent of Title VI of the 1964 Civil Rights Act and Title IX of the Education Amendments of 1972. That is, Section 504 attached an antidiscrimination mandate to federal funds and thereby leveraged the power of the purse to combat inequality. Those who have traced the history of Section 504 describe it as the work of a small number of enterprising congressional staffers; these staffers, according to interviews conducted by Richard Scotch, added a significant antidiscrimination mandate into a complex bill and hoped it would not attract controversy. See RICHARD K. SCOTCH, *FROM GOOD WILL TO CIVIL RIGHTS: TRANSFORMING FEDERAL DISABILITY POLICY* 51-53 (2d ed. 2001).

and disability, having been blind since childhood.<sup>34</sup> And his pre-HEW work for a California legislator during Ronald Reagan's governorship taught him how to preserve, and even expand, the welfare state under hostile circumstances.<sup>35</sup> (Legend has it that by identifying an underutilized federal matching program for "social services" for "former or potential welfare recipients," Joe funneled hundreds of millions of additional federal dollars into California's social welfare programs in the late 1960s.)<sup>36</sup> Interviewed about the SSI kids program in 1994, Joe claimed that he added child-inclusive language into draft legislation at an opportune moment and then hoped his handiwork would escape controversy.<sup>37</sup>

Legislative history suggests that Joe's wish came true. At that time, the real debate among legislators was over the long-embattled AFDC program—whether it should be replaced by some version of a universal basic income (such as President Nixon's ill-fated Family Assistance Plan) or instead preserved, but made even more restrictive and work-focused.<sup>38</sup> As for the idea

<sup>34</sup> David E. Rosenbaum, *Tom Joe, 64, Policy Maker on Poverty*, N.Y. TIMES (Oct. 5, 1999), <https://www.nytimes.com/1999/10/05/us/tom-joe-64-policy-maker-on-poverty.html?searchResultPosition=1> [<https://perma.cc/FL8D-N25B>].

<sup>35</sup> *Id.* (noting that Joe had worked on the staff of the California assembly before working on welfare reform in Washington, D.C.); Interview by Larry DeWitt with Mary Ross, Advisory Council, SSA, in Washington, D.C. (Oct. 26, 1995), <https://www.ssa.gov/history/orals/maryross.html> [<https://perma.cc/SMX4-UM7E>] (describing Joe's work in the California Assembly as giving Joe "considerable background in Federal-State relations and in State finances"); W. Russell G. Byers, *City Dollars in Federal Till*, PHILA. DAILY NEWS, June 4, 1990, at 36 (emphasizing what Joe learned about federal funds from serving as a staff member for the California state assembly at a time when Governor Reagan "was trying to clamp down on social service programs").

<sup>36</sup> See, e.g., Jodie Allen, *Back Door Revenue Sharing—and On a Big Scale*, WASH. POST, Aug. 7, 1972, at A20; Byers, *supra* note 35 (describing the increase in federal funding for California's social services that Joe's innovations generated); John K. Iglehart, *Welfare Report/HEW Program Doubles in Size as Officials Scramble to Check Its Growth*, 4 NAT'L J. 1007, 1013 (1972).

<sup>37</sup> According to the interview, quoted in the *Washington Post* in 1994, Joe explained his actions as part of an "incremental strategy" to help as many low-income people as possible. Woodward & Weiser, *supra* note 20, at A13. Unfortunately, the quoted portions of the interview do not shed much additional light on Joe's motivations. In addition, the interview may have been colored by the interviewers' apparent dislike for what the SSI children's program had become by 1994. *Id.* (emphasizing SSI's "skyrocketing costs" and citing the program as an example of "what can happen when a law is enacted without much debate or study and then becomes subject to interpretation by regulators, advocates and the Supreme Court"); Interview with Jonathan Stein (Mar. 5, 2021) (on file with author) [hereinafter Stein Interview I] (noting Woodward's interest in the kind of story that might show "entitlements run amok"). For a fuller account of the legislative process that produced the SSI kids program, and one that is more alert than Woodward and Weiser to democratic engagement with Joe's proposed language, see generally Mary E. O'Connell, *Supplemental Security Income's "Dedicated Account": A Debunked Urban Legend and Twenty Years of Waste* (Ne. L. Sch. Pub. L. Paper Series, Paper No. 289, 2017), [https://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=2962370](https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2962370) [<https://perma.cc/CU7Z-5GRL>].

<sup>38</sup> On the debate over Nixon's Family Assistance Plan, see generally FELICIA KORNBLUH, *THE BATTLE FOR WELFARE RIGHTS: POLITICS AND POVERTY IN MODERN AMERICA* (2007) (documenting the forces that led to the proposal of the Family Assistance Plan and explaining why

of giving disability-based support to children, some criticism came from Senate Finance Committee Chairman Russell B. Long (D-La.),<sup>39</sup> but that criticism could easily have struck listeners as a mild reiteration of one of Long's standard anti-welfare talking points.<sup>40</sup> When it came time to vote on what became the Social Security Amendments of 1972, Long called the legislation "a good bill that every Senator can support."<sup>41</sup>

Once Congress signed the new SSI program into law, it was largely up to SSA administrators to decide how to process applications, including applications from children. Ultimately, the Agency settled on an implementation process that treated child claimants differently from their adult counterparts. To summarize in broad strokes, the Agency's practice at the time of the *Zebley* filing allowed an adult SSI claimant to establish disability via two routes, both of which treated the labor market as the ultimate touchstone. The first route involved a showing that the claimant's diagnosed impairment matched, or was the equivalent of, an item on the government's official Listing of Impairments ("the Listing"). Because the Listing set a high threshold for severity of disability, a claimant who met its terms was presumptively unemployable and therefore deserving of benefits (assuming the claimant also established economic need). The second route, which the SSA made available if the first route was unavailing, focused on the claimant's functional capacity. Pairing that functional capacity with the claimant's age, education, and work history, the question at the heart of this second route was whether the claimant could work in the national economy. If not, the claimant was eligible for SSI. (And if so, the denial of disability benefits would in theory push the claimant into the labor market, to find a job that was compatible with their capabilities.) The SSA did not offer child

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the plan failed to become law) and MARISA CHAPPELL, *THE WAR ON WELFARE: FAMILY, POVERTY, & POLITICS IN MODERN AMERICA* (2011) (detailing the criticisms from both the right and the left that doomed the Family Assistance Plan).

<sup>39</sup> According to a committee report authored by Senator Long's staff, Long believed that disabled children who needed additional support should receive that support via Medicaid, not cash assistance. DISABILITY POL'Y PROJECT, NAT'L ACAD. SOC. INS. ACADEMY, *RESTRUCTURING THE SSI DISABILITY PROGRAM FOR CHILDREN AND ADOLESCENTS* 15 (Jerry L. Mashaw, James M. Perrin & Virginia P. Reno eds., 1996).

<sup>40</sup> In 1967, for example, Senator Long infamously labeled women receiving AFDC as "female broodmares." When some of these women petitioned Congress for better treatment, he suggested that "those people" spend their time "pick[ing] up some beer cans in front of their house" rather than "imped[ing] the work of the Congress." ALICE KESSLER-HARRIS, *IN PURSUIT OF EQUITY: WOMEN, MEN, AND THE QUEST FOR ECONOMIC CITIZENSHIP IN 20TH-CENTURY AMERICA* 272-73 (2001); STAFF OF S. COMM. ON FIN., 92ND CONG., *ADDRESS OF HON. RUSSELL B. LONG 3* (Comm. Print 1971) (presenting Long's address to the Committee and assailing Nixon's proposed Family Assistance Plan as likely to exacerbate the existing "welfare mess").

<sup>41</sup> Renato Anthony DiPentima, *The Supplemental Security Income Program: A Study of Implementation* (May 9, 1984) (Ph.D. dissertation, University of Maryland) (University Microfilms International).

claimants anything resembling that second, functionality-focused route.<sup>42</sup> For them, the entire inquiry turned on how their medical impairments compared to the Listing and its strict understanding of severe disability.<sup>43</sup>

In an era in which children were not expected to work, the “Listing Only” approach to establishing disability had some logic. But it also risked the denial or withdrawal of support to children who seemed obviously and significantly disabled.<sup>44</sup> Such was the experience of Brian Zebley, the plaintiff named in the case caption. Born with brain damage, Zebley was developmentally delayed, with vision problems and muscle skeletal impairments on one side of his body.<sup>45</sup> These impairments manifested in a limp and slurred speech.<sup>46</sup> At age five, Zebley could not descend stairs independently, nor was he toilet trained.<sup>47</sup> As one of Zebley’s lawyers summarized years later, “he was a kid with massive medical problems that any lay person would recognize. If disability means anything it means this.”<sup>48</sup>

Starting in September 1980, and for the next two years, the SSA seemed to share that “lay person” view. The Agency treated Zebley as eligible for SSI and made payments to his family.<sup>49</sup> The stable income was a welcome respite

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<sup>42</sup> This is a simplified overview of the evaluation process, written to underscore the salient legal question in *Zebley*. For a more precise explanation of the disability evaluation process for adults and children at the time *Zebley* was filed, see U.S. GOV’T ACCOUNTABILITY OFF., GAO/HEHS-95-66, SOCIAL SECURITY: NEW FUNCTIONAL ASSESSMENTS FOR CHILDREN RAISE ELIGIBILITY QUESTIONS 6-8 (1995) [hereinafter NEW FUNCTIONAL ASSESSMENTS], and *Zebley v. Heckler*, 642 F. Supp. 220, 221 (E.D. Pa. 1986) (setting forth the text of the regulation that the plaintiffs challenged, including its reference to “impairment[s] listed,” and explaining the plaintiffs’ objection). On the logic behind the disability determination process, see DUGGAN ET AL., *supra* note 10, at 32 (“A key justification for a program with a categorical disability requirement is that by targeting such individuals, the program can transfer more resources to truly ‘needy’ individuals, achieving greater targeting efficiency at a lower cost of productivity efficiency.”).

