

# Clearinghouse REVIEW

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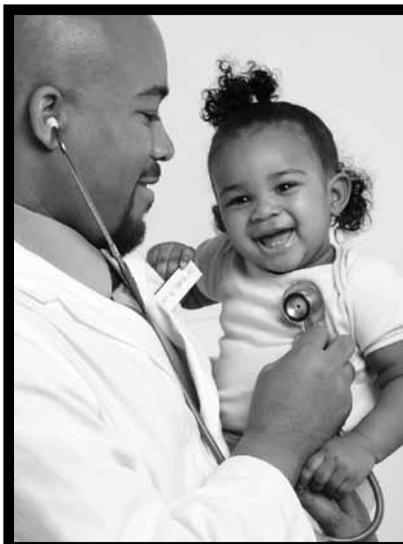
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## Children's SSI Disability Benefits at Risk...

# Again

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**S**upplemental Security Income (SSI) serves as a critical lifeline for more than 1.2 million low-income children with severe mental and physical disabilities.<sup>1</sup> To help families offset some of the additional costs of raising a child with disabilities, replace some of the parental income lost due to staying home to care for the child, and provide basic necessities such as food, clothing, and shelter, so they can raise their child at home rather than in an institution, SSI provides a modest income supplement.<sup>2</sup> In most states, SSI also provides automatic Medicaid eligibility.<sup>3</sup>

Children's SSI disability benefits have at times been a lightning rod of negative attention by the media and Congress alike. Today SSI is once again in the spotlight, the subject of spurious claims and allegations, particularly regarding mental impairments. How this round of the decades-long debate over children's SSI will play out is unclear. However, as discussed in greater detail below, renewed attention to the Social Security Administration's failure to perform timely childhood continuing disability reviews will almost certainly lead to a significant increase in the number of childhood continuing disability reviews conducted and the number of children facing termination of benefits.

Here we give a brief overview of children's SSI, including the evolution of the childhood disability standard and the significance of the benefit to families; discuss the threats to the program; survey enrollment trends from the past decade; and look ahead to possible changes, with special attention given to what the legal services community can do.

<sup>1</sup>SOCIAL SECURITY ADMINISTRATION, ANNUAL STATISTICAL REPORT OF THE SUPPLEMENTAL SECURITY INCOME PROGRAM, 2010, tbl.43, at 17 (2011) [hereinafter ANNUAL STATISTICAL REPORT 2010].

<sup>2</sup>JERRY MASHAW ET AL., NATIONAL ACADEMY OF SOCIAL INSURANCE, RESTRUCTURING THE SSI DISABILITY PROGRAM FOR CHILDREN AND ADOLESCENTS: REPORT OF THE COMMITTEE ON CHILDHOOD DISABILITY OF THE DISABILITY POLICY PANEL (1996). The full Supplemental Security Income (SSI) benefit amount in 2011 was \$674 per month; in 2012 it is \$698 per month (Social Security Online, Office of the Chief Actuary, Social Security Administration, SSI Federal Payment Amounts (Oct. 19, 2011), <http://1.usa.gov/lf2inn>). Most recipients get less than the full amount, however, because grants are reduced if there is other household income; the average monthly benefit received in 2010 was \$596 (see ANNUAL STATISTICAL REPORT 2010, *supra* note 1, tbl.17, at 43). States also have the option of supplementing the federal benefit rate, and most do, at varying amounts (Social Security Administration, Understanding Supplemental Security Income (2012), <http://1.usa.gov/birOXh>).

<sup>3</sup>42 U.S.C. § 1396a(f) (§ 209(b)). States have the option of using their own eligibility criteria in determining Medicaid eligibility for the elderly and disabled, rather than providing Medicaid coverage to all SSI recipients. About a dozen states, known as 209(b) states, exercise this option. For most children, however, there are many other ways to qualify for Medicaid, and those who are financially ineligible for Medicaid likely qualify for the State Children's Health Insurance Program.

### Overview of SSI Childhood Disability

SSI was established in 1972 to provide a minimum income to individuals 65 years of age or older, and adults and children who are blind or disabled.<sup>4</sup> “Disability” was defined as the inability to engage in “substantial gainful activity by reason of a medically determinable physical or mental impairment expected to result in death, or that has lasted or can be expected to last for a continuous period of at least 12 months.”<sup>5</sup> Children with impairments of “comparable severity” to that of an adult were deemed eligible for benefits, in recognition of the additional expenses and lost parental income incurred by families raising children with disabilities.<sup>6</sup>

Childhood disability was assessed initially on the basis solely of whether a child's impairments “met” or “medically equaled” one of the Social Security Administration's listing of impairments—a catalog of disorders and conditions, organized by body system (e.g., skin disorders), each with an accompanying description of required severity or symptoms.<sup>7</sup> In 1990, in *Sullivan v. Zebley*, the U.S. Supreme Court held that the Social Security Administration's process for evaluating childhood disability was inconsistent with the statutory standard and ruled that the agency

must consider the *functional impact* of the child's impairment(s) in determining eligibility—as was done with adults—rather than just whether the impairment met or medically equaled a listing.<sup>8</sup>

