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SSI: A Lifeline for Children with Disabilities

By Kathleen Romig

Supplemental Security Income (SSI) is the only source of federal income support targeted to families caring for children with disabilities, and it reaches only the lowest-income and most severely impaired children. These children live with conditions such as Down Syndrome, cerebral palsy, autism, intellectual disability, and blindness. Their vulnerable families face higher costs, more demands on their time, and more insecurity than families not caring for a child with a disability. The modest income that SSI provides doesn't solve every problem these families face, but it reduces their struggles and helps provide the highly individualized supports their children may need.

Despite the vital support SSI provides low-income children with disabilities and their families, the program could face cuts this year. House Republicans are reportedly considering substantial entitlement cuts in their budget resolution and in budget legislation later this year, potentially including cuts to SSI for children, which was targeted in the "Better Way" plan that House Republicans put forward last year.¹ That proposal would have eliminated income support for children through SSI and included vague promises to use some of the savings for "services" for these families. SSI cuts could come on top of the \$839 billion Medicaid cut in the House-passed bill to repeal the Affordable Care Act, which threatens crucial health care services for children with disabilities — including those that help them succeed in school.²

Without SSI, many more children with disabilities would be in poverty. SSI benefits lift half of otherwise-poor child beneficiaries out of poverty. Benefits particularly reduce deep poverty, lifting nearly 200,000 children with disabilities above 50 percent of the poverty line. In all, 1.2 million children with disabilities receive SSI benefits, averaging \$650 a month.

Though 11 million American children have special health care needs, few meet SSI's strict eligibility standards — either because their disabling conditions aren't severe enough or because

¹ Sahil Kapur and Erik Wasson, "House GOP Eyes Fast-Tracking \$500 Billion in Federal Budget Cuts," Bloomberg, May 3, 2017, <https://www.bloomberg.com/news/articles/2017-05-03/house-gop-eyes-fast-tracking-500-billion-in-federal-budget-cuts>; Kathleen Romig, "GOP Poverty Plan Would Hurt Some of Most Vulnerable Children," Center on Budget and Policy Priorities, June 15, 2016, <http://www.cbpp.org/blog/gop-poverty-plan-would-hurt-some-of-most-vulnerable-children>.

² Rebecca Ullrich, "Cuts to Medicaid Would Harm Young Children with Disabilities," Center for American Progress, May 3, 2017, <https://www.americanprogress.org/issues/early-childhood/reports/2017/05/03/431766/cuts-medicaid-harm-young-children-disabilities/>; Jessica Schubel, "Medicaid Helps Schools Help Children," Center on Budget and Policy Priorities, April 18, 2017, <http://www.cbpp.org/research/health/medicaid-helps-schools-help-children>.

their families' income and savings exceed the program's low limits. Indeed, just 1.7 percent of all children receive SSI benefits. To qualify for SSI, a child must have a very serious condition that is backed up by medical evidence. Children's eligibility is periodically reviewed — and many children lose eligibility after their conditions improve.

For those who qualify, SSI benefits help families meet their children's needs and make ends meet. Many children with disabilities also receive essential support through Medicaid and special education — but these services, while critical, cannot substitute for income support. SSI benefits help families pay rent and put food on the table, helping to maintain a stable home environment. They also pay for a broad range of disability-related expenses, many of which are not offered by schools or covered by insurance — things like specialized therapies, medically prescribed diets, diapers for older children, and home modifications for accessibility.

SSI benefits also allow parents to provide the care their children need. Caring for a child with a disability requires significant time and energy, requiring parents to take their children to appointments with doctors and therapists, attend meetings at school, meet intensive daily needs, and cope with all-too-common medical emergencies and illnesses. Though many parents of children receiving SSI work, working fewer hours — or even leaving the workforce — can sometimes be the best decision for families' health and well-being, particularly if a child's care needs are high and a parent's job prospects and earnings potential are low. SSI benefits provide some of America's most vulnerable families a stable source of income, reducing their insecurity and improving their children's lives.

Children Must Meet Strict Criteria to Qualify for and Keep Benefits

SSI provides critical support for 1.2 million children with disabilities across the nation, making up 15 percent of SSI recipients, and 1.7 percent of all children.³

Children must meet stringent criteria to receive SSI benefits.⁴ A child's impairments must match or equal in severity a list of disabilities compiled by the Social Security Administration (SSA). Qualified medical professionals — physicians, licensed or certified psychologists, or certain other experts — must submit evidence of the disability; the opinions of the child's parents or teachers do not suffice. Children can qualify based on mental or physical disorders, but only if they severely limit the child's functioning. Mental conditions include autism, intellectual disability, schizophrenia, or bipolar disorder; physical conditions include cerebral palsy, muscular dystrophy, Down Syndrome, blindness, or cancer.