<sup>43</sup> DUGGAN ET AL., *supra* note 10, at 8 (noting that, prior to the *Zebley* decision, the disability determination process for children focused on “establishing that a child applicant had a medical impairment that appeared on the SSA list of qualifying medical conditions”); HARRIETTE B. FOX & ANN GREANEY, A PRELIMINARY ASSESSMENT OF DISABLED CHILDREN’S ACCESS TO SUPPLEMENTAL SECURITY INCOME AND MEDICAID BENEFITS 59 (1988) (describing a disability determination process for children pre-*Zebley* that “ignor[ed] functional capacity” and focused solely on “meeting or equaling criteria contained in the Listing of Impairments”). For child claimants, there were technically two “[L]istings,” a general listing and a special listing of children’s impairments. See *Sullivan v. Zebley*, 493 U.S. 521, 526 (1990).

<sup>44</sup> FOX & GREANEY, *supra* note 43, at 59-61 (offering two examples of children who were severely functionally impaired and denied support under the Listing Only approach).

<sup>45</sup> Complaint at 20-21, *Zebley v. Heckler*, 642 F. Supp. 220, 221 (E.D. Pa. 1986) (No. 83-3314) [hereinafter *Zebley* Complaint].

<sup>46</sup> *Id.* at 21.

<sup>47</sup> *Id.*

<sup>48</sup> Sutton Interview, *supra* note 2.

<sup>49</sup> *Zebley* Complaint at 20.

for a family that, in their words, “had been through a whole gamut of turmoil” in the previous years.<sup>50</sup>

Unbeknownst to the Zebleys, however, the SSI program and its close cousin, SSDI, were experiencing their own stress. By the late 1970s, policymakers in both Congress and the Executive Branch had grown concerned about the two programs. Expenditures for SSDI had risen from \$2.5 billion in 1969 to \$13.7 billion in 1979.<sup>51</sup> SSI was overall less concerning, but the SSA’s reports showed a significant rise in the number of recipients who qualified on the basis of disability (as opposed to old age or blindness, which the program treated as distinct from disability).<sup>52</sup> These changes helped spur the Social Security Disability Amendments of 1980, which addressed the alleged disincentives to work that these programs created and also required regular review (once every three years) of any program beneficiary whose disability seemed potentially transitory.<sup>53</sup>

The Reagan Administration pursued these reviews aggressively, initiating the process a year earlier than the law required. The result was “a purge.”<sup>54</sup> The numbers were especially striking in the SSDI program, where Social Security Commissioner John Svahn reportedly focused Agency resources:<sup>55</sup> the “Reagan disability reviews,” as they came to be known,<sup>56</sup> reached 1.2 million cases over three years and produced 495,000 benefit terminations.<sup>57</sup> Some SSI recipients, including Brian Zebley, also lost program access during this period.<sup>58</sup> Eventually, the Zebley family turned to the court system and to local legal aid lawyer Mark Kaufman, who had previously helped Zebley’s

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<sup>50</sup> Dan Hardy, *A Victory for Disabled Youngsters*, PHILA. INQUIRER, Feb. 18, 1991, at 2-B.

<sup>51</sup> MARTHA DERTHICK, *AGENCY UNDER STRESS: THE SOCIAL SECURITY ADMINISTRATION IN AMERICAN GOVERNMENT* 33 (1990).

<sup>52</sup> Lenna Kennedy, *SSI: Trends and Changes, 1974-80*, SOC. SEC. BULL., July 1982, at 4 (noting that SSI recipients who qualified on the basis of disability rose from 1.3 million recipients in January of 1974 to over 2.2 million recipients by the end of 1979).

<sup>53</sup> Staff of Off. of Legis. Regul. Pol’y, *Social Security Disability Amendments of 1980: Legislative History and Summary of Provisions*, SOC. SEC. BULL., Apr. 1981, at 15-16.

<sup>54</sup> DERTHICK, *supra* note 51, at 36.

<sup>55</sup> David Treadwell & Marlene Cimons, *Purge of Disability Rolls Ruins Lives*, L.A. TIMES, Mar. 21, 1982, at 27.

<sup>56</sup> Jennifer L. Erkulwater, *The Judicial Transformation of Social Security Disability: The Case of Mental Disorders and Childhood Disability*, 8 CONN. INS. L.J. 401, 412 (2002) [hereinafter Erkulwater, *Judicial Transformation of Social Security Disability*].

<sup>57</sup> DERTHICK, *supra* note 51, at 5. Courts later found that more than 200,000 of these terminations were erroneous. *Id.*

<sup>58</sup> The SSA deemed Zebley ineligible for the SSI program in January 1983. See Zebley Complaint at 20.

father John win veterans' benefits.<sup>59</sup> The family hoped Kaufman would have similar success with this other facet of the federal social welfare system.<sup>60</sup>

## II. THE *ZEBLEY* CASE AS IMPACT LITIGATION

When Kaufman filed the *Zebley* case in the Eastern District of Pennsylvania in 1983, he had a credible legal argument, but not one that seemed likely to prevail. He contended that the SSA's approach to cases like *Zebley's* was not a faithful interpretation of the statute that Congress had charged the Agency with administering.<sup>61</sup> Unfortunately for Kaufman, the Eleventh Circuit had recently rejected a similar argument,<sup>62</sup> and as the case was pending before District Court Judge John Fullam, the First Circuit did the same.<sup>63</sup> Perhaps that was why Judge Fullam ultimately treated the question as an easy one. Although he ordered administrative reviews of Brian *Zebley's* claim and those of the other named plaintiffs,<sup>64</sup> he dismissed the broader challenge to the federal Agency's regulations.<sup>65</sup>

At that point, the lawyers at Community Legal Services ("CLS") in Philadelphia largely took over the litigation. CLS was a heavy hitter in the worlds of legal aid and class action litigation,<sup>66</sup> thanks to its lawyers' involvement in high-profile welfare rights cases<sup>67</sup> and other significant victories for poor people and consumers.<sup>68</sup> It is worth pausing, however, to ask why CLS attorneys were interested in the *Zebley* case. To be sure, some CLS clients had disabilities or family members with disabilities, and some CLS lawyers specialized in mental health law and prison law (which intersected with deinstitutionalization), but disability benefits were not a

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<sup>59</sup> See Dan Hardy, *For the Poor, Strong Voice in the Courts*, PHILA. INQUIRER, Nov. 22, 1990, at 39-M.

<sup>60</sup> *Id.*

<sup>61</sup> *Zebley* Complaint at 23-24.

<sup>62</sup> *Powell v. Schweiker*, 688 F.2d 1357, 1363 (11th Cir. 1982) (holding that the disputed regulations were not "arbitrary, capricious, an abuse of discretion, or otherwise inconsistent with the law").

<sup>63</sup> See *Hinkley v. Sec'y Health & Hum. Servs.*, 742 F.2d 19, 21 (1st Cir. 1984) (upholding the regulations as a "reasonable" standard in their current form, rather than an abuse of discretion).

<sup>64</sup> The two other named plaintiffs, Joseph Love, Jr., and Evelyn Raushi, had stories similar to that of Brian *Zebley*. See *Zebley* Complaint at 18-20.

<sup>65</sup> *Zebley ex rel. Zebley v. Bowen*, 855 F.2d 67, 76-77 (3d Cir. 1988).

<sup>66</sup> See Redlich, *supra* note 19, at 773 ("The most successful of all legal services programs is Community Legal Services of Philadelphia.").

<sup>67</sup> See, e.g., *Graham v. Richardson*, 403 U.S. 365, 366 (1971) (presenting an argument by CLS lawyer Jonathan M. Stein before the Supreme Court); *Shapiro v. Thompson*, 394 U.S. 618, 620 (1969) (same, by CLS lawyer Jonathan Weiss).

<sup>68</sup> See, e.g., *Fuentes v. Shevin*, 407 U.S. 67, 68-69 (1972) (listing CLS lawyers David A. School and Harvey N. Schmidt as counsel presenting before the Supreme Court); *Poverty Law Developments: Consumer Picketing*, 5 CLEARINGHOUSE REV. 125, 156 (1971) (noting that David A. [School] and Harvey N. Schmidt worked as attorneys for CLS).

CLS specialty.<sup>69</sup> “I don’t even think we did SSI kids’ cases,” recalled then-director Jonathan Stein.<sup>70</sup> Nor was CLS part of the burgeoning disability rights movement,<sup>71</sup> although the group had allies who were.<sup>72</sup>

Perhaps the best way to understand CLS’s attorneys from that era is as first-generation poverty lawyers. The primary CLS lawyers on the *Zebley* case entered legal practice as poverty law was becoming a recognized legal field and when it enjoyed its most robust institutional support. Stein, a 1967 graduate of the University of Pennsylvania Law School, spent his law school summers working for Mobilization For Youth (“MFY”) Legal Services on the Lower East Side of Manhattan, under the direction of “welfare rights guru” Ed Sparer.<sup>73</sup> One of the most important legal aid organizations of its era and an inspiration for the federal Legal Services Program,<sup>74</sup> MFY Legal Services was involved with such landmark welfare rights victories as *King v. Smith*<sup>75</sup> and *Goldberg v. Kelly*.<sup>76</sup> After Stein graduated from law school, he received a fellowship funded by the federal Office of Economic Opportunity, designed to funnel young lawyers towards the practice of poverty law.<sup>77</sup> Stein’s CLS colleague Richard Weishaupt entered the profession in 1974, when, in

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<sup>69</sup> Interview with Richard Weishaupt (Jan. 18, 2022) (on file with author) [hereinafter Weishaupt Interview].

<sup>70</sup> Stein Interview I, *supra* note 37.

<sup>71</sup> Indeed, some of CLS’s cases arguably perpetuated negative conceptions of disability. See, for example, the 1974 lawsuit in which CLS attorneys sought, and won, AFDC benefits on behalf of unborn children. To support their case, CLS attorneys emphasized how such payments would reduce the incidence of physical and intellectual disability in the population. See Pamala Haynes, *Unborn Children of Welfare Mothers to Get Full Grants*, PHILA. TRIBUNE, July 13, 1974, at 3. CLS attorneys were also involved with *Youngberg v. Romeo*, in which counsel for an intellectually disabled client won recognition for the liberty interests of people who were involuntarily committed to state institutions, but in doing so conceded that “no amount of training” would “make possible” their client’s release from such an institution. See 457 U.S. 307, 317 (1982).