The decision in *Zebley* and the subsequent increase in SSI child enrollment—in particular among children with mental impairments—sparked a backlash from critics who argued that the program's eligibility criteria had become too lax, and the program too costly. A wave of news reports alleged that thousands of children had been “coached” by their parents to “fake insanity or disabilities” in order to be approved for so-called crazy checks (a slang term, which remains in use today, for SSI benefits paid to individuals with mental impairments).<sup>9</sup> Nonpartisan investigations into such claims later showed them to be unsubstantiated, but the damage was done.<sup>10</sup> Congress sprang into action to “correct” a grossly exaggerated, if not altogether invented, “problem” before all the facts were in. Congress severely narrowed, as part of “welfare reform,” the definition of disability for children's SSI benefits.<sup>11</sup> Some hundred thousand children were terminated from SSI.<sup>12</sup> Countless more have had their claims denied in the years since under the more restrictive disability standard.

<sup>4</sup>*Id.* §§ 1381–1383(f).

<sup>5</sup>*Id.* § 423(d)(1)(A).

<sup>6</sup>MASHAW ET AL., *supra* note 2, at 15–19.

<sup>7</sup>40 C.F.R. §§ 416.924–416.925; Social Security Listing of Impairments, *id.* § 404, subpart P, app. 1.

<sup>8</sup>*Sullivan v. Zebley*, 493 U.S. 521 (1990).

<sup>9</sup>The most visible and influential such article ran on the front page of the WASHINGTON POST (Bob Woodward & Benjamin Weiser, *Costs Soar for Children's Disability Program: How 26 Words Cost the Taxpayers Billions in New Entitlement Payments*, WASHINGTON POST, Feb. 4, 1994, at A1). For a discussion and analysis of the mid-1990s' “crazy checks” frenzy, see Christopher Georges, *A Media Crusade Gone Haywire*, 3 FORBES MEDIA CRITIC 66 (1995). For a definition of the slang term “crazy checks,” see, e.g., www.UrbanDictionary.com, which lists, among others, the following definition: “Some unnecessary monthly payment from ... SSI which is made purportedly for a disability suffered by the payee... [Crazy checks are often approved for simple and common conditions such as a child (usually in a single-parent household) who can't behave in school.”

<sup>10</sup>See e.g., MASHAW ET AL., *supra* note 2; U.S. Department of Health and Human Services, Office of the Inspector General, A-03-94-02602, *Concerns About the Participation of Children with Disabilities in the Supplemental Security Income Program* (Oct. 1994); U.S. General Accounting Office, B-271255, *Letter Report to Rep. Blanche Lincoln* (March 5, 1996); Social Security Administration, *Findings from the Study of Title XVI Childhood Disability Claims* (May 1994). See also Georges, *supra* note 9.

<sup>11</sup>42 U.S.C. § 1382c(a)(3)(C)(i) (as amended by Personal Responsibility and Work Opportunity Reconciliation Act of 1996, Pub. L. No. 104-193, § 211(a), 110 Stat. 2105). For a discussion of the welfare reform law's SSI provisions, see Thomas Yates, *The Aftermath of Welfare Reform: SSI Childhood Disability*, 31 CLEARINGHOUSE REVIEW 358 (Nov.–Dec. 1997).

<sup>12</sup>See Yates, *supra* note 11.

**SSI Childhood Disability Standard.** To qualify for SSI benefits under current law, a child must have a “medically determinable physical or mental impairment, which results in marked and severe functional limitations.”<sup>13</sup> In practice, a child must either “meet or medically equal” a listed impairment, or must qualify via “functional equivalence,” which requires that an impairment or combination of impairments result in disabling functional limitations that are the same as those of a listed impairment.<sup>14</sup> The Social Security Administration looks at six broad areas of functioning, or *domains*:

- acquiring and using information;
- attending and completing tasks;
- interacting and relating with others;
- moving about and manipulating objects;
- caring for yourself;
- and health and physical well-being.<sup>15</sup>

A child's impairment(s) is considered functionally equivalent and thus disabling if the impairment(s) causes *extreme* limitations in one domain, or *marked* limitations in two domains.<sup>16</sup> In contrast to adult disability determination, there is no vocational analysis.<sup>17</sup>

After initial approval for benefits, the statute further requires that children subsequently be reviewed to determine continuing eligibility for SSI benefits.<sup>18</sup> Continuing disability reviews are required at age 1 for all children awarded benefits due to low birth weight.<sup>19</sup> Such reviews are required every three years in all child cases where medical improvement is expected.<sup>20</sup> And, in order to continue receiving benefits as an adult, all child SSI recipients are required to be reevaluated at 18 under the adult standard.<sup>21</sup>

**Children's SSI Benefit: A Critical Lifeline.** As recently as the 1960s, parents had little choice other than to put children with intellectual disabilities (formerly called mental retardation) or other physical or mental impairments into institutions.<sup>22</sup> Since the dawn of the deinstitutionalization movement, a network of community services and supports has gradually developed to enable parents to care at home for their children with special needs.<sup>23</sup> The advent of SSI childhood disability benefits marked a critical milestone along the way; it provided vital income support to low-income families with children with severe disabilities.