For a child to qualify for SSI benefits, his or her family must also have very low income and assets. Typically, a working family may qualify for a full benefit for a child with a disability if they

³ Social Security Administration (SSA), "SSI Monthly Statistics, December 2016," https://www.ssa.gov/policy/docs/quickfacts/stat_snapshot/; Office of the Chief Actuary, *Annual Report of the Supplemental Security Income Program*, 2016, Table IV.B7, <https://www.ssa.gov/oact/ssir/SSI16/ssi2016.pdf>.

⁴ Center on Budget and Policy Priorities, "Policy Basics: Introduction to Supplemental Security Income," December 2, 2015, <http://www.cbpp.org/research/social-security/policy-basics-introduction-to-supplemental-security-income>.

earn up to about 100 percent of poverty. The benefit gradually declines as earnings rise, and eligibility phases out at about 200 percent of poverty.⁵ Their countable assets are limited to \$2,000 if the child lives with one parent, or \$3,000 if the child lives with two parents. SSI's benefits are modest, averaging \$650 a month for a disabled child.⁶

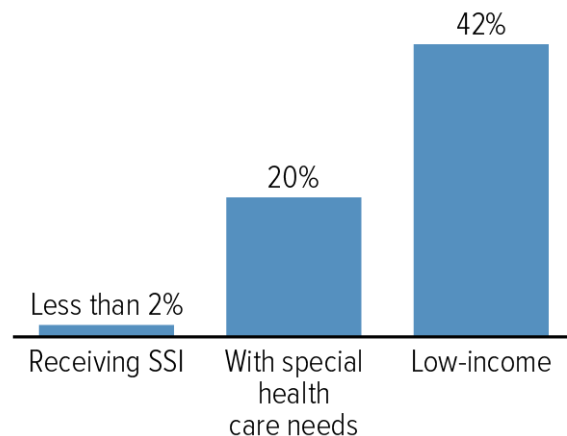
Though 11 million American children have special health care needs, few meet SSI's strict eligibility standards — either because their disabling conditions aren't severe enough or because their families' income and savings exceed the program's low limits.⁷ A small fraction of children meet all the criteria for benefits.⁸ (See Figure 1.) SSA approves less than half of child applicants for SSI.⁹

Because eligibility for SSI depends on meeting both medical and financial criteria, the rate of SSI receipt varies geographically depending on local health, economic, and demographic factors. For example, areas with higher child poverty rates will have a greater proportion of children with disabilities who qualify for SSI, because their families are more likely meet SSI's strict income criteria.

FIGURE 1

Few Children Meet SSI's Strict Financial and Medical Criteria

Percent of all children, 2016



Notes: SSI = Supplemental Security Income; Low-income children = children in families with income below 200 percent of poverty line.

Source: U.S. Census Bureau, Health Resources & Services Administration, Social Security Administration

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⁵ The family's countable income must be under \$735 per month, or less than \$9,000 a year. Countable income is essentially half of earnings over \$65 a month, plus all unearned income with minor exceptions, minus amounts allocated (or "deemed") to other family members for their own needs. For more information, see <https://www.ssa.gov/ssi/text-child-ussi.htm>. Although SSI does not explicitly use the federal poverty guidelines to weigh eligibility, the deeming rules mean that working families may qualify for a *full* benefit for a disabled child with earnings up to about 100 percent of poverty, and may qualify for a *small* SSI benefit with earnings up to about 200 percent of poverty.

⁶ Federal SSI benefits top out at \$735 in 2017. Many states supplement the federal SSI benefit, though some have cut those additional payments over the years.

⁷ National Survey of Children with Special Health Care Needs, 2009-10, data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website, <http://childhealthdata.org/browse/survey/results?q=1792&r=1>.

⁸ Susan L. Parish, Subharati Ghosh, and Leah Igdalsky, "Hardship among Low-income US Families that receive Children's Supplemental Security Income (SSI)," Brandeis University, Lurie Institute for Disability Policy, October 2013, <http://lurie.brandeis.edu/pdfs/SSI%20hardship%20pol%20brief%20final.pdf>.

⁹ SSA, *SSI Annual Report*, Table V.C2, https://www.ssa.gov/oact/ssir/SSI16/V_C_AllowanceData.html#220522.