<sup>72</sup> See Interview with Jonathan Stein (Dec. 10, 2021) (on file with author) [hereinafter Stein Interview II] (describing CLS’s allyship with certain groups, such as Protection and Advocacy, that would now fall under the umbrella of the National Disability Rights Network).

<sup>73</sup> On this phase of Sparer’s career and the nickname “welfare rights guru,” see DAVIS, *supra* note 8, at 22, 26-27.

<sup>74</sup> See HOUSEMAN & PERLE, *supra* note 3, at 11.

<sup>75</sup> 392 U.S. 309, 311, 334 (1968) (precluding the Alabama legislature from denying AFDC to an otherwise qualifying child on the grounds that the child’s mother “cohabits” “in or outside her home with any single or married able-bodied man”).

<sup>76</sup> 397 U.S. 254, 262-64 (1970) (holding that procedural due process requirements attach to particular federal and state income support benefits and finding that, in this instance, due process meant a pre-termination evidentiary hearing).

<sup>77</sup> See E-mail from Jonathan Stein to Karen Tani (Feb. 24, 2021, 8:59 PM) (on file with author). The fellowship was named for Reginald Heber Smith and was administered by the University of Pennsylvania. During the fellowship’s lifespan from 1967 to 1985, approximately 2,000 “Reggies,” as the fellows were known, fanned out across the country. See *Reginald Heber Smith Community Lawyer Fellowship Program*, Georgetown L. Libr. Special Collections, [https://aspace.ll.georgetown.edu/public/agents/corporate\\_entities/36](https://aspace.ll.georgetown.edu/public/agents/corporate_entities/36) [https://perma.cc/JV4U-QKBE].

retrospect, the tide had turned against welfare rights litigation (at least at the Supreme Court level). But, like Stein, Weishaupt benefited from the mentorship of a prominent figure in the legal aid world—Gary Bellow, a leader in the movement for clinical legal education. After joining CLS, Weishaupt also developed a close friendship with Ed Sparer.<sup>78</sup> Tom Sutton, who joined the *Zebley* legal team around 1988, was another acolyte of Ed Sparer and had also worked on and off for Ralph Nader.<sup>79</sup> In short, these were lawyers who believed in the power of litigation to benefit society's most disadvantaged members and who had positioned themselves to be changemakers, even as the political winds blew against them.

The CLS team saw *Zebley* as exactly the kind of case they were looking for, albeit hardly a sure win. First, it had the potential for high impact. The district court may not have been well disposed to the *Zebley* plaintiffs' class-wide claim, but before ruling on that claim, it had certified a capacious class encompassing all persons "who are now, or who in the future will be, entitled to an administrative determination . . . as to whether [SSI] benefits are payable on account of a child who is disabled, or as to whether such benefits have been improperly denied, or improperly terminated, or should be resumed."<sup>80</sup> If CLS lawyers could convince an appellate court to take a different view of the merits of the case, that ruling could have national implications for the size and scope of a major public benefits program.

Second, the case offered the chance to bring economic security to more people. The whole legal services "ethos," Stein explained decades later, "was to expand benefits for poor people"; the *Zebley* case "was a vehicle to do that."<sup>81</sup> In this regard, it mirrored the welfare rights litigation that had helped put CLS on the map years earlier.<sup>82</sup> Around the country, other legal aid groups made a similar calculus. As political scientist Jennifer Erkulwater observed in 2002, CLS took the *Zebley* case at the same time that other advocates for the poor were using litigation to try to make disability benefits more available to people with mental illness diagnoses and people with drug and alcohol addiction.<sup>83</sup> Simply stated, these legal advocates saw economic precarity, and they matched it to legal opportunity.

Third, CLS lawyers understood that from a broader safety net perspective, SSI payments were not just about income support; they were

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<sup>78</sup> Weishaupt Interview, *supra* note 69.

<sup>79</sup> Sutton Interview, *supra* note 2.

<sup>80</sup> *Sullivan v. Zebley*, 493 U.S. 521, 527 (internal quotation marks omitted).

<sup>81</sup> Stein Interview I, *supra* note 37.

<sup>82</sup> *See id.* ("[T]o me it just looked like an opportunity of expanding benefits, in . . . the same way that . . . for the fifteen years before we were seeking to expand welfare benefit programs and looking for any opportunity.").

<sup>83</sup> Erkulwater, *Judicial Transformation of Social Security Disability*, *supra* note 56, at 412.



also about access to government-funded healthcare, at a time when private insurance companies routinely discriminated on the basis of “preexisting conditions” and the Children’s Health Insurance Program (CHIP) did not yet exist.<sup>84</sup> In most states, gaining access to SSI meant automatic access to Medicaid.<sup>85</sup> Thus, SSI was a lifeline in more ways than one.

In strategizing about how they might turn the *Zebley* case around on appeal, CLS lawyers tried to compensate for their legal vulnerabilities by recruiting powerful and respected allies to file amicus briefs.<sup>86</sup> For example, the legal team brought in organized medicine via the American Academy of Child and Adolescent Psychiatry and the American Psychiatric Association.<sup>87</sup> They recruited disability-focused groups, ranging from disease-based groups (such as the Pennsylvania Tourette Syndrome Association and the Sickle Cell Genetic Disease Council) to parent groups (such as the Pennsylvania Association for Retarded Children) to the National Association of Protection and Advocacy Systems.<sup>88</sup> And they secured the support of more traditional poverty law allies, such as the Center for Law and Social Policy and the Welfare Recipients League.<sup>89</sup> Before the case, these groups had only limited familiarity with SSI and the SSI kids program.<sup>90</sup> CLS was creating a coalition from scratch.

Meanwhile, the Social Security Administration was struggling. In the late 1970s and early 1980s, as the SSA had responded to pressure to pare down the SSDI and SSI rolls, the Agency had not only faced intense media criticism<sup>91</sup>

<sup>84</sup> Weishaupt Interview, *supra* note 69.

<sup>85</sup> See Richard P. Weishaupt & Robert E. Rains, *Sullivan v. Zebley: New Disability Standards for Indigent Children to Obtain Government Benefits*, 35 ST. LOUIS U. L.J. 539, 582-83 (1991) (explaining that “[i]ndividuals eligible for SSI are generally eligible for medical assistance (Medicaid)” because “the vast majority of states automatically grant [such] coverage” to SSI recipients); see also Jill Quadagno, *Incentives to Disability in Federal Disability Insurance and Supplemental Security Income*, 336 CLINICAL ORTHOPEDICS & RELATED RSCH. 11, 15 (1997) (“Many Supplemental Security Income recipients state that the risk of losing Medicaid is a greater work disincentive than is the loss of cash benefits. Earnings alone cannot buy healthcare coverage when that coverage is unavailable to persons with severe chronic conditions.”).

<sup>86</sup> See Stein Interview I, *supra* note 37 (explaining how and why CLS lawyers, including Stein, approached potential amici when *Zebley* was on appeal to the Third Circuit); see also Stein Interview II, *supra* note 72 (explaining that by recruiting amici, the *Zebley* team hoped to “give legitimacy” to claims that seemed only weakly supported by existing case law).

<sup>87</sup> Brief of American Academy of Child & Adolescent Psychiatry et al. as Amici Curiae Supporting Respondents, *Sullivan v. Zebley*, 493 U.S. 521 (1990) (No. 88-1377), 1989 WL 1127021 [hereinafter Brief of American Academy].

<sup>88</sup> *Zebley ex rel. Zebley v. Bowen*, 855 F.2d 67, 71 n.3 (3d Cir. 1988).

<sup>89</sup> *Id.*

<sup>90</sup> See Stein Interview I, *supra* note 37 (observing that the amici who were not “legal aid people” knew “almost nothing” about SSI and the SSI kids program).

<sup>91</sup> See, e.g., Treadwell & Cmons, *supra* note 55, at 27 (providing examples of the human casualties resulting from the Reagan Administration’s drive “to purge ineligible beneficiaries” from the SSDI program); Sam Smith, *Social Security: Unkindest Cut of All*, CHI. TRIB., May 30, 1982, at 4

but had also received sharp rebukes from various federal courts for its approach to evaluating recipients' continued eligibility.<sup>92</sup> The Agency had responded with formal declarations of "nonacquiescence," in which the SSA explained its disagreement with particular court decisions and indicated that it would continue to adhere to its own policies.<sup>93</sup> In 1982, it had also issued to its own personnel a more general statement (which would later become part of the Congressional Record) stating, "[t]he Federal courts do not run SSA's programs, and [SSA's adjudicators] are responsible for applying the Secretary's policies and guidelines regardless of court decisions below the level of the Supreme Court."<sup>94</sup>

Nonacquiescence among federal agencies had some precedent, and it arguably aligned with the SSA's need to apply its policies uniformly across the nation,<sup>95</sup> but the posture lost some credibility when the SSA repeatedly failed to seek guidance from the Supreme Court. Critics accused the Agency of flouting the authority of the lower federal courts, not unlike how some segregationists had resisted judicial authority in the era following *Brown v. Board of Education*.<sup>96</sup> "By the end of 1984," Martha Derthick summarized, "motions or threats of motions to hold the [S]ecretary of Health and Human Services in contempt numbered in the hundreds; and judges all over the

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("[T]ens of thousands of Americans . . . have been deleted from the Social Security disability rolls in the government's attempt to catch cheats. . . . [Thousands were] left to apply for welfare or beg to stay alive."); Doug Brown, *Regarded As Fit to Work: 11 Denied Social Security Disability Died of Illnesses*, L.A. TIMES, Sept. 17, 1982, at 1 (attributing eleven deaths to the Reagan Administration's purge of the SSDI program and documenting "angry cries from congressional critics who were already aroused by stories of what they considered cold and arbitrary decision-making in the removal of 200,000 people from the Social Security disability payment rolls during the past fiscal year").

<sup>92</sup> For example, in *Patti v. Schweiker*, 669 F.2d 582, 587 (9th Cir. 1982), the Ninth Circuit held that the SSA could not terminate an SSI recipient's benefits without first showing that the recipient's condition had improved. For further discussion of this criticism, see DERTHICK, *supra* note 51, at 138-39.