A growing array of research indicates that families with disabled children are

<sup>13</sup>42 U.S.C. § 1381; 20 C.F.R. § 416.906.

<sup>14</sup>20 C.F.R. § 416.924.

<sup>15</sup>*Id.* § 416.926.

<sup>16</sup>*Id.* § 416.926a(a). “Marked” and “extreme” are terms of art and have different meanings for younger and older children. For more discussion of these and other aspects of childhood disability evaluation and practice tips, see Thomas Yates, *New Rules, Same Standard: The Social Security Administration Adopts New Rules for Evaluating SSI Childhood Disability*, 35 CLEARINGHOUSE REVIEW 59 (May–June 2001); Thomas Yates, *Preparing a Children's Supplemental Security Income Disability Case for Hearing*, 32 *id.* 463 (Jan.–Feb. 1999); Catherine Callery et al., *Social Security Rulings—Guiding Hand in SSI Childhood Disability Evaluations*, 44 *id.* 174 (July–Aug. 2010).

<sup>17</sup>20 C.F.R. §§ 416.905, 416.920(e), 416.945. The vocational analysis in adult disability determination is referred to as “step 5” of the sequential evaluation.

<sup>18</sup>42 U.S.C. §§ 421(i), 1382c(a)(3)(h)(ii)(I). Continuing disability reviews are also required by law in many adult cases. For a detailed discussion of continuing disability reviews and helpful practice tips, see Linda Landry, *Continuing Disability Reviews: What Advocates Need to Know*, 40 CLEARINGHOUSE REVIEW 415 (Nov.–Dec. 2006).

<sup>19</sup>Program Operations Manual System (POMS) DI 25235.006.

<sup>20</sup>20 C.F.R. § 416.990. See *infra* text accompanying notes 66–72 for a more detailed discussion of childhood continuing disability reviews.

<sup>21</sup>42 U.S.C. § 1382c(a)(3)(h); 20 C.F.R. § 416.987. This type of review is commonly referred to as an age-18 redetermination.

<sup>22</sup>See, e.g., JACQUELINE VAUGHN SWITZER, *DISABLED RIGHTS: AMERICAN POLICY AND THE FIGHT FOR EQUALITY* (2003); see also DORIS ZAMES FLEISCHER & FREIDA ZAMES, *THE DISABILITY RIGHTS MOVEMENT: FROM CHARITY TO CONFRONTATION* (2001).

<sup>23</sup>SWITZER, *supra* note 22; FLEISCHER & ZAMES, *supra* note 22.

## My Family Would Literally Be Homeless Without Help from Supplemental Security Income

I am the mother of Tyler and Noah, 5-year-old autistic twins. Both twins have severe symptoms—one is nonverbal and engages in typical autism behaviors like flapping his arms, spinning, and throwing tantrums; the other is verbal but has severe anxiety, intestinal problems, sensory problems. I am separated from my husband, and we have no other source of income besides food stamps; I cannot keep or find a job that allows me the flexibility needed to provide for my kids. I am on call all day every day to pick them up from day care when they need care, get sick, or need to see a doctor.

—Rhonda Roberts, Eglin, Texas

significantly more likely to face material hardship than families with nondisabled children. One recent study found that children with disabilities lived in homes “with fewer resources” which were “less likely to be healthy and safe”; their health status was worse; and overall their socioeconomic and family situations were “poorer” than nondisabled children.<sup>24</sup> Other studies have found that—even at the same income levels—families with disabled children are considerably more likely to experience food insecurity, as well as housing and utility-related hard-

ship, than families with children without disabilities.<sup>25</sup>

The income lost when a parent must work fewer hours or loses a job because of unavoidable absences to care for a child's special needs can be crushing.<sup>26</sup> For single-parent households, this can present a particular hardship.<sup>27</sup> Furthermore, a multitude of extra expenses may be associated with raising a child with special needs; many of such expenses may not be covered by Medicaid or private insurance plans, forcing parents to pay for them out of pocket.<sup>28</sup>

Thus, for many families, the modest income support from SSI—on average just \$593 per month in 2010—means the difference between living above and below the poverty line, between being able to provide for their disabled child and having to forgo basic necessities.<sup>29</sup> Even with that income support, nearly half of children receiving SSI remain below the poverty line.<sup>30</sup> One recent longitudinal study found that child SSI enrollment is associated with a statistically significant and persistent 11 percent reduction in the probability that a child lives in poverty.<sup>31</sup> Also noteworthy from this study, receiving SSI was *not* a disincentive for parental employment.<sup>32</sup>

<sup>24</sup>Dennis Hogan et al., *Functional Limitations and Key Indicators of Well-Being in Children with Disabilities*, 154 ARCHIVES OF PEDIATRIC AND ADOLESCENT MEDICINE 1042 (2000).