Participation Has Stabilized

Congress established SSI in 1972 to replace a patchwork system of federal grants to states to assist the aged, blind, and disabled.¹⁰ Before SSI, states typically provided income support only to blind children, not children with other impairments. As Robert Finch, President Nixon’s Secretary of Health, Education and Welfare, testified before Congress to explain the Administration’s rationale for providing SSI benefits to children: “Disabled children living in low-income households are among the most disadvantaged of all Americans and are deserving of special assistance in order to help them become self-supporting members of our society.”¹¹

As the program became established, more children applied for benefits. The medical criteria for children to qualify for SSI also changed, expanding after a 1984 law and subsequent mental health regulations broadened eligibility, then again in response to the Supreme Court’s 1990 *Zebley* decision, which required SSA to consider a child’s ability to function in an age-appropriate way. Congress established stricter standards in 1996, which have remained in place since.

Over the past 20 years, the rate of SSI receipt among children rose modestly, then leveled off. (See Figure 2.) The growth occurred for two main reasons. First, the number of children screened for and diagnosed with mental disorders has risen as medical science has advanced and awareness of mental health problems has grown — not just for SSI children, but for children up and down the income ladder. As the Institute of Medicine (IOM) noted in a comprehensive study on SSI for children with mental disorders, “the increase in the percentage of children in low-income households receiving SSI benefits for mental disorders . . . is consistent with and proportionate to trends in prevalence of mental disorders among children in the general population.”¹² For example, the number of childhood autism diagnoses increased substantially in recent years — largely because screening has become more common and the diagnostic criteria for autism have expanded.¹³ At the same time, the number of SSI children receiving benefits for autistic disorders has increased.¹⁴

Second, because SSI is available only to children who are disabled *and* whose families have very low incomes and assets, more children with disabilities become financially eligible for SSI when

¹⁰ SSI is distinct from Old-Age, Survivors, and Disability Insurance, commonly known as Social Security, although the Social Security Administration (SSA) runs both programs. Social Security pays benefits to certain *adults* with disabilities — disabled workers, disabled widow(er)s, and disabled *adult* children (of retired, deceased, or disabled workers) whose disabilities began before age 22 — but pays no benefits to younger children with disabilities. Social Security Administration, “Benefits for Children with Disabilities,” 2016, <https://www.ssa.gov/pubs/EN-05-10026.pdf>.

¹¹ Testimony of Robert Finch, Secretary of the Department of Health, Education and Welfare, “Social Security and Welfare Proposals” H.R. Rep. No. 231, 92nd Cong., 2d Sess., U.S.C.C.A. News 4989, 5133 (1972).

¹² Thomas F. Boat and Joel T. Wu, *Mental Disorders and Disabilities Among Low-Income Children*, National Academies of Sciences, Engineering, and Medicine, 2015, <https://doi.org/10.17226/21780>.

¹³ Eric Fombonne, “Epidemiology of Pervasive Developmental Disorders,” *Pediatric Research*, 2009, <http://www.nature.com/pr/journal/v65/n6/full/pr2009131a.html>.

¹⁴ At the same time, the number of children receiving SSI for intellectual disability (formerly known as mental retardation) decreased, suggesting some diagnostic substitution.

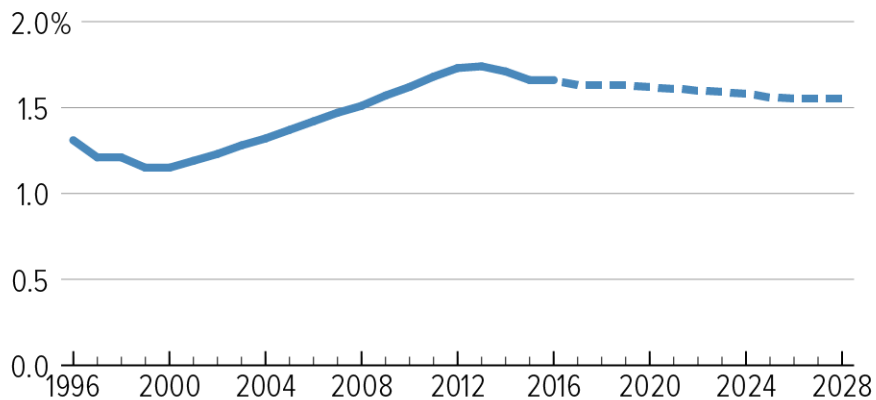
poverty rates rise.¹⁵ The Great Recession and its effects caused child poverty rates to rise from 2010 to 2012 — and the fraction of children with disabilities who met SSI’s financial criteria rose temporarily. The IOM study found that “[i]ncreases in numbers of children applying for and receiving SSI benefits on the basis of mental health diagnoses are strongly tied to increasing rates of childhood poverty because more children with mental health disorders become financially eligible for the program when poverty rates increase.”¹⁶

SSI’s eligibility criteria remain stringent and child poverty rates have fallen slightly. As a result, the number of children receiving SSI is lower now than just after the Great Recession. Social Security’s actuaries project the fraction of children receiving SSI will remain stable over the next several decades.¹⁷

FIGURE 2

Share of Children Receiving SSI Has Levelled Off

SSI prevalence rates for children age 0-17



Note: SSI = Supplemental Security Income; dotted line indicates projection

Source: Social Security Administration

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¹⁵ The official rate of child poverty rose gradually from 16 percent in 2000 to 19 percent in 2008, then spiked to about 22 percent from 2010-12 before returning to about 20 percent in 2015. See Table 3 in the Census Bureau’s historical poverty tables here: <http://www.census.gov/data/tables/time-series/demo/income-poverty/historical-poverty-people.html>. The percentage of children with incomes less than 200 percent of poverty — which is roughly the cutoff for SSI eligibility for working families — is consistently about twice as high.