<sup>93</sup> See DERTHICK, *supra* note 51, at 139 ("Confident that its rules were sufficiently grounded in law, the [A]gency met the court's challenge with a defiant response. It issued formal rulings of 'nonacquiescence' in both the *Patti* and *Finnegan* cases."). Samuel Estreicher and Richard L. Revesz, the legal scholars best known for describing and analyzing nonacquiescence, define it as the "selective refusal of administrative agencies to conduct their internal proceedings consistently with adverse rulings of the courts of appeals." Samuel Estreicher & Richard L. Revesz, *Nonacquiescence by Federal Administrative Agencies*, 98 YALE L.J. 679, 681 (1989).

<sup>94</sup> Estreicher & Revesz, *supra* note 93, at 694 (internal quotation marks and citations omitted).

<sup>95</sup> *Id.* at 681 (observing that "[o]ver the past sixty years, many agencies have insisted, in varying degrees, on the authority to pursue their policies, despite conflicting court decisions, until the Supreme Court is prepared to issue a nationally binding resolution" and citing as examples the National Labor Relations Board and the Internal Revenue Service).

<sup>96</sup> See Anthony Lewis, *A Profound Contempt*, N.Y. TIMES, May 21, 1984, at A17 (connecting the Agency's "refusal to respect [certain] court decisions" to the "period of dangerous lawlessness" after "the Supreme Court's school segregation decision of 1954 when some Southern politicians and lawyers argued that the decision affected only the particular plaintiffs and need not be respected as law generally").

country were berating the SSA from their benches.”<sup>97</sup> In the wake of these many reprimands, the SSA softened its position,<sup>98</sup> but enjoyed a less-than-sterling reputation in the courts.

Whether because of CLS’s amicus strategy, skepticism of the SSA, or some other factor, the result was a victory for the *Zebley* plaintiffs. A three-judge panel of Third Circuit judges heard the case on May 3, 1988; three months later, the panel vacated the District Court’s decision.<sup>99</sup> Applying the standard of review that the Supreme Court announced in the famous case *Chevron U.S.A. Inc. v. Natural Resources Defense Council, Inc.*,<sup>100</sup> the Third Circuit panel first asked whether “Congress ha[d] directly spoken on the precise question at issue” (that is, the question of which children were disabled enough to qualify for benefits).<sup>101</sup> The court found that Congress had expressed an “unambiguous[.]” intent to treat as disabling “any medically determinable physical or mental impairment” that was of “comparable severity” to that which would qualify an adult for benefits.<sup>102</sup> This finding meant that the court owed no special deference to the SSA’s interpretation of the Social Security Act and would ask for itself whether the regulations crafted under that Act effectuated Congress’s intent.<sup>103</sup> Ultimately, the court determined that the regulations did *not* effectuate Congress’s intent, as they failed to provide child claimants with the kind of individualized assessment opportunity available to adult claimants.<sup>104</sup> Accordingly, the Third Circuit remanded the case to the District Court with instructions to enter summary judgment in favor of the plaintiff class on the statutory interpretation claim.<sup>105</sup>

Because that class had been described so capaciously, without any geographic boundaries, the case had significant implications for the SSA. The Agency’s representatives argued in their petition to the Supreme Court that the Third Circuit’s ruling would require a nationwide reevaluation of cases dating back to 1983; that process alone would cost over \$41 million.<sup>106</sup>

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<sup>97</sup> DERTHICK, *supra* note 51, at 140; *see also* Estreicher & Revesz, *supra* note 93, at 699-702 (providing examples of cases in which district court and appellate judges rebuked the SSA’s nonacquiescence policy).

<sup>98</sup> After 1985, the SSA backed away from its “blanket nonacquiescence” policy. *See* Estreicher & Revesz, *supra* note 93, at 695-96.

<sup>99</sup> *Zebley ex rel. Zebley v. Bowen*, 855 F.2d 67, 72-73 (3d Cir. 1988) (vacating not all of the district court’s decision, but the parts crucial to the *Zebley* plaintiffs).

<sup>100</sup> 467 U.S. 837, 842-43 (1984).

<sup>101</sup> *Zebley ex rel. Zebley*, 855 F.2d at 73.

<sup>102</sup> *Id.* (citations omitted).

<sup>103</sup> *Id.* at 73-74.

<sup>104</sup> *Id.*

<sup>105</sup> *Id.* at 77.

<sup>106</sup> Petition for Writ of Certiorari, *Sullivan v. Zebley*, 493 U.S. 521 (1990) (No. 88-1377), 1989 WL 1174081, at \*17.

According to the Agency, the decision's nationwide reach also meant that the Third Circuit effectively "over[rode] the prior contrary decisions of the First and Eleventh Circuits" and "preempted the further development of the law in other circuits."<sup>107</sup>

### III. ZEBLEY AT THE SUPREME COURT

In recognition of a conflict between circuit courts, the Supreme Court granted certiorari in the *Zebley* case in 1989.<sup>108</sup> By then, the Court was well acquainted with the Social Security Administration. Some of the Court's most famous decisions from the 1970s involved the SSA and its governing statutes.<sup>109</sup> And in the subsequent decade, the Agency appeared before the Court multiple times, as it attempted to defend exclusions from the SSDI and SSI programs,<sup>110</sup> contest court-imposed deadlines for adjudicating disputed disability claims,<sup>111</sup> insulate itself from judicial challenges to SSDI/SSI eligibility and redetermination decisions,<sup>112</sup> and avoid paying costs associated with erroneous benefit determinations.<sup>113</sup> Sometimes the SSA lost and sometimes it won, but the picture that had emerged by the late 1980s was

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

<sup>108</sup> *Sullivan v. Zebley*, 490 U.S. 1064 (1989) (granting the petition for writ of certiorari).

<sup>109</sup> *See, e.g., Weinberger v. Wiesenfeld*, 420 U.S. 636, 653 (1975) (finding unconstitutional a provision of the Social Security Act that allowed the surviving spouses of male wage earners to receive benefits but denied similar protection to the spouses of female wage earners); *Mathews v. Eldridge*, 424 U.S. 319, 334-35 (1976) (establishing a balancing test to determine whether due process requires an evidentiary hearing before the government may terminate a recipient's SSDI benefits); *Califano v. Goldfarb*, 430 U.S. 199, 202 (1977) (striking down a provision of the Social Security Act that provided less protection to the surviving spouses of female wage earners than to the surviving spouses of male wage earners).

<sup>110</sup> *See Schweiker v. Wilson*, 450 U.S. 221, 225 (1981) (defending the exclusion of adults in public mental institutions from SSI eligibility); *Bowen v. Yuckert*, 482 U.S. 137, 143-45 (1987) (defending the Agency's method for determining whether an SSI claimant is "severely impaired").

<sup>111</sup> *See Heckler v. Day*, 467 U.S. 104, 111 (1984) (arguing that a statewide injunction outlining deadlines for adjudicating disputed disability benefit claims was contrary to congressional intent and was not "appropriate").

<sup>112</sup> *See Bowen v. City of New York*, 476 U.S. 467, 477 (1986) (contesting the composition of a class of disability benefit recipients that a lower court had certified).

<sup>113</sup> *See Schweiker v. Chilicky*, 487 U.S. 412, 415, 419-20 (1988) (contesting a court of appeals decision that would have allowed disability benefit claimants to seek money damages against government officials whose administration of the "continuing disability review" program allegedly violated the claimants' due process rights); *Sullivan v. Hudson*, 490 U.S. 877, 882-83 (1989) (disputing a court of appeals finding that under the Equal Access to Justice Act, a claimant seeking SSDI was entitled to an award of attorney's fees for legal representation in a judicially mandated redetermination proceeding before an Administrative Law Judge). The SSA also appeared before the Court in several cases unrelated to SSI and SSDI. *See, e.g., Schweiker v. Hansen*, 450 U.S. 785, 786 (1981) (contending that an incorrect statement by an SSA field representative did not estop the Agency "from denying retroactive benefits" to respondent "for a period in which she was eligible for benefits but had not filed a written application").

that of an Agency that made high-stakes decisions, also made errors, and resisted accountability to program beneficiaries.

The SSA was still “the government,” however, and the *Zebley* litigation team saw themselves as disadvantaged. Their strategy, again, was to surround themselves with amici, ideally ones that would appeal to key justices. While Richard Weishaupt focused on briefing and other legal issues, Jonathan Stein labored to get just the right amicus briefs into the record.<sup>114</sup> For example, knowing that Justice Blackmun had been a lawyer for the Mayo Clinic, and having seen him draw on this medical background in the important *Roe v. Wade* decision,<sup>115</sup> Stein again solicited support from the American Medical Association, the American Psychiatric Association, and the American Academy of Pediatrics.<sup>116</sup> Likewise, in an effort to appeal to the Court’s social conservatives, Stein reached out to the influential anti-abortion activist James Bopp, Jr.<sup>117</sup> “[O]f course he knew nothing about the SSI kids program, like all the other amici,” Stein recalled,<sup>118</sup> but Bopp appeared interested in challenging any kind of government action that suggested bias against children with disabilities or that deemed such children undeserving of investment.<sup>119</sup> Confronted with these biases from government officials and medical professionals, parents might be drawn to the “repulsive option” of

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<sup>114</sup> See Stein Interview I, *supra* note 37; Weishaupt Interview, *supra* note 69.

<sup>115</sup> 410 U.S. 113, 163 (1973) (drawing on “present medical knowledge” to determine the point at which to recognize a “compelling” state interest in the health of a pregnant woman, such that regulation of an abortion procedure may be legitimate).

<sup>116</sup> Stein Interview I, *supra* note 37. Stein was ultimately successful, garnering briefs from the American Academy of Child and Adolescent Psychiatry, the American Psychiatric Association, and the National Mental Health Association, amongst others. See Brief of American Academy, *supra* note 87. Justice Blackmun’s history of engagement with the medical profession has been widely recognized. See, e.g., LINDA GREENHOUSE, BECOMING JUSTICE BLACKMUN 82-91 (2005) (chronicling Justice Blackmun’s time as resident counsel of the Mayo Clinic and detailing his research on abortion history at the Mayo Clinic library). It became “conventional wisdom” that Justice Blackmun’s respect for medicine decisively shaped his landmark opinion in *Roe*, although, as Nan Hunter has argued, that interpretation is overly simplistic. See Nan D. Hunter, *Justice Blackmun, Abortion, and the Myth of Medical Independence*, 72 BROOK. L. REV. 147, 149 (2006) (“The long-standing ‘Mayo made him do it’ explanation of *Roe* is wrong and should be jettisoned.”).