<sup>25</sup>Susan L. Parish et al., *Material Hardship in U.S. Families Raising Children with Disabilities*, 75 EXCEPTIONAL CHILDREN 71 (2008); Susan L. Parish et al., *Material Hardship in U.S. Families Raising Children with Disabilities: Research Summary and Policy Implications*, U.N.C. SCHOOL OF SOCIAL WORK RESEARCH BRIEF, March 2009, <http://bit.ly/lbZ4zp>.

<sup>26</sup>See sources cited in *supra* note 25; see also Shanna Shulman et al., *Quality Care for Special Kids: Profiles of Children with Chronic Conditions and Disabilities: Impact on Family and Work*, Mathematica Policy Research Update No. 5 (Feb. 2007), <http://bit.ly/lFyYkU>; see also Whitney P. Witt et al., *The Impact of Childhood Activity Limitations on Parental Health, Mental Health, and Workdays Lost in the United States*, 9 ACADEMY OF PEDIATRICS 263 (2009), <http://1.usa.gov/Ktcc5f>.

<sup>27</sup>The Social Security Administration reports that over 60 percent of children receiving SSI in 2010 lived in one-parent households (ANNUAL STATISTICAL REPORT 2010, *supra* note 1, tbl.24, at 51).

<sup>28</sup>Medicaid is required by federal law to cover all “medically necessary” services and treatments (42 U.S.C. §§ 1396–1396a). However, in practice, denials of coverage often go unchallenged and can prevent access to those services and payment out of pocket. Many extra expenses that are the result of a disability—e.g., special day care—may not be considered “medically necessary” for purposes of Medicaid or otherwise covered by private insurance.

<sup>29</sup>Mark Duggan & Melissa Kearney, *The Impact of Child SSI Enrollment on Household Outcomes*, 26 JOURNAL OF POLICY ANALYSIS AND MANAGEMENT 861 (2007); see also Kalman Rupp et al., *A Profile of Children with Disabilities Receiving SSI: Highlights from the National Survey of SSI Children and Families*, 66 SOCIAL SECURITY BULLETIN 21 (2005–2006), <http://1.usa.gov/IYGr0w>; see also Center on Budget and Policy Priorities, *Introduction to the Supplemental Security Income (SSI) Program* (Jan. 10, 2011), <http://bit.ly/HVqLe5>.

<sup>30</sup>Rupp et al., *supra* note 29.

<sup>31</sup>Duggan & Kearney, *supra* note 29.

<sup>32</sup>*Id.*

## Threats to Children's SSI

Disability benefit programs, particularly SSI and Social Security Disability Insurance, have once again become a popular target for criticism, fueled by an onslaught of critical media coverage, much of it flawed and misleading. Efforts to undermine SSI have picked up momentum as political fault lines have developed over federal spending and the deficit. Among some critics, children's SSI is viewed as "the new welfare."

In December, 2010 the *Boston Globe* ran a series of articles criticizing children's SSI, labeling the program "the new welfare."<sup>33</sup> In its claims of widespread abuse by families falsely alleging that their children have mental impairments in order to collect SSI, reminiscent of the mid-1990s "crazy checks" media blitz, the series was based almost entirely on anecdotal "evidence" drawn from interviews with a handful of families. It spurred a heated response from parents, medical providers, and advocates for the disabled, pointing out serious factual errors and the appearance of one-sidedness in the *Globe's* reporting.<sup>34</sup>

The series nonetheless sparked concern by some in Congress, which called for a study by the Government Accountability Office (GAO) and held a hearing on children's SSI.<sup>35</sup> The central focus of congressional scrutiny is recent growth in SSI child enrollment, particularly among children with mental impairments.<sup>36</sup> In this way the current debate very much mirrors the "crazy checks" firestorm of the mid-1990s, with perceived "fraud and abuse" again likely reflecting veiled skepticism of mental impairments. In 2011 the U.S. House of Representatives passed a budget resolution including an array of cuts in safety-net programs, specifically \$1.4 billion in cuts in children's SSI.<sup>37</sup> The Republican Study Committee called for block-granting SSI altogether.<sup>38</sup> In 2012 a House budget resolution passed even more drastic cuts in children's SSI—\$3.5 billion.<sup>39</sup> While no cuts in SSI have become law, we expect proposals for these and other major changes to keep coming. Moreover, they illustrate the extent of political will for making significant cuts in SSI.