¹⁶ National Academies of Sciences, Engineering, and Medicine, *Mental Disorders and Disabilities Among Low-Income Children*, The National Academic Press, 2015, <https://www.nap.edu/catalog/21780/mental-disorders-and-disabilities-among-low-income-children>.

¹⁷ SSA, *SSI Annual Report*, 2016, Table IV.B7, <https://www.ssa.gov/oact/ssir/SSI16/ssi2016.pdf>.

SSA Conducts Thorough Reviews

SSA takes pains to ensure that only the most severely impaired applicants qualify for and remain eligible for benefits. Before a child's application is finalized, many undergo quality reviews by the agency to check the accuracy of the disability examiner's decision.¹⁸ Once a child qualifies, SSA reviews his or her eligibility regularly: for low birth-weight babies, by age 1; for children whose medical impairments are likely to improve, at least every three years; and for all children, at age 18. The adult receiving SSI payments on the child's behalf — usually a parent — must provide medical evidence and bring the child to a consultative examination if requested.¹⁹ These “continuing disability reviews” end benefits for over half of low-birth-weight infants, for about one-quarter of other SSI children, and for over 40 percent of those still receiving benefits at age 18.²⁰

SSA conducts these frequent reviews — and often discontinues benefits — because disability among children can be fluid, especially as treatments advance. For example, an increasing number of profoundly deaf children receive cochlear implants, which may improve their hearing,²¹ and many more children survive cancer than did a generation ago.²² When children's health improves, parents are better able to work longer hours to support their families, so they no longer need SSI.

¹⁸ SSA, *Program Operations Manual System (POMS)*, <https://secure.ssa.gov/poms.nsf/lnx/0204440008>.

¹⁹ Code of Federal Regulations, § 416.994a, https://www.ssa.gov/OP_Home/cfr20/416/416-0994a.htm.

²⁰ *Annual Report*, Table V.D4, https://www.ssa.gov/oact/ssir/SSI16/V_D_Redet_CDRdata.html#389380.

²¹ National Institutes of Health, National Institute of Deafness and Other Communication Disorders, “Science Capsule — Cochlear Implants,” July 2, 2014, <https://www.nidcd.nih.gov/about/strategic-plan/2012-2016/science-capsule-cochlear-implants>.

²² In 1975, only about half of children diagnosed with cancer survived at least five years. In 2004-2010, more than 80 percent did. National Cancer Institute, “Cancer in Children and Adolescents,” <https://www.cancer.gov/types/childhood-cancers/child-adolescent-cancers-fact-sheet>.

SSI, Medicaid, and Special Education Play Complementary Roles

Programs to support children with disabilities — including SSI, special education, and Medicaid — played a key role in the dramatic evolution of the care of children with disabilities in American society.^a In the past, many such children were institutionalized and even more were isolated, at great expense, lacking access to schools and the tools to grow up to live independently.

Now, children with disabilities are typically cared for by their families and included in schools and their broader communities. State and federal legislation in the 1960s and 1970s enabled the shift toward inclusion and family-centered care.

Around the same time Congress established SSI in 1972, children with disabilities gained greater access to public schools. In 1975, legislation now known as the Individuals with Disabilities Education Act (IDEA) guaranteed that students with disabilities get a free, appropriate public education that meets their individual needs.^b IDEA requires that a team of teachers and staff works with parents of students with disabilities to create an Individualized Education Plan (IEP) that includes necessary accommodations and services. By the time they are 16, students served by IDEA and their IEP teams must prepare a transition plan that identifies appropriate post-school goals, such as higher education, vocational training, or employment, and refers students to community agencies that can assist with job placement and other services.