<sup>117</sup> Stein Interview I, *supra* note 37. For further discussion of Bopp’s role in the anti-abortion movement, see Mary Ziegler, *Beyond Balancing: Rethinking the Law of Embryo Disposition*, 68 AM. U. L. REV. 515, 534-38 (2018), which identifies Bopp as one of “the pro-life movement’s leading lawyers” and a proponent of creative strategies to undermine abortion rights.

<sup>118</sup> Stein Interview I, *supra* note 37.

<sup>119</sup> See, e.g., Glen Elsasser, *Hospital Lets Infants Die, Group Charges*, CHI. TRIB., May 9, 1985, at 6 (documenting Bopp’s work as president of the National Legal Center for the Medically Dependent and Disabled); Craig Wolff, *Baby’s Grieving Parents Sue to Keep Respirator On*, N.Y. TIMES, Oct. 17, 1989, at B2 (quoting Bopp for the views of the National Right to Life Committee on “brain death” and whether that condition may justify termination of life-saving medical treatment for children).

essentially consenting to their disabled child's destruction, Bopp's amicus brief argued.<sup>120</sup>

Perhaps the most powerful amicus brief that Stein secured involved attorneys general from twenty-seven states and the District of Columbia.<sup>121</sup> By 1989, the Court had taken a clear interest in empowering the states vis-à-vis the federal government and had repeatedly expressed concern about the fiscal burdens that Congress and lower federal courts imposed on state governments.<sup>122</sup> Stein also recognized that expanding SSI benefitted states' interests, because children that received aid through the federally funded SSI program were less likely to seek support from state-funded social welfare programs.<sup>123</sup>

These incentives actually had been clear since the earliest days of the SSI program. In September 1973, as officials at various levels of government prepared for the rollout of the new program, government officials in New York City sent letters to 250,000 "welfare women" telling them to report for physical examinations or risk losing their benefits come January.<sup>124</sup> City officials estimated that some 60,000 of these women could meet the new federal definition of disability,<sup>125</sup> but if even 25,000 were reclassified, the city and the state would save up to \$12.5 million each in 1974.<sup>126</sup> After news of this effort broke, Congress passed a law preventing states from transferring masses of adult welfare recipients onto the SSI rolls.<sup>127</sup> But it did not change the basic fiscal incentives that New York City officials had recognized.

Stein, in fact, had more than a passing familiarity with these incentives. In the early 1980s, when his law school classmate Walter Cohen served as

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120 Brief of the Medical Issues Task Force of the United Handicapped Federation & the Ethics and Advocacy Task Force of the Nursing Home Action Group as Amici Curiae Supporting Respondents, *Sullivan v. Zebley*, 493 U.S. 521 (1990) (No. 88-1377), 1989 WL 1127020.

121 Brief of the Commonwealths of Massachusetts & Pennsylvania et al. as Amici Curiae Supporting Respondents, *Sullivan v. Zebley*, 493 U.S. 521 (1990) (No. 88-1377), 1989 WL 1127024 [hereinafter Brief of the Commonwealths]; see also Stein Interview I, *supra* note 37 (describing his role in encouraging the state attorneys general to file an amicus brief).

122 Louise Weinberg, *The New Judicial Federalism*, 29 STAN. L. REV. 1191, 1192-95 (1977) (noting a new "counterassault" on federal judicial power and the Supreme Court's reaction to a trend toward "deference[] to state administration and state adjudication" (citations omitted)); Karen M. Tani, *The Pennhurst Doctrines and the Lost Disability History of the "New Federalism"*, 110 CALIF. L. REV. 1157, 1160-62 (2022) (discussing the Supreme Court's sympathetic response to the concerns that some state officials in the 1970s and 1980s voiced about federal grants-in-aid and the affirmative obligations that federal courts were attaching to them).

123 Stein Interview I, *supra* note 37.

124 Pranay Gupte, *65% of Welfare Mothers Proving Disabled in Tests*, N.Y. TIMES, Sept. 24, 1973, at 1.

125 *Id.* at 2.

126 *Id.* at 1.

127 See DiPentima, *supra* note 41, at 191 (explaining that the new law restricted the circumstances under which existing recipients of income support benefits could be converted to recipients of SSI).

Pennsylvania's Secretary of Public Welfare, Stein (with Cohen's blessing) ran an advocacy project that used state funding to help identify welfare recipients who might meet the disability requirements of the SSI program.<sup>128</sup> Stein also understood that some state officials did not react kindly to the infamous Reagan disability reviews.<sup>129</sup>

By September 1989, when the state attorneys general filed their amicus brief in *Zebley*, states had become so accustomed to the federal government supporting poor, disabled children that they accused the SSA's administrative policies of "cost-shifting" onto the backs of the states.<sup>130</sup> In their version of events, "Congress intended to relieve the states of the fiscal burden of caring for the disabled, and to assume that burden at the federal level."<sup>131</sup> In defining disability too restrictively, the SSA had, in effect, created a "gap," which states now had to fill.<sup>132</sup>

Ultimately, seven justices agreed with the plaintiffs' position (including Justice Scalia, one of the Court's most conservative members). Writing for the majority, Justice Blackmun took particular issue with the SSA's argument that its "listings-only approach" was "the only practicable way" to determine whether a child claimant's impairment was comparable in severity to that of a qualifying adult.<sup>133</sup> Although it was true that a *vocational* analysis would be inappropriate for children—who, after all, did not work—a *functional* analysis was fully within the capacities of modern medical experts.<sup>134</sup> "[S]tandard medical diagnostic techniques often include assessment of the functional impact of the disorder," Blackmun noted, citing the American Medical Association's amicus brief.<sup>135</sup> Finding the SSA's policies "manifestly contrary to the statute," the majority affirmed the judgment of the Third Circuit.<sup>136</sup>

Justice White's dissent, joined by Chief Justice Rehnquist, emphasized the "exceptionally broad authority" that Congress conferred on the Secretary of Health and Human Services regarding the development of a methodology

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<sup>128</sup> Interview with Jonathan Stein (Dec. 22, 2021) (on file with author) [hereinafter Stein Interview III].

<sup>129</sup> E-mail from Jonathan Stein to Karen Tani (Dec. 9, 2021, 11:06 PM) (on file with author) (recalling that during the Reagan Administration's mass reviews of people receiving SSDI and SSI, many state officials "acted to try to stop the reviews and terminations to people in their states"); see also Peter Kihss, *Cut from U.S. Benefits, Disabled Seek Welfare*, N.Y. TIMES, May 19, 1982, at B1 ("[P]eople cut off from Social Security disability benefits in New York State are showing up three or four months later on home relief, a welfare program paid for only by the state and local communities.").

<sup>130</sup> Brief of the Commonwealths, *supra* note 121, at 4.

<sup>131</sup> *Id.* at 6-7.

<sup>132</sup> *Id.* at 4.

<sup>133</sup> *Sullivan v. Zebley*, 493 U.S. 521, 539 (1990).

<sup>134</sup> *Id.* at 539-41.

<sup>135</sup> *Id.* at 541.

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

for evaluating disability applications—or so the Court had said “[o]nly two Terms ago.”<sup>137</sup> As for how the Agency had deployed its authority in this case, Justice White understood the task as one of comparing “apples and oranges” and was therefore sympathetic to the Agency’s decision to employ different methodologies for children and adults.<sup>138</sup> He concluded by reminding his colleagues of the SSA’s “finite” funds, which, in his view, meant that some children would inevitably suffer as a result of the individualized determinations that the majority would now require.<sup>139</sup>

In retrospect, the most striking feature of the entire exchange was not the disagreement, however, but the consensus. All the justices seemed to understand the work that the concept of disability was doing for the state. Entrusted to medical gatekeepers, disability had become a mechanism for making difficult distributional choices. The only question was how much one trusted the Social Security Administration to define and police that concept.

#### IV. “IT’S NOT OVER”: EXPANSION AND BACKLASH

“People think that when the Supreme Court rules that you’ve waved a magic wand and it’s all over. But it’s not over,” CLS lawyer Richard Weishaupt told the *Philadelphia Inquirer* in July 1990.<sup>140</sup> Four months after the Court’s ruling in *Zebley*, the Social Security Administration continued to quarrel with the plaintiffs’ attorneys over how to identify individuals who might be entitled to payments and what the reevaluation process might look like.<sup>141</sup> In November 1990, the situation seemed little improved, with no payments yet issued to hundreds of thousands of children who likely satisfied the Court’s interpretation of the relevant eligibility criteria.<sup>142</sup>

Two years later, however, the situation looked quite different. By February of 1991, the SSA had adopted final regulations requiring functional assessments of child claimants who, under previous Agency policies, would have been denied SSI payments for failing to fit one of the Agency’s medical listings. Now, a child claimant could establish eligibility by showing that their impairment (or combination of impairments) limited their ability “to function independently, appropriately, and effectively in an age-appropriate manner.”<sup>143</sup> Importantly, this functional assessment was not grounded in the child’s ability to work or do work-like tasks; rather, it focused on the child’s

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<sup>137</sup> *Id.* at 541-42.

<sup>138</sup> *Id.* at 543.

<sup>139</sup> *Id.* at 548.

<sup>140</sup> *Inquirer Wire Services, Disabled-Child Ruling Still Disputed*, PHILA. INQUIRER, July 3, 1990, at 13-D.

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

<sup>142</sup> Robert Pear, *Despite Order, U.S. Stalls Aid to Poor Children*, N.Y. TIMES, Nov. 19, 1990, at A1.