<sup>33</sup>Patricia Wen, *A Legacy of Unintended Side Effects*, *Boston GLOBE*, Dec. 12, 2010, at 1; Patricia Wen, *A Coveted Benefit: A Failure to Follow Up*, *id.* Dec. 13, 2010, at 1; Patricia Wen, *A Cruel Dilemma for Those on the Cusp of Adult Life*, *id.* Dec. 14, 2010, at 1; Editorial, *Revamp SSI to Help Caregivers While Discouraging Abuses*, *id.* Dec. 16, 2010, at 22 [hereinafter *GLOBE SERIES*]. Economists critical of children's SSI have adopted the "new welfare" line of argument, as well, even suggesting (without substantiation) that SSI is harmful for children with disabilities (see, e.g., RICHARD BURKHAUSER & MARY DALY, *AMERICAN ENTERPRISE INSTITUTE, THE DECLINING WORK AND WELFARE OF PEOPLE WITH DISABILITIES: WHAT WENT WRONG AND A STRATEGY FOR CHANGE* (2011)).

<sup>34</sup>The series also provoked a complaint to the ombudsman of the paper. Signed by some ten national organizations including the National Alliance on Mental Illness, the Bazelon Center for Mental Health Law, and Mental Health America, the complaint called attention to a number of serious factual errors and the reporter's questionable and limited methodology and sourcing. For a collection of letters to the editor and the ombudsman complaint, see Community Legal Services of Philadelphia, *CLS Efforts to Protect the Supplemental Security Income (SSI) Disability Program* (n.d.), <http://bit.ly/13UNys>.

<sup>35</sup>Jenny Gold, *SSI Program for ADHD, Other Disabled Kids Under Scrutiny*, *KAISER HEALTH NEWS*, Aug. 24, 2011, <http://bit.ly/HFVvAc> (containing a link to the Government Accountability Office (GAO) request); Committee on Ways and Means, U.S. House of Representatives, Chairman Davis Announces Hearing on Supplemental Security Income Benefits for Children (Oct. 27, 2011), <http://bit.ly/10oQaW>; U.S. GOVERNMENT ACCOUNTABILITY OFFICE, *GAO-12-196T, SUPPLEMENTAL SECURITY INCOME: PRELIMINARY OBSERVATIONS ON CHILDREN WITH MENTAL IMPAIRMENTS* (Oct. 27, 2011), <http://1.usa.gov/lvGQYp> (statement of Daniel Bertoni, Director, Education, Workforce, and Income Security, before the Subcommittee on Human Resources, Committee on Ways and Means, U.S. House of Representatives). Release of the GAO study is expected in May 2012.

<sup>36</sup>See, e.g., Patricia Wen, *Children's SSI Program Examined*, *BOSTON GLOBE*, Oct. 28, 2011, *Metro* at 1, <http://bo.st/11KtWD>; Gold, *supra* note 35. See further discussion *infra* text accompanying notes 55–64.

<sup>37</sup>H.R. Con. Res. 34, 111th Cong. (2011) (U.S. House of Representatives Committee on Budget, Fiscal Year 2012 Budget Resolution). Budget Committee documents provide that the \$1.4 billion in savings would be achieved by reducing "incentives to medicate children" for SSI benefits.

<sup>38</sup>Republican Study Committee, *RSC Budget for FY 2012: Honest Solutions* (2011), [www.rsc.jordan.house.gov](http://www.rsc.jordan.house.gov).

<sup>39</sup>H.R. Con. Res. 112, 112th Cong. (2012) (U.S. House of Representatives Committee on Budget, Fiscal Year 2013 Budget Resolution). Budget Committee report language provides that the savings would be achieved by paying SSI on a "sliding scale," thus reducing benefits for the second SSI child recipient in a household.

Ongoing scrutiny is focused also on the Social Security Administration's failure to conduct childhood continuing disability reviews in a timely manner, due in large part to Congress' failure to provide the agency with sufficient administrative resources.<sup>40</sup> In response to growing public attention to this issue, the agency is expected to step up performance of childhood continuing disability reviews. This, we believe, will mean an increase in disability cessations for child claimants who are found to have medically improved.<sup>41</sup>

### The Facts

Amid the swirl of myths, anecdotes, and "conventional wisdom," largely missing from the debate over children's SSI has been a serious, fact-based examination of the program and its enrollment trends.<sup>42</sup>

**Only a Tiny Fraction of Children with Disabilities Receive SSI.** Approximately 1.2 million children with disabilities received SSI in 2010—about 1.6 percent of the U.S. child population.<sup>43</sup> In compari-

son, estimates of the prevalence of childhood disabilities range from 9 percent to 19 percent of the U.S. child population.<sup>44</sup> Thus we estimate that the share of children who have disabilities and receive SSI is less than 10 percent.<sup>45</sup> Due to the stringent medical and financial eligibility criteria, over 60 percent of children who apply for benefits are denied.<sup>46</sup>