Medicaid, established in 1965 and for which most children receiving SSI automatically qualify, provides both health insurance coverage and long-term services and supports for children whose disabilities limit their daily activities. Medicaid largely meets the health care needs of children with disabilities who receive SSI, but it does not cover many of the other disability-related expenses that families face.^c Some states also have Medicaid home- and community-based services waivers, which allow beneficiaries to receive services in their own home or community to meet their medical needs and support daily living. Research shows that parents of children with disabilities who received home- and community-based services are less likely to stop working.^d

SSI, special education, and Medicaid complement each other. For example, Medicaid helps families meet medical needs, while SSI helps with other disability-related expenses and meeting families' basic needs so that kids grow up in a stable home environment. SSI helps families meet their children's needs and make ends meet, while IDEA requires schools to help students reach their full potential in adulthood. Without the combination of income support, health care, and education-related supports, the progress of the last several decades in fostering independence for children with disabilities would be threatened.

^a Sheryl Larson *et al.*, "Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2010," University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, 2012, <http://rtc.umn.edu/docs/RISP2010.pdf>.

^b Before IDEA, the Rehabilitation Act of 1973 required schools to accommodate the needs of students with disabilities, among other things.

^c Anne DeCesaro and Jeffrey Hemmeter, "Unmet Health Care Needs and Medical Out-of-Pocket Expenses of SSI Children," *Journal of Vocational Rehabilitation*, 2009.

^d Douglas L. Leslie *et al.*, "Medicaid Waivers Targeting Children With Autism Spectrum Disorder Reduce The Need For Parents To Stop Working," *Health Affairs*, February 2017, <http://content.healthaffairs.org/content/36/2/282.abstract>.

SSI Reduces Childhood Poverty and May Improve Adult Prospects

Families caring for children with disabilities are more likely than other families with the same level of income to face material hardships, such as struggling to put food on the table, being forced out of their homes, having their electricity shut off, or going without the medical care they need.²³ The modest income SSI provides doesn't solve all of these problems, but it does reduce the struggles of these vulnerable families. A stable source of income to pay for housing, for example, may prevent a child from having to leave his or her community and school, an upheaval that can be especially challenging for a child with special needs. Conversely, financial insecurity can pose additional challenges for children with disabilities. For example, children with special needs often require special diets, which raises their food costs and makes them more vulnerable than other children to the harmful effects of food insecurity.²⁴

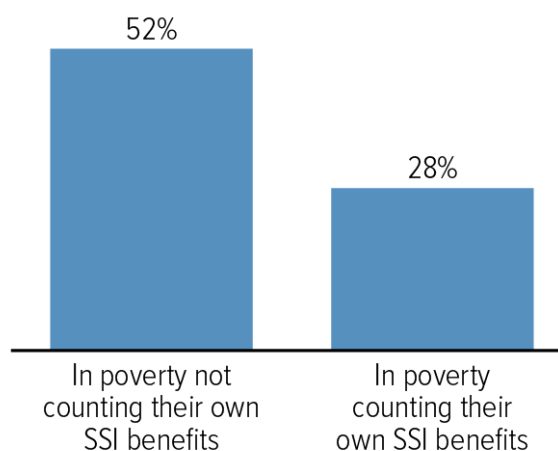
SSI helps families make ends meet while paying for the highly individual supports their children may require, many of which are not offered by schools or covered by insurance — things like specialized therapies, medically prescribed diets, diapers for older children, home modifications for accessibility, adaptive equipment, tutors, specialized child care, and transportation to doctors and specialists.²⁵

Without SSI, many more children with disabilities would be poor. SSI benefits for children lift half of otherwise poor child beneficiaries out of poverty. (See Figure 3.) They particularly reduce deep poverty, lifting nearly 200,000 children with

FIGURE 3

SSI Cuts Poverty for Children with Disabilities Nearly in Half

Poverty rate for SSI beneficiaries under 18 years old, 2014



Note: SSI = Supplemental Security Income. Figures show the percent of children living below the poverty line using the Supplemental Poverty Measure (SPM) with corrections for underreporting.

Source: CBPP analysis of 2014 Census Bureau data from the March Current Population Survey, SPM public use file; corrections for underreported benefits from U.S. Department of Health and Human Services/Urban Institute TRIM model

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²³ Susan Parish *et al.*, “Material Hardship in U.S. Families Raising Children with Disabilities,” *Exceptional Children*, Vol. 75:1, 71-92 (2008) and “Material Hardship in U.S. Families Raising Children with Disabilities: Research Summary and Policy Implications,” University of North Carolina, March 2009.

²⁴ National Commission on Hunger, *Freedom from Hunger: An Achievable Goal for the United States of America*, 2015, https://www.aei.org/wp-content/uploads/2016/01/Hunger_Commission_Final_Report.pdf.