<sup>143</sup> See NEW FUNCTIONAL ASSESSMENTS, *supra* note 42, at 8.



ability to achieve developmental milestones and to function in the kinds of settings where children would be expected to grow and learn.<sup>144</sup>

Following the release of these new guidelines, in the spring of 1991, the Agency launched a major outreach effort (as required by the settlement with plaintiffs' counsel). It targeted some 452,000 children whom the *Zebley* ruling may have affected, going back to 1980.<sup>145</sup> Around the country, families learned that their children may be "Zebleys," to use the parlance of the SSA. Cash infusions followed. For example, a "Zebley" named Jessica, profiled in the *Philadelphia Inquirer*, received \$40,000 in back payments.<sup>146</sup> By 1994, some 150,000 other children shared this experience. Back payments averaged \$15,000 but could be as high as \$75,000, at a total cost to the government of \$2 billion, plus administrative costs.<sup>147</sup>

New applications to the program also went up, both because of the *Zebley* decision and because of an unrelated change to the definition of disability: in December 1990, new SSA regulations expanded the listing of mental impairments that could qualify a child for SSI and also clarified that mental impairments might cause a child to be functionally disabled.<sup>148</sup> Low-income parents and their advocates were alert to these changes. So were state officials, who since the earliest days of SSI had understood the fiscal benefits of shifting poor people off of state-funded programs such as AFDC and "general assistance," and onto federally funded disability-based assistance.<sup>149</sup> In the seven years after *Zebley*, the number of children covered by SSI nearly tripled, to a total of nearly one million people.<sup>150</sup> As a share of the total child

144 *Id.* ("To implement the *Zebley* decision, SSA convened a group of experts in April 1990 to help formulate new regulations using age-appropriate functional criteria.").

145 A. Bowen Garrett & Sherry Glied, *The Effect of U.S. Supreme Court Ruling Sullivan v. Zebley on Child SSI and AFDC Enrollment* 5 (Nat'l Bureau of Econ. Rsch., Working Paper No. 6125, 1997).

146 Lucia Herndon, *How Disabled Children Can Benefit from Ruling*, PHILA. INQUIRER, Sept. 16, 1992, at E3. This would be a sum of over \$83,000 in 2022 dollars. See *CPI Inflation Calculator*, U.S. BUREAU LAB. STAT., [https://www.bls.gov/data/inflation\\_calculator.htm](https://www.bls.gov/data/inflation_calculator.htm) [perma.cc/G2W7-KGZZ].

147 Woodward & Weiser, *supra* note 20. This figure does not appear to have included the cost of the medical assistance that, in many states, automatically followed from a finding of SSI eligibility. DISABILITY POL'Y PROJECT, *supra* note 39, at 12.

148 Norma B. Coe & Matthew S. Rutledge, *What Is the Long-Term Impact of Zebley on Adult and Child Outcomes?*, CTR. RET. RSCH. B.C., Jan. 2013, at 4-5. This expansion followed from the 1985 expansion of the adult listings, which in turn followed from court decisions and Congress's 1984 amendments to the program. DISABILITY POL'Y PROJECT, *supra* note 39, at 12 ("The update of the childhood mental disorders listings in December 1990 was based on the same conceptual framework used to update the adult mental disorders listings in 1985. . . . [required] by legislation enacted in 1984.").

149 See DiPentima, *supra* note 41, at 191; Gupte, *supra* note 124 (documenting the state savings expected to accrue from reclassifying AFDC recipients as "disabled"). "General assistance" refers to need-based income support programs that are funded by state and/or local governments, rather than the federal government, and that capture people who are very poor but do not meet the eligibility requirements of federally funded programs.

150 Garrett & Glied, *supra* note 145, at 1.

population age zero to seventeen, SSI recipients went from 0.4 percent to 1.4 percent.<sup>151</sup> This figure tells us nothing, unfortunately, about the percentage of eligible children who actually received the benefits to which they were statutorily entitled (the “take up” rate), but it does signify growth.<sup>152</sup>

These numbers also signify need. For many recipients, SSI benefits fulfilled needs that the state left otherwise unattended. Consider Charol Jamison, who in March 1995 was receiving \$490 per month in SSI payments for a son with severe asthma.<sup>153</sup> Combined with her wages from three shifts per week as a mental-health aide in a group home, these payments allowed Jamison to pay her family’s bills and also personally provide much of her son’s medical care, including medication administration and airway treatments.<sup>154</sup> Before gaining access to SSI, when Jamison was working full time, her son had been hospitalized a dozen times in three years; eventually Jamison missed so much work that she felt compelled to reduce her working hours, leaving her family financially vulnerable.<sup>155</sup> SSI brought with it economic security and, for the most part, kept her son out of the hospital.<sup>156</sup>

These stories of enhanced social and economic security did not insulate the expanded SSI program from critique, however. Building on the English Poor Law tradition, U.S. social welfare policy has long embraced the principle of “less eligibility.” This is the notion that when the government provides need-based support, that support should be less generous than the worst-paid position in the formal labor market.<sup>157</sup> U.S. history abounds with examples of vigilante enforcement of this principle, including via surveillance of people who appeared to have more than their economic station warranted.<sup>158</sup> Closely

<sup>151</sup> Mark G. Duggan & Melissa Schettini Kearney, *The Impact of Child SSI Enrollment on Household Outcomes*, 26 J. POL’Y ANALYSIS & MGMT. 861, 863 (2007).

<sup>152</sup> It is likely that the “take up” rate was low, or in other words, that the number of children receiving SSI was far lower than the number of children who were legally eligible for benefits. See NAT’L ACADS. SCIS., ENG’G, & MED, *MENTAL DISORDERS AND DISABILITIES AMONG LOW-INCOME CHILDREN 12-16* (Thomas F. Boat & Joel T. Wu eds., 2015), <https://doi.org/10.17226/21780> [<https://perma.cc/PQG5-Y7YF>] (drawing on 2012 data to conclude that only a small proportion of children who were eligible for SSI benefits on account of various mental disorders were actually receiving such benefits).

<sup>153</sup> Mary Flannery, *Breathing Room: Would Loss of SSI Fund Devastate Disabled Poor?*, PHILA. DAILY NEWS, Mar. 15, 1995, at 31.

<sup>154</sup> *Id.* at 32; cf. Rita Giordano, *A Crisis Is Looming for Disabled Children*, PHILA. INQUIRER, Nov. 21, 1996, at A1, A15 (profiling parents in similar situations).

<sup>155</sup> John B. O’Donnell, *Affected Families Offer Differing Views*, BALT. SUN, May 21, 1995, at 19A.

<sup>156</sup> *Id.*

<sup>157</sup> See generally FRANCES FOX PIVEN & RICHARD A. CLOWARD, *REGULATING THE POOR: THE FUNCTIONS OF PUBLIC WELFARE* (2d Vintage ed. 1993) (rooting the principle of “less eligibility” in the English Poor Law and explaining how, in practice, that principle helped ensure local employers a ready supply of low-wage labor).

<sup>158</sup> TANI, STATES OF DEPENDENCY, *supra* note 8, at 206-07 (discussing, for example, surveillance accompanying ADC grants and a proposal to require benefit claimants to submit their

linked to this is what Disability Studies scholar Ellen Samuels has identified as a “cultural investment in distinguishing between real and fake disabilities, authentic and fraudulent bodily claims,” leading to the recruitment of “a wide swath of the population into the ranks of lay diagnosticians and enforcers of disability identification.”<sup>159</sup>

Arkansas insurance salesman Pat Flanagin was operating in this mode in 1993 when he encountered a client who “wanted a new house” and had “\$10,000 in the bank,” but “had no job” and “lived in government housing.”<sup>160</sup> Skeptical, he first hypothesized that she must be selling either sex or drugs, but eventually he discovered that she was receiving about \$15,000 per year in SSI payments for each of her children—all of whom Flanagin considered healthy.<sup>161</sup> Outraged, Flanagin used his power as a state legislator to launch an investigation and, when that went nowhere, a series of articles in the local newspaper.<sup>162</sup> He alleged that parents were securing “crazy checks” from the federal government by encouraging their children to fake or exaggerate mental and behavioral problems.<sup>163</sup>

What might have remained a local or regional story became a national one when Bob Woodward, of Watergate fame, took an interest. Social welfare programs were hardly Woodward’s beat—much of his reporting concerned high-level political figures—but in 1993, he teamed up with reporter Benjamin Weiser, who was digging into Justice Thurgood Marshall’s recently released papers,<sup>164</sup> to form a collaboration that would eventually lead to

fingerprints). For a general discussion of suspicion and surveillance of the poor, see JOHN GILLIOM, *OVERSEERS OF THE POOR: SURVEILLANCE, RESISTANCE, AND THE LIMITS OF PRIVACY* (William M. O’Barr & John M. Conley eds., 2001), and JULILLY KOHLER-HAUSMANN, *GETTING TOUGH: WELFARE AND IMPRISONMENT IN 1970S AMERICA* (2017).

<sup>159</sup> ELLEN SAMUELS, *FANTASIES OF IDENTIFICATION: DISABILITY, GENDER, RACE* 132 (2014). The phenomenon that Samuels identifies is amply documented by other scholars, as well. See, e.g., SUSAN M. SCHWEIK, *THE UGLY LAWS: DISABILITY IN PUBLIC* 110, 112-14 (2009) (documenting the cultural power of the idea of a “fake cripple”); STONE, *supra* note 1, at 28 (“In the modern understanding of disability, deception has become part and parcel of the concept itself, and the nature of this deception is tied to the particular form of validation used to detect it.”); Dorfman, *Fear of the Disability Con*, *supra* note 31, at 1060-63 (using legal historical and social-scientific research to document the enduring connection “between disability and fakery”); Dorfman, *[Un]Usual Suspects*, *supra* note 31, at 559 (describing a “moral panic about abuse of rights by ‘nondisabled fakers’”).

<sup>160</sup> Christopher Georges, *A Media Crusade Gone Haywire*, *FORBES MEDIA CRITIC*, Sept. 1995, at 66-71.