**Recent Growth in Children's SSI Is Explained by Rising Child Poverty and Increased Access to Children's Health Insurance.** The number of children receiving SSI has increased over the past decade.<sup>47</sup> However, that increase has largely kept pace with population growth and the surge in child poverty during that same period.<sup>48</sup> Today more than 16.4 million U.S. children live in poverty—a staggering 22 percent and an increase of nearly 1 million since 2009.<sup>49</sup> In 2000 the number of children who received SSI comprised 7.3 percent of children living below the poverty line.<sup>50</sup> In 2010 children receiving SSI constituted nearly the same share—7.9 percent of all poor children.<sup>51</sup> Thus claims

<sup>40</sup>According to a recent report by the Social Security Administration's Office of the Inspector General, as many as 79 percent of childhood continuing disability reviews are not being timely completed. That report recommended special targeted funding to enable the agency to tackle its continuing disability review backlog (Office of the Inspector General, Social Security Administration, A-01-11-11118, Follow-up: Childhood Continuing Disability Reviews and Age-18 Redeterminations (Sept. 2011), <http://bit.ly/HWG9ea>).

<sup>41</sup>See *infra* text accompanying notes 66–72 on continuing disability reviews.

<sup>42</sup>Much of the trends and data analysis that follow are drawn from Shawn Fremstad & Rebecca Vallas, The Children's Supplemental Security Income Program: A Review of Recent Research and Trends (Center for Economic and Policy Research & Community Legal Services, Working Paper, Aug. 2011) (presentation slides at <http://bit.ly/HTTYPK>; executive summary at <http://bit.ly/ISv8oK>). Due to the lack of a fact-based examination of children's SSI, advocates, some in Congress, and the Social Security Administration have called for a study by the Institute on Medicine (Patricia Wen, *SSI Program Is Flawed, Chief Says; Wants a \$10M Study of Disability System*, BOSTON GLOBE, May 24, 2011, Metro at 1).

<sup>43</sup>Our analysis of ANNUAL STATISTICAL REPORT 2010, *supra* note 1, and U.S. Census Bureau data, e.g., U.S. Census Bureau, Current Population Survey, Housing and Household Economic Statistics Division, Fertility and Family Statistics Branch, tbl.C9 (2011).

<sup>44</sup>Child Trends, Children with Limitations (2010), <http://bit.ly/HLCjpE>; Coleen Boyle et al., *Trends in the Prevalence of Developmental Disabilities in U.S. Children, 1997–2008*, 127 PEDIATRICS 1034 (2011); Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services, The National Survey of Children with Special Health Care Needs Chartbook 2005–2006 (2007).

<sup>45</sup>Our analysis of ANNUAL STATISTICAL REPORT 2010, in *supra* note 1, and sources cited in *supra* notes 43 and 44.

<sup>46</sup>Social Security Online, SSA State Agency Monthly Workload Data (Feb. 9, 2011), <http://1.usa.gov/IAxsp0>.

<sup>47</sup>The number of children receiving SSI has increased from 844,747 in 2000 to about 1.2 million in 2010 (ANNUAL STATISTICAL REPORT 2010, *supra* note 1, at 38).

<sup>48</sup>Our analysis of sources and data cited in *supra* notes 43–44.

<sup>49</sup>Children's Defense Fund, The State of America's Children (2011); U.S. Census Bureau, Current Population Survey, Annual Social and Economic Supplement to the Current Population Survey, Historical Poverty Tables, People (2010).

<sup>50</sup>See sources cited in *supra* note 49.

<sup>51</sup>*Id.*

of “staggering” growth in children’s SSI are overblown and fail to take into account the unhappy truth of more poor children in America than in recorded history, and thus more children who have disabilities and are financially eligible for SSI.

Another, happier factor that is likely to have contributed to the increase in children’s SSI enrollment is the significant expansion in access to medical care and treatment through Medicaid, Early Periodic Screening Diagnostic and Treatment (EPSDT) services, and the State Children’s Health Insurance Program (SCHIP).<sup>52</sup> Between 1998 and 2008, children receiving Medicaid EPSDT services shot up from about six million to nearly twenty-one million.<sup>53</sup> Similarly SCHIP enrollment rose from just over one million children to nearly five million children during that same period.<sup>54</sup> Greater access to diagnosis and treatment has likely resulted in more children identified as meeting the SSI disability definition.

**Children with Severe Mental Impairments Have Long Been the Majority of Child SSI Recipients.** Children receive SSI for a variety of medical conditions that result in marked and severe functional limitations.<sup>55</sup> In 2010 about 33 percent of children who received SSI had a primary diagnosis of a physical disabil-

ity, while approximately 67 percent had a primary diagnosis of a mental impairment.<sup>56</sup> This breakdown has remained steady at between 65 percent and 70 percent for nearly two decades.<sup>57</sup> That children with mental impairments have long formed the majority of child SSI recipients should come as no surprise since mental disorders are the leading causes of childhood disability.<sup>58</sup> Indeed, mental impairments account for 68 percent of disability in 10- to 24-year-olds.<sup>59</sup>