²⁵ Consortium for Citizens with Disabilities, “Preserve Supplemental Security Income for Children with Disabilities: Speaker Ryan’s Poverty Plan Proposes Harmful Elimination of Benefits,” June 7, 2016, <http://www.c-c-d.org/fichiers/Preserve-SSI-for-Children-and-Families-06-07-16.pdf>.

disabilities above 50 percent of the poverty line.²⁶ Research shows that SSI benefits for children have “potentially played a large role in lowering [overall] child poverty rates.”²⁷

While SSI reduces hardship, many families receiving SSI benefits remain poor — and, because of SSI’s very low income and asset limits, many families with disabled children do not get benefits at all.²⁸ In addition, measures of poverty based on income alone can overstate the level of economic well-being among people with disabilities and their families, because of the higher expenses required to meet their basic needs.

Income support can improve poor children’s long-term prospects. A substantial body of evidence shows that poor children whose families receive a significant income boost do better in school and work and earn more as adults.²⁹ Most of this research has focused on the long-term gains from other safety net programs (such as SNAP, the Earned Income Tax Credit, the Child Tax Credit, housing assistance, and Medicaid) on children in poor families.

Growing up poor *and* with a disability poses further challenges for children receiving SSI. Childhood health problems — especially mental health problems — damage adult prospects.³⁰ Disability can hurt employment prospects and increase poverty.³¹ Many children with disabilities struggle with the transition to adulthood, when they often lose key supports like those they receive through the Individuals with Disabilities Education Act (IDEA) at school, Medicaid (especially in states that have not expanded the program), and SSI. SSA has developed several pilot programs,

²⁶ CBPP analysis of the March 2014 Current Population Survey and SSI income data from the Urban Institute/HHS Transfer Income Model version 3, downloaded from the TRIM3 project website, trim3.urban.org, on January 12, 2017.

²⁷ Research shows that child SSI benefits have “potentially played a large role in lowering child poverty rates” overall, as well. Mark Duggan and Melissa Schettini Kearney, “The Impact of Child SSI Enrollment on Household Outcomes: Evidence from the Survey of Income and Program Participation,” National Bureau of Economic Research, August 2005.

²⁸ Kathy Ruffing, “Rich Man, Poor Man: Lawmakers Should Raise and Index the SSI Asset Limits,” CBPP, January 17, 2013, <http://www.cbpp.org/blog/rich-man-poor-man-lawmakers-should-raise-and-index-the-ssi-asset-limits>.

²⁹ Greg J. Duncan and Katherine Magnuson, “The Long Reach of Early Childhood Poverty,” *Pathways*, Winter 2011, http://inequality.stanford.edu/sites/default/files/PathwaysWinter11_Duncan.pdf; Kristen Butcher, “Assessing the Long-Run Benefits of Transfers to Low-Income Families,” Hutchins Center Working Paper #26, The Brookings Institution, January 2017, pp. 31, https://www.brookings.edu/wp-content/uploads/2017/01/wp26_butcher_transfers_final.pdf; Kerris Cooper and Kitty Stewart, “Does Money Affect Children’s Outcomes?,” Joseph Rowntree Foundation, October 22, 2013, <https://www.jrf.org.uk/report/does-money-affect-children%E2%80%99s-outcomes>; Kathleen M. Ziol-Guest *et al.*, “Early Childhood Poverty, Immune-Mediated Disease Processes, and Adult Productivity,” *Proceedings of the National Academy of Sciences*, Vol. 109, October 16, 2012, pp. 17289–17293, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3477379/>.

³⁰ Jason Fletcher, “Adolescent Depression and Adult Labor Market Outcomes,” NBER Working Paper No. 18216, July 2012, <http://www.nber.org/papers/w18216>; Jason Fletcher, “The Effects of Childhood ADHD on Adult Labor Market Outcomes,” NBER Working Paper No. 18689, January 2013, <http://www.nber.org/papers/w18689>.

³¹ Gina A. Livermore and Todd C. Honeycutt, “Employment and Economic Well-Being of People With and Without Disabilities before and After the Great Recession,” *Journal of Disability Policy Studies*, Vol. 26, No. 2, 2015.

including the Youth Transition Demonstration project and Promoting Readiness of Minors in SSI (PROMISE) to help children receiving SSI navigate the transition to adulthood.³²

SSI benefits help mitigate the many challenges low-income children with disabilities face over the long term. As the IOM study noted, “access to Medicaid and income supports via the SSI disability program may improve long-term outcomes for both children with disabilities and their families.” One study found individuals who received SSI benefits as children had longer workforce attachment and lower welfare receipt in the long run.³³ Another study found reduced earnings for child beneficiaries during the transition to adulthood, but that gap essentially closed by the time they reached their mid-20s — and the author points out that “it is not clear that this means giving children SSI benefits for a longer time should be viewed as counterproductive. Particularly because these people likely suffer from adverse health stemming from their disability, it is important to consider the impacts of SSI receipt on long-term outcomes other than earnings, such as health and the ability to live independently as an adult.”³⁴