<sup>161</sup> *Id.*

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

<sup>163</sup> *Id.*

<sup>164</sup> See Benjamin Weiser & Bob Woodward, *Roe’s Eleventh-Hour Reprieve*, *WASH. POST*, May 23, 1993, at A1, A21 (recounting debate within the Supreme Court regarding overturning *Roe*, uncovered from Justice Marshall’s papers); see also Stein Interview III, *supra* note 128 (recalling that when Weiser approached Stein to discuss *Zebley* and the SSI kids program, Weiser explained that he had been reviewing some recently opened Supreme Court papers).

articles regarding *Zebley* and SSI.<sup>165</sup> “Costs Soar for Children’s Disability Program,” read the Woodward and Weiser headline in February 1994.<sup>166</sup> The article opened with pediatrician and lawyer Nora Cooke Porter, who complained that she routinely reviewed claims from children “not suffering from any disability” but deemed eligible for SSI.<sup>167</sup> Of particular note to Woodward and Weiser were the children “who curse teachers, fight with classmates, perform poorly in school or display characteristics of routine rebellion” and thereby received diagnoses of behavioral disorders.<sup>168</sup> The article went on to cast the SSI children’s program as untethered to congressional will and riddled with pathologies.<sup>169</sup> The interviewees that Woodward and Weiser chose to spotlight characterized the program as a subsidy for drug and alcohol abusers and sexual deviants.<sup>170</sup> The implication was that parents created behavioral and emotional problems in their children via neglect and abuse and then “receiv[ed] a cash award” for their terrible parenting.<sup>171</sup>

From there, the story took off. “Thousands of parents in Alabama are seeking ‘crazy checks’ for their disabled children,” reported the *Montgomery Advertiser* in May 1994.<sup>172</sup> Citing professionals who helped evaluate SSI claims, as well as public school teachers and counselors who had to fill out SSI paperwork, the article described “shell-game hustlers” (mothers, generally) who encouraged their children to act inappropriately so that their families could buy new cars, nice houses, video game systems, and fancy sneakers.<sup>173</sup> Education professionals in Arkansas and Louisiana offered similar anecdotes, supplying content for outlets such as the *Baltimore Sun*,<sup>174</sup> the *Boston Globe*, and *ABC Prime Time*.<sup>175</sup>

<sup>165</sup> Woodward & Weiser, *supra* note 20.

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

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

<sup>168</sup> *Id.*

<sup>169</sup> *Id.*

<sup>170</sup> *Id.* (citing “a senior examiner in Maryland for eight years” who “said ‘at least one-third’ of her cases involve[d] families in which a parent is a drug or alcohol abuser” and “a psychologist in Maryland” who “said a quarter of the 4,000 children’s cases she ha[d] reviewed involve[d] sexual abuse by a family member”).

<sup>171</sup> *Id.*; see also Heather Mac Donald, *Teaching Johnny to Fail: The Mixed-Up Messages of Disability Welfare for Troubled Kids*, WASH. POST, June 18, 1995, at C7 (“[T]eachers and psychologists question the wisdom of giving cash benefits to the parents of emotionally disturbed children. Often, parental neglect and abuse have created the problem to begin with.”).

<sup>172</sup> Michael Wilson, *Cashing In?*, MONTGOMERY ADVERTISER, May 22, 1994, at A1.

<sup>173</sup> *Id.* at A12.

<sup>174</sup> See, e.g., John B. O’Donnell & Jim Haner, *America’s Most Wanted Welfare Plan*, BALT. SUN, Jan. 22, 1995, at 1A, 12A; John B. O’Donnell & Jim Haner, *Benefit Cutoff Sought for 200,000 Children*, BALT. SUN, Jan. 28, 1995, at 1A; John B. O’Donnell, *‘Coached’ Children Wrongly Get Benefits*, BALT. SUN, Mar. 11, 1995, at 1A.

<sup>175</sup> Georges, *supra* note 160, at 68.

Barely under the surface was the “welfare queen,” popularized by Ronald Reagan in the 1980s but a familiar trope since the 1960s.<sup>176</sup> In this iteration, the “welfare queen” profited not from the birth of her children, but from her children’s pretended incapacities. She was still racialized Black. For example, the *Baltimore Sun* treated as emblematic a Louisiana woman named Rosie Watson, who claimed (in journalist John O’Donnell’s words) to be “too stressed out to work” but persisted in an “18-year crusade” to get disability-based income support “for her entire family,” including all seven of her children.<sup>177</sup> A series of photographs showed a dark-skinned woman and her relatives in various states of repose—napping, eating, staring off into space, and casually “cut[ting] okra.”<sup>178</sup>

Such critiques bore a troubling relationship to reality, not least because some of the most startling examples of beneficiary spending stemmed from the SSA’s own requirements. The SSA treated back payments as assets that, if not “spent down” quickly, could result in a finding that a child claimant was not financially needy and therefore ineligible for continued support.<sup>179</sup> The media critiques were also miles away from the experience of Brian Zebley, who by 1995 was no longer receiving SSI. His father’s wages had grown substantial enough that the family surpassed the income limit. Brian, meanwhile, appeared to be thriving. According to a local newspaper, he walked unassisted, followed the standard curriculum for his grade level, and even served on his high school’s student council.<sup>180</sup>

By then, however, Zebley’s case had intersected with, and had become conflated with, the SSA’s treatment of mental impairments. “[T]he [A]gency gave away the store” after the *Zebley* ruling, psychologist Kenneth Carroll told the *Chicago Tribune* in 1995.<sup>181</sup> Once a consultant to the SSI system, Carroll reportedly severed his relationship with the program after feeling pressured to approve applications that he found questionable. As an example, he cited a teenage SSI recipient who, in his description, was not so much disabled as delinquent. “Because he doesn’t go to school, he reads at a 4th-grade level,”

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<sup>176</sup> See generally Julilly Kohler-Hausman, “*The Crime of Survival*”: *Fraud Prosecutions, Community Surveillance, and the Original “Welfare Queen”*, 41 J. SOC. HIST. 329 (2007).

<sup>177</sup> O’Donnell & Haner, *supra* note 174.

<sup>178</sup> *Id.*; see also Sutton Interview, *supra* note 2 (recalling that the complaints seemed often to come from white schoolteachers who were disturbed by the benefits that their Black pupils were receiving).

<sup>179</sup> Stein Interview II, *supra* note 72 (explaining how the SSA’s rules incentivized recipients of back payments to spend those payments quickly); Weishaupt Interview, *supra* note 69 (recalling that critics seemed especially outraged by the spending sprees that the SSA’s own rules incentivized).

<sup>180</sup> Flannery, *supra* note 153, at 32.

<sup>181</sup> Carol Jouzaitis, *Despite Successes, Aid for Disabled Draws Fire*, CHI. TRIB., Apr. 16, 1995, at L10; see also Mac Donald, *supra* note 171, at C7 (“The Supreme Court . . . radically altered the composition of the rolls, by opening them to the vast and growing world of learning and behavioral disorders.”).

Carroll opined, which translated into a “learning disability.”<sup>182</sup> Should the same teenager decide to “steal[] cars,” Carroll suggested, hyperbolically, he would then have “a conduct disorder” and another reason to get benefits.<sup>183</sup>

These critiques about “learning disabilities” and “conduct disorders” went beyond moral judgments; they intersected with the notion of a “culture of poverty,” an idea that had captivated policymakers and commentators since the 1960s.<sup>184</sup> A defining feature of this “culture,” according to its theorists, was a sort of learned helplessness, fueled by government programs and their low expectations. “Mom gets a bonus check and kids [with behavior problems] get an excuse,” in Carroll’s words.<sup>185</sup> The kids also got “a label that says, ‘you can’t cut it.’”<sup>186</sup> It was a one-way ticket to the “permanent underclass.”<sup>187</sup>

The same kind of critiques surfaced in the spring of 1996, when the *New York Times* covered an “aggressive[]” four-year effort by the New York City Board of Education and the City’s Human Resources Administration to “steer[] thousands of poor students classified with learning difficulties or emotional problems off municipal welfare and onto Federal disability payments.”<sup>188</sup> They did so by stationing “coordinators” at special education offices in all of the City’s school districts; these coordinators would “go to schools, visit homes and walk parents through the application forms.”<sup>189</sup> Their efforts worked. Between 1992 and the date of the reporting (April 1996), the City had steered 11,000 children onto SSI, about eight percent of the children in special education.<sup>190</sup> To proponents of the New York City effort, it was “a mitzvah” to poor families, as well as a fiscal win for the City during “lean times”: they reported savings to the City and State of an estimated \$5.2 million.<sup>191</sup> Critics, however, worried that once families began receiving SSI, they would have less incentive to help their children “overcome[]” their disabilities.<sup>192</sup> Critics also speculated that if parents saw special education as a route to receiving SSI, some children would be channeled there unnecessarily and their life chances would suffer. “[Receiving SSI] could lead

<sup>182</sup> Jouzaitis, *supra* note 181, at L10.

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

<sup>184</sup> Jessi Streib, SaunJuhi Verma, Whitney Welsh & Linda M. Burton, *Life, Death, and Resurrections: The Culture of Poverty Perspective*, in *THE OXFORD HANDBOOK OF THE SOCIAL SCIENCE OF POVERTY* (David Brady & Linda M. Burton eds., 2016).

<sup>185</sup> Jouzaitis, *supra* note 181, at L10.

<sup>186</sup> *Id.*

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

<sup>188</sup> Lynda Richardson, *U.S. Cash Keeps Children of Poor from Leaving Special Education*, N.Y. TIMES, Apr. 6, 1996, at 1.

<sup>189</sup> *Id.* at 29.

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

<sup>191</sup> *Id.* at 1, 29.

<sup>192</sup> *Id.* at 29.

them to be dependent for the rest of their lives,” an economist with the Urban Institute suggested.<sup>193</sup>

These concerns help explain why, less than five months after this *New York Times* story, the SSI kids program underwent reform. Government investigators had by then debunked the notion of widespread “coaching”<sup>194</sup> and a prominent media watchdog (*Forbes Media Critic*) had condemned media outlets for the damaging stories they published,<sup>195</sup> but Congress’s conservative majority was not going to lose sight of a program that so directly implicated its “Contract with America.” That suite of campaign promises prioritized fiscal responsibility and welfare reform.<sup>196</sup> The SSI kids program, while small relative to other social support programs, was an expansive form of “welfare” that remained associated in the public mind with Blackness, delinquency, fraud, and cultural deficits.