Mental disorders are exceedingly complex, and our understanding of them has improved a great deal over time.<sup>60</sup> Some critics of SSI point to certain mental impairments, such as attention deficit hyperactivity disorder and autism, that today constitute a greater share of SSI enrollment as evidence of “fraud” or “abuse.”<sup>61</sup> When individual impairment categories are looked at in isolation, such “concerns” miss the larger picture. While there has been virtually no change over the last two decades in the share of children qualifying for SSI due to mental impairments, what *has* changed over that period is proportional distribution *within* the overall mental category, with some impairment categories expanding and others shrinking. What is most notable is that, while the share of children receiving SSI for intellectual disabilities (formerly “mental re-

<sup>52</sup>Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services, Child Health USA 2000 (n.d.), <http://bit.ly/ZGFFH>; *id.*, Child Health USA 2008–2009 (Sept. 2009), <http://bit.ly/leabaW>; Fremstad & Vallas, *supra* note 42.

<sup>53</sup>See *supra* note 52.

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

<sup>55</sup>A significant data limitation must be noted when discussing the impairment categories of children receiving SSI: the Social Security Administration tracks only primary impairment codes, thus failing to capture the full picture for the many children with more than one impairment (ANNUAL STATISTICAL REPORT 2010, *supra* note 1, tbls.20–21, at 47–48).

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

<sup>57</sup>SOCIAL SECURITY ADMINISTRATION, ANNUAL STATISTICAL REPORT OF THE SUPPLEMENTAL SECURITY INCOME PROGRAM 1994–2010 (each report is a separate edition of ANNUAL STATISTICAL REPORT 2010, *supra* note 1, and is published in the year subsequent to the year covered and named in the title).

<sup>58</sup>Despite erroneous media reports suggesting otherwise, the statutory language governing SSI has always explicitly encompassed individuals (including children) with a “medically determinable *physical or mental* impairment” (42 U.S.C. § 1381 (emphasis added)); Fiona M. Gore et al., *Global Burden of Disease in Young People Aged 10–24 Years: A Systematic Analysis*, 37 LANCET 2093 (2011).

<sup>59</sup>Gore et al., *supra* note 58.

<sup>60</sup>Adding to this complexity is that nearly half of children with mental disorders have more than one diagnosable mental condition—and nearly 20 percent have three or more (Kathleen R. Merikangas et al., *Lifetime Prevalence of Mental Disorders in U.S. Adolescents: Results from the National Comorbidity Survey Replication—Adolescent Supplement*, 49 JOURNAL OF THE AMERICAN ACADEMY OF CHILD AND ADOLESCENT PSYCHIATRY 980 (2010).

<sup>61</sup>See, e.g., GLOBE SERIES, *supra* note 33; Gold, *supra* note 35.

tardation”) has dropped over time (from 42 percent in 1991 to just 12.7 percent in 2010), there has been a corresponding increase in the share of children receiving SSI for other mental impairments such as attention deficit hyperactivity disorder, communication disorders, or learning disorders (up from 23 percent to 53 percent in the same period).<sup>62</sup>

These trends are not unique to children qualifying for SSI.<sup>63</sup> Rather the trends reflect improved understanding of childhood mental health and resulting advances in diagnostic practice. Put simply, children who once might have been diagnosed with mental retardation are now more accurately diagnosed with autism, communication disorders, or learning disabilities, among others.<sup>64</sup>

### The Road Ahead

In addition to the congressional and GAO scrutiny discussed earlier, proposals for “reforming” children’s disability benefits (including block-granting SSI) abound in economic and policy circles.<sup>65</sup> What will come of this renewed scrutiny of children’s SSI benefits is not clear, but at a minimum the Social Security Administration appears likely to step up its childhood continuing disability reviews and seek to tackle its backlog and to get back on schedule.

An increase in such continuing disability reviews could lead tens of thousands of children—or more—receiving SSI to be reevaluated and subjected to termination

of benefits. The rate at which childhood continuing disability reviews result in disability cessations is about half.<sup>66</sup> Thus a renewed focus on childhood continuing disability reviews may mean a wave of children terminated from SSI in the near future.

Continuing disability reviews use a “medical improvement” standard: It asks whether the child continues to have the original disabling condition. This is a different inquiry from an initial disability determination.<sup>67</sup>

Step 1: Has there been “medical improvement”? SSA defines medical improvement as any decrease in the medical severity of the impairment(s) present at approval. If no medical improvement, the child is still disabled and benefits continue. If yes, proceed to step 2.

Step 2: Do the impairments the child had at the time of approval *now* meet the standard for child disability? If yes, the child remains disabled and benefits continue. If no, proceed to step 3.

Step 3: Do all of the child’s current impairments (including impairments other than those considered at prior approval) meet the standard for child disability? If yes, disability benefits will continue. If no, benefits will cease.<sup>68</sup>

Children who, upon review, are found no longer disabled can, through their parents or caregivers appeal the decision by requesting reconsideration and asking for an in-person hearing before a disability

<sup>62</sup>SOCIAL SECURITY ADMINISTRATION, *supra* note 57.