Parents of Children with Disabilities Face Hard Choices Between Working and Caregiving

Families caring for children with disabilities face many demands on their time, which compete with paid work.³⁵ Their children’s care requires significant amounts of time and energy, and can involve tasks that are physically, emotionally, socially, or financially demanding. Many parents reduce their hours, make different job choices, turn down promotions, or leave the workforce altogether. As a result, parents of children with special needs — especially mothers — work less.³⁶ The kinds of care they provide their children include:

- **Appointments with doctors, therapists, and other health professionals.** Half of children receiving SSI kids need to visit the doctor five or more times each year, including specialists such as developmental pediatricians or audiologists — and some must go much more

³² Jeffrey Hemmeter, “Earnings and Disability Program Participation of Youth Transition Demonstration Participants after 24 Months,” Social Security Administration, 2014, <https://www.ssa.gov/policy/docs/ssb/v74n1/v74n1p1.html>; PROMISE is a joint initiative of the Departments of Education, Health and Human Services, and Labor, as well as the Social Security Administration. Through multi-year state grants, PROMISE partners with state agencies to develop and implement six model projects that provide coordinated services and supports to the families of children receiving SSI in order to improve the children’s education and career outcomes. For more, see <http://www.promisetacenter.org/home>.

³³ Norma Coe and Matthew Rutledge, “What is the Long-Term Impact on Zebley Kids?” Boston College Center for Retirement Research, Working Paper No. 2013-3, January 1, 2013, <https://ssrn.com/abstract=2196648>.

³⁴ Michael Levere, “The Labor Market Consequences of Receiving Disability Benefits During Childhood,” Mathematica Policy Research, February 6, 2017, <https://www.mathematica-mpr.com/our-publications-and-findings/publications/the-labor-market-consequences-of-receiving-disability-benefits-during-childhood>.

³⁵ Paul J. Chung *et al.*, “Need for and Use of Family Leave Among Parents of Children With Special Health Care Needs,” *Pediatrics*, May 2007, <http://pediatrics.aappublications.org/content/119/5/e1047>.

³⁶ Mark Stabile and Sara Allin, “The Economic Costs of Childhood Disability,” *The Future of Children*, Spring 2012.

frequently.³⁷ A typical doctor's visit takes over two hours, and specialist visits are often hard to schedule and located far from home.³⁸ More than half of SSI children require regular speech and language, physical, and/or occupational therapy.³⁹ Therapies for children with disabilities often require large time commitments from parents over long periods. For example, a common intervention for autism, Applied Behavior Analysis, can require 25 to 40 hours a week for one to three years.⁴⁰ In addition, many children with disabilities have mental health needs that require regular visits to psychologists, therapists, or social workers.

- **School meetings.** Children with disabilities often receive special education services — including more than two-thirds of SSI kids.⁴¹ Children in special education have Individualized Education Plans (IEPs), which require regular meetings of the IEP team, including the child's parents. Schools — again, with the participation of parents — may also accommodate special-needs children with so-called 504 plans or a Response to Intervention process.⁴²
- **Their children's daily needs.** Nearly 40 percent of SSI kids — including older children and teens — need extra help with activities of daily living such as mobility, using the toilet, eating, bathing, and dressing.⁴³ Some children's disabilities also require frequent monitoring — for example, a child may have frequent seizures, breathe with the support of a respirator, or need regular blood sugar checks and insulin injections. Parents, as primary caregivers, often must provide this kind of care. Few child care providers will serve children with intensive daily needs, forcing many parents to cut back on work or leave the workforce altogether.⁴⁴
- **Emergencies.** Children with disabilities are more likely to suffer from emergencies and acute health care needs. For example, in one 12-month period, nearly 1 in 5 children receiving SSI had been hospitalized, nearly 1 in 5 had a surgery, and almost half visited the emergency room.⁴⁵ These crises require parents to take time off work, often unexpectedly and for days or weeks at a time, making it difficult for parents to maintain jobs.

³⁷ Kalman Rupp *et al.*, "A Profile of Children with Disabilities Receiving SSI: Highlights from the National Survey of SSI Children and Families," *Social Security Bulletin*, 2005/2006, <https://www.ssa.gov/policy/docs/ssb/v66n2/v66n2p21.html>.

³⁸ Kristin N. Ray *et al.*, "Opportunity Costs of Ambulatory Medical Care in the United States," *The American Journal of Managed Care*, August 18, 2015, <http://www.ajmc.com/journals/issue/2015/2015-vol21-n8/opportunity-costs-of-ambulatory-medical-care-in-the-united-states>.

³⁹ Rupp *et al.*, 2005/2006.

⁴⁰ Autism Speaks, Applied Behavior Analysis (ABA), available at: <https://www.autismspeaks.org/what-autism/treatment/applied-behavior-analysis-aba>.