Changes to the SSI kids program came via the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (“PRWORA”), which President Bill Clinton signed into law in August 1996 and advertised as “the end of welfare as we know it.”<sup>197</sup> PRWORA modified the eligibility determination for child SSI applicants such that *Zebley*’s “functional” path to benefits became narrower. Under the new regime (still in effect today), qualifying based on functional limitations necessitates evidence of more severe limitations than previously required. In 1997, nearly 100,000 children lost their benefits as a result of this change.<sup>198</sup> Another provision of PRWORA placed new restrictions on how parents of disabled children may spend retroactive benefits awarded to their children, thus creating new

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<sup>193</sup> *Id.*

<sup>194</sup> U.S. GOV’T ACCOUNTABILITY OFF., GAO/HEHS-96-96R, SSA: INITIATIVES TO IDENTIFY COACHING (1996). As this essay has tried to emphasize, there were multiple reasons for this trend, including (1) *Zebley* and the ensuing requirement of individualized functional assessments; (2) the SSA’s decision to add more mental impairments to the Listings, including mood, personality, and attention deficit disorders; and (3) the awareness by state officials that they could realize cost savings by helping to shift people onto SSI. See NEW FUNCTIONAL ASSESSMENTS, *supra* note 42; DAVID KOITZ, GEOFFREY KOLLMANN & JENNIFER NEISNER, CONG. RSCH. SERV., RL 94-477, STATUS OF THE DISABILITY PROGRAMS OF THE SOCIAL SECURITY ADMINISTRATION 9, 12 (1994) (describing changes in criteria for mental illness diagnoses).

<sup>195</sup> Georges, *supra* note 160.

<sup>196</sup> See KEVIN M. KRUSE & JULIAN E. ZELIZER, FAULT LINES: A HISTORY OF THE UNITED STATES SINCE 1974 at 216 (2019) (describing the Contract with America as “a slick ten-point program” that called for “a balanced budget amendment, a line-item veto for the president, welfare rollbacks, more money for defense, term limits, stringent measures for crime control, and a fifty percent reduction in the capital gains tax”).

<sup>197</sup> See CHAPPELL, *supra* note 38, at 20 (referring to the 1996 reform as “the end of welfare as we know it”); Daly & Duggan, *supra* note 23, at 236 (noting that changes to the SSI kids program came via the broader 1996 welfare reform legislation).

<sup>198</sup> Daly & Duggan, *supra* note 23, at 236.

administrative burdens and further subjecting poor families to surveillance and suspicion.<sup>199</sup>

What may be most striking about this history, however, is how the SSI kids program endured. In the short term, the program shrunk slightly, but as of 2017, it was serving 1.6 percent of the nation's children.<sup>200</sup> It remains an appealing program from the beneficiary perspective because it is generous relative to other welfare programs, such as TANF. It appeals to policymakers because it channels income support towards children in need without committing the government to supplying universal basic income. Redistribution occurs, but policymakers can continue to insist that only the "deserving poor" are benefitting.

## V. REFLECTIONS ON THE "DISABLED STATE"

On November 28, 1989, as the *Zebley* litigation team listened to their colleague Richard Weishaupt argue their case before the Supreme Court, lawyer Tom Sutton received a phone call. In an instant, he "went from the highest point professionally" he could imagine to "the lowest point of [his] life."<sup>201</sup> Sutton learned that his only brother, Kevin, had died.<sup>202</sup> An early member of the HIV/AIDS activist organization ACT UP, Kevin had helped educate Sutton about HIV/AIDS and the inadequacies of the government's response.<sup>203</sup> Sutton carried these lessons, and Kevin's memory, with him into his next major class action lawsuit.<sup>204</sup> That case centered on Peter Rosetti and "Mary Doe," two Philadelphia-area residents who were HIV-positive and unable to work because of their symptoms, but had nonetheless been denied

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<sup>199</sup> See Richard P. Weishaupt, Jonathan M. Stein & Robert J. Lukens, *The Dedicated Account Rules: Retroactive Supplemental Security Income Benefits for Disabled Children*, 32 CLEARINGHOUSE REV. 469, 473 (1998) (describing how the dedicated account system works and noting the significant consequences for poor families of violating the new restrictions); see also O'Connell, *supra* note 37, at 70-72 (documenting how the dedicated account system works in practice and characterizing it as wasteful and counterproductive).

<sup>200</sup> O'Connell, *supra* note 37, at 70-72. Looking at total enrollment is another way to gauge significance. For the past several years, the SSI kids program has served around 1.2 million children annually. SSA, SSI ANNUAL STATISTICAL REPORT (2020), [https://www.ssa.gov/policy/docs/statcomps/ssi\\_asr/2020/sect01.html](https://www.ssa.gov/policy/docs/statcomps/ssi_asr/2020/sect01.html) [<https://perma.cc/L7WY-7NWG>].

<sup>201</sup> Sutton Interview, *supra* note 2.

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

<sup>203</sup> *Id.* On Kevin Sutton's involvement in ACT UP, see Garance Franke-Ruta, *The Plague Years, In Film and Memory*, ATLANTIC (Feb. 24, 2013), <https://www.theatlantic.com/entertainment/archive/2013/02/the-plague-years-in-film-and-memory/273449/> [<https://perma.cc/F8DX-D4EH>] (recounting memories of ACT UP and memorializing Sutton's death), and *Kevin Sutton*, OUTWEEK (Dec. 10, 1989) (on file with author) (providing notice of Kevin Sutton's death and suggesting ACT UP as an organization to donate to in his memory).

<sup>204</sup> Sutton Interview, *supra* note 2.



disability benefits.<sup>205</sup> On behalf of these individuals and others similarly situated, CLS sued the SSA, alleging an overly narrow approach to claims based on HIV/AIDS.<sup>206</sup>

The outcome of the *Rosetti* case exemplifies the good that resulted from broader awareness of disability and its capaciousness. The case helped inspire the SSA to revise its regulations and also secured reevaluations for thousands of claimants with HIV/AIDS.<sup>207</sup> Once again, a widening of the disability aperture allowed government support to flow to people in need. Indeed, the path was just as political scientist Deborah Stone had identified in 1984: the legal concept of disability was flexible; when subjected to the right economic, political, and moral pressure, it expanded.<sup>208</sup>

Not all expansions of the disability category merit the same ultimate judgment, however, and it is worth scrutinizing each one, lest we accept too uncritically the phenomenon of distribution-via-disability.

The *Zebley* expansion was special in that it subtly undermined, rather than reinforced, the notion that disability-based support must be tethered to the appetites of the formal labor market (recall that historically, a working-age adult would be recognized as “disabled” only if the market had no use for them). *Zebley* and the reforms it triggered imagined a world in which not only might the gatekeepers of social support pay greater attention to functioning (rather than looking solely at medical diagnosis), but also *the relevant functionality might have nothing to do with producing value for an employer*. It is not a far leap to imagine that perhaps individuals have a value apart from what they can produce for profit. Perhaps our social welfare system could prioritize human dignity, or civic belonging, over the desire to discipline workers.<sup>209</sup>

If *Zebley* opened up that possibility, however, other expansions of the disability category have occluded it—by failing to challenge, and thereby reinscribing, the message that disability means inability to work and that only inability to work proves “true” disability.

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205 Kitty Caparella, *Lawsuit Filed for Benefits*, PHILA. DAILY NEWS, June 5, 1991, at 12.

206 *Rosetti v. Sullivan*, 788 F. Supp. 1380, 1382-83 (E.D. Pa. 1992).

207 Stipulation and Order at \*1-4, *Rosetti v. Sullivan*, 788 F. Supp. 1380 (E.D. Pa. 1992) (No. 91-3389), 1994 WL 655803. The reevaluations applied to claimants who lived within the jurisdiction of the Third Circuit and had been denied benefits between the time of the case’s filing and the implementation of the new regulations.

208 STONE, *supra* note 1, at 140-60 (explaining why individual claimants, professional gatekeepers, and high-level policymakers all might have reasons to exert expansionary pressure on the “highly flexible” concept of disability).

209 For general discussion of this alternative vision, see MARTA RUSSELL, *CAPITALISM & DISABILITY* (Keith Rosenthal ed., 2019) and LEAH LAKSHMI PIEPZNA-SAMARASINHA, *CARE WORK: DREAMING DISABILITY JUSTICE* (2018).

Moreover, in the SSI/SSDI context, expansions to the concept of disability have only augmented, rather than contested, the authority of “helping professionals,” such as doctors and vocational experts (and lawyers).<sup>210</sup> Even as more people have been allowed to enter the “disability” category, policymakers have insisted on an intense form of border control. A 2017 study characterized “[t]he SSA’s current anti-fraud strategy” as “compris[ing] eighteen separate components,” ranging from national review committees to specialized investigation and prosecution units.<sup>211</sup> Expert authorities, most of whom do not identify as disabled, act as crucial gatekeepers within this system.

This is troubling from a disability justice perspective in that it devalues and disempowers people who have personal experience with disability.<sup>212</sup> But it is also troubling because of its spillover effects into other areas of law and society. In the context of an ungenerous and non-uniform social welfare system, disability-based benefits may appear to be a “privilege.” They may look like special treatment. From that skeptical and scarcity-minded vantage point, it becomes easier to see inclusion guarantees for disabled people in the same terms—that is, not as civil rights or human rights, but as privileges, to be jealously guarded and bestowed only upon the truly deserving.

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<sup>210</sup> On the empowerment of helping professionals and what this means for the participation of disabled laypersons, see Doron Dorfman & Mariela Yabo, *The Professionalization of Urban Accessibility*, 47 *FORDHAM URB. L.J.* 1213 (2020).

<sup>211</sup> Henry J. Whittle, Kartika Palar, Nikhil A. Ranadive, Janet M. Turan, Margot Kushel & Sheri D. Weiser, “*The Land of the Sick and the Land of the Healthy*”: *Disability, Bureaucracy, and Stigma Among People Living with Poverty and Chronic Illness in the United States*, 190 *SOC. SCI. & MED.* 181, 182 (2017).

<sup>212</sup> See Dorfman & Yabo, *supra* note 210, at 1256 (“Despite the urgent need for truly accessible built environments, the process of creating or standardizing new professions in the field of disability access should be done carefully.”).

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