<sup>63</sup>Ilan Harpaz-Rotem & Robert A. Rosenheck, *Changes in Outpatient Psychiatric Diagnosis in Privately Insured Children and Adolescents from 1995 to 2000*, 34 CHILD PSYCHIATRY AND HUMAN DEVELOPMENT 329 (2004).

<sup>64</sup>See, e.g., Dorothy Bishop et al., *Autism and Diagnostic Substitution: Evidence from a Study of Adults with a History of Developmental Language Disorder*, 50 DEVELOPMENTAL MEDICINE AND CHILD NEUROPSYCHOLOGY 341 (2008); Marissa King & Peter Bearman, *Diagnostic Change and the Increased Prevalence of Autism*, 38 INTERNATIONAL JOURNAL OF EPIDEMIOLOGY 1224 (2009); Paul Shattuck, *The Contribution of Diagnostic Substitution to the Growing Administrative Prevalence of Autism in U.S. Special Education*, 117 PEDIATRICS 1028 (2006); see also Mike Stobbe, *Autism Epidemic May Be All in the Label*, ASSOCIATED PRESS, Nov. 4, 2007.

<sup>65</sup>See, e.g., BURKHAUSER & DALY, *supra* note 33.

<sup>66</sup>Office of the Inspector General, *supra* note 40.

<sup>67</sup>For a discussion of the childhood continuing disability review, with practice tips, see Thomas Yates, *Changes in the Children’s Supplemental Security Income Disability Program May Spell Loss of Benefits for Tens of Thousands of Children*, 30 CLEARINGHOUSE REVIEW 1026 (Jan.–Feb. 1997).

<sup>68</sup>20 C.F.R. § 416.994a; POMS DI 28005.025-030.

hearing officer.<sup>69</sup> If they lose at the reconsideration level, they may request a hearing before an administrative law judge.<sup>70</sup> They can elect that SSI disability benefits be continued while their appeals are pending at both the reconsideration and hearing levels. Children found not disabled after a hearing before an administrative law judge can seek further review by the Appeals Council and judicial review in federal district court.<sup>71</sup> Parents or caregivers must elect continuation of children's benefits within ten days of the date that they receive notice of the Social Security Administration's decision finding them not disabled.<sup>72</sup>

From the inception of the SSI program, legal aid advocates have been critical in protecting the rights of low-income individuals, especially children, who have disabilities and claim SSI benefits.<sup>73</sup> Because most disability cessation cases are not fee-generating, they, too, fall almost entirely to the legal aid and pro bono community.<sup>74</sup> If and when a wave of low-income children with disabilities face termination of SSI benefits, legal aid and pro bono programs will be their only realistic option for legal representation. In light of the importance of the appeal deadline to elect continuation of benefits, we must proactively inform our client communities of their rights.<sup>75</sup>

Critics of antipoverty programs considered "welfare reform" a signal achievement. After Aid to Families with Dependent Children was ended and the more restrictive Temporary Assistance for Needy Families installed in its place, SSI became one of the last remaining cash assistance entitlement programs in our nation's weakening safety net. Thus it should come as no surprise to see SSI under threat once again. Making this salvo even more troubling is that, this time around, critics have an additional tool in their arsenal: the guise of deficit reduction. We have seen what can happen when sensational media reports drive policy before all the facts are in; let us not let history repeat itself.

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<sup>69</sup>20 C.F.R. §§ 416.995, 416.996. While a parent can waive the right to a hearing before a disability hearing officer, attending that hearing is recommended because many cases are won at this stage.

<sup>70</sup>*Id.* §§ 416.1429–416.440.

<sup>71</sup>*Id.* §§ 416.1466–416.1485. Benefits cannot be continued at these levels of review.

<sup>72</sup>The Social Security Administration presumes that notice is received five days from the date of the notice; thus action must be taken within fifteen days. If a request for continuation of benefits pending appeal is not made within ten days (plus five for mailing), continued benefits may be requested at a later date if "good cause" is shown for missing the deadline. Some parents are reluctant to ask for payment continuation due to fear of overpayment; however, overpayments may be waived absent bad faith or noncooperation with the appeal process (20 C.F.R. § 416.996c).

<sup>73</sup>Legal services advocates have also been crucial as among the few sources of representation in postentitlement SSI matters, such as benefit changes, under- and overpayments, and alleged receiving of in-kind support and maintenance. The advent of direct-fee payment increased access to representation in SSI appeals beyond legal services and pro bono attorneys to the private bar (*id.* §§ 1700, 1717–1725).

<sup>74</sup>These cases are not fee-generating except where payment continuation is not requested at time of appeal, and back benefits are thus owed at the favorable completion of subsequent review.

<sup>75</sup>Advocates interested in the SSI Coalition for Children and Families, a national coalition supporting children and families, may contact Dominic Holt at dominic@bazelon.org or Rebecca Vallas at RVallas@clsphila.org, or visit www.bazelon.org or www.clsphila.org for more information.



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