⁴¹ Rupp *et al.*, 2005/2006.

⁴² RTI Action Network, "What is RTI?," available at <http://www.rtinetwork.org/learn/what/whatisrti>.

⁴³ Rupp *et al.*, 2005/2006.

⁴⁴ Kalman Rupp and Steve Ressler, "Family Caregiving and Employment Among Parents of Children with Disabilities on SSI," *Journal of Vocational Rehabilitation*, September 30, 2009, <https://www.mathematica-mpr.com/our-publications-and-findings/publications/family-caregiving-and-employment-among-parents-of-children-with-disabilities-on-ssi>.

⁴⁵ *Ibid.*

Together, these demands are daunting for parents, and they're especially tough for low-income families.⁴⁶ Low-wage workers are less likely to have jobs with flexible schedules, sick days, and paid family and medical leave, and more likely to work irregular schedules.⁴⁷ They have less income to afford the help of caregivers or convenient transportation. One study puts the extra cost of raising a child with a disability, including lost parental income, at \$6,150 a year — and \$20,000 when raising the most severely impaired children, which can make it difficult to afford both basic needs and disability-related expenses.⁴⁸

Working less — or leaving the workforce — can be the best decision for the health and well-being of some families. One study that found little impact of SSI benefits on parents' work pointed out that, "to the extent that parents are reducing their earnings to stay home and provide care for a disabled child, any offset of earnings might actually be considered in line with child SSI program goals."⁴⁹ Another study, which found SSI benefits reduced parents' work, pointed out that increasing work hours "may be costly in the sense that it reduces the amount of time available for parents to care for their disabled children."⁵⁰ In fact, a recent study looked at low-birth-weight babies just below the 1200-gram (2.6-pound) cutoff for SSI benefits; it found that mothers whose children qualified worked fewer hours — and both their parenting behavior and their children's motor skill development significantly improved.⁵¹

Despite these obstacles, many parents of SSI kids do work. Two-thirds of SSI children in two-parent families have a parent who works; more than one-third of children in one-parent families have a parent who works.⁵² The SSI benefit structure provides an incentive for parents who can work to do so. Because only half, at most, of parental earnings are counted against a child's SSI

⁴⁶ Jiyeon Park, Ann P. Turnbull, and H. Rutherford Turnbull III, "Impacts of Poverty on Quality of Life in Families of Children with Disabilities," Council for Exceptional Children, Winter 2002; Susan L. Parish, "Why Dismantling the Safety Net for Children with Disabilities and Their Families Is a Poor Idea," *Health Social Work*, 2013, <https://academic.oup.com/hsw/article/38/4/195/830208/Why-Dismantling-the-Safety-Net-for-Children-with>.

⁴⁷ Lisa Clemans-Cope *et al.*, "Access to and Use of Paid Sick Leave Among Low-Income Families With Children," *Pediatrics*, August 2008, <http://pediatrics.aappublications.org/content/122/2/e480>; Leila Morsy and Richard Rothstein, "Parents' Non-Standard Work Schedules Make Adequate Childrearing Difficult," Economic Policy Institute, August 6, 2015, <http://www.epi.org/publication/parents-non-standard-work-schedules-make-adequate-childrearing-difficult-reforming-labor-market-practices-can-improve-childrens-cognitive-and-behavioral-outcomes/>.

⁴⁸ Stabile and Allin.

⁴⁹ Mark Duggan and Melissa Schettini Kearney, "The Impact of Child SSI Enrollment on Household Outcomes: Evidence from the Survey of Income and Program Participation," National Bureau of Economic Research, August 2005.

⁵⁰ Manasi Deshpande, "The Effect of Disability Payments on Household Earnings and Income: Evidence from the Supplemental Security Income Children's Program," *The Review of Economics and Statistics*, October 2016.

⁵¹ Melanie Guldi *et al.*, "Supplemental Security Income and Child Outcomes: Evidence from Birth Weight Eligibility Cutoffs," Williams College Working Paper, March 2017.

⁵² SSA, *SSI Annual Statistical Report*, 2015, Tables 25 and 26, available at: https://www.ssa.gov/policy/docs/statcomps/ssi_asr/.

benefit, parents who work have higher incomes than those who do not, making their families better off. And that reduction doesn't even kick in until earnings exceed a threshold — determined by family size — for parents' and siblings' needs, further mitigating concerns about possible work disincentives.⁵³ Moreover, families in which a parent works are eligible for the EITC, often a significant earnings supplement, while those that do not have earnings are not.

⁵³ A summary of these so-called “deeming” rules may be found at <http://www.socialsecurity.gov/ssi/text-child-ussi.htm>.