



April 10, 2020

The Honorable Richard E. Neal
Chairman of the House Ways and Means
2309 Rayburn House Office Building
Washington, DC 20515

Re: Recommendations – Setting a Moratorium and Lifting Burdensome Restrictions on Dedicated Account Funds During The Coronavirus (Corvid-19) Pandemic, Ensuring Families of Children with Disabilities Access To These Funds for Basic Necessities

Dear Chairman Neal:

We are writing to you on behalf of the Children's Disability Project at Greater Boston Legal Services (GBLS-CDP) regarding our recommendations concerning setting a moratorium on the Social Security Administration's (SSA) burdensome restrictions on the use of dedicated account funds connected to children's Supplemental Security Income (SSI) disability benefits. The dedicated account rules are meant to help children with disabilities by making sure these funds are spent on their needs. However, in practice the dedicated account system is so restrictive, complex, unclear, and ambiguously applied that often all it achieves is preventing children and their families from accessing the funds at all, even when they are trying to make expenditures that are clearly within the rules. This leaves at-risk children without basic necessities, even as they are legally entitled to thousands of dollars.

In light of the added strain put on low-income families during the COVID-19 crises, we urge the Social Security Administration (SSA) and congress to lift restrictions on access to these funds, clarifying the rules and allowing families to immediately use the money their children are owed to pay for basic necessities such as food, rent, educational materials, diapers, medicine, masks, and cleaning supplies.

During this emergency situation, we propose the following:

- The Social Security Administration (SSA) set a moratorium on dedicated account restrictions, lifting burdensome rules and allowing families to make full use of their children's funds for basic necessities such as food, rent, utilities, toilet paper, diapers,

CDP Co-Founders: Jane G. Smith, J.D. M.Ed., Taramattie Doucette, Esq.
"A person's a person, no matter how small" – Dr. Seuss

Tylenol and any other items that the family needs to survive and maintain a home for their child during this pandemic.

- After the emergency ends, SSA should not penalize families for their use of the funds for basic needs.
- We also urge Congress to add language in the next stimulus bill ensuring a waiver of the basic needs exclusion (that is, allow families to use dedicated account funds for basic necessities without penalties).

Our recommendations stem from over a decade of representing children with disabilities on individual Supplemental Security Income (SSI) appeals. Many of our clients come from minority communities—the very communities most impacted by COVID-19.¹ As the pandemic unfolds, we fear that one of the most vulnerable populations we serve, children with disabilities, will greatly suffer. We applaud the national efforts through the recently passed Coronavirus Aid, Relief, and Economic Security (CARES) Act, Public Law Number 116-136, which will help many people during the current pandemic. However, low-income families of children with disabilities, many of whom do not file tax returns, will have difficulty getting the CARES Act funds.² In addition, these families will need further ongoing support due to the specific and costly disability related needs of their children.

One immediate step Congress can and should take to alleviate this burden is to allow families to access their children’s retroactive SSI benefits, which SSA currently requires to be held under the restrictive dedicated accounts system. These benefits legally belong to the child SSI recipient, but SSA’s strict rules create numerous barriers preventing access to the benefits. In this time of urgent need, those unnecessary barriers should be lifted.

I. Introduction to Signatories

Greater Boston Legal Services (GBLS) traces its origins to 1900. It is the primary provider of free, civil legal assistance to low-income individuals and families in Boston, Massachusetts, serving an area that includes the City of Boston and 31 surrounding towns. GBLS’ mission helps ensure equal justice for all. GBLS is a national leader in such varied areas as affordable housing, tenant rights, emergency shelter regulations, family law, welfare, immigration, unemployment and other workplace benefits, and health and disability benefits.

¹ See, e.g., Junaid Nabi & Quoc-Dien Trinh, *How COVID-19 Can Exacerbate Racial Disparities*, Boston Globe, (Apr. 7, 2020, 4:20 PM), <https://www.bostonglobe.com/2020/04/07/opinion/how-covid-19-can-exacerbate-racial-disparities/>.

² The system to distribute CARES Act funds to low income families who do not file income tax forms is complex. There are ongoing advocacy efforts aimed at getting CARES Act payments to SSI recipients without the need to file anything with the IRS; however, even if those efforts are successful, SSI recipients wanting to get the payments for children under age 17 may have to file documents showing that their children are qualified children for Child Tax Credit purposes. Also, grandparents and other non-parents who are representative payees and caregivers of children with disabilities will face challenges accessing CARES Act funds.

The Children's Disability Project (CDP) at GBLS was founded in 2007. The CDP serves the most vulnerable population in Massachusetts: children whose mental and physical disabilities are exacerbated by overwhelming circumstances, including poverty, domestic violence, familial instability, inadequate education, malnutrition, and homelessness. CDP advocates for families to secure Supplemental Security Income (SSI) benefits, which have been shown to alleviate the strains of poverty more effectively than any other public benefit.³ CDP provides full advocacy to children and young adults who have been wrongfully denied SSI disability benefits. GBLS-CDP is the only organization in the country that has devoted significant resources to addressing the dedicated account and its paradoxical effects. While poor children with disabilities are entitled by law to receive benefits, the dedicated account rule in fact bars many children from receiving the aid to which they are legally entitled. Through individual advocacy, community legal education, and cooperation with health care providers and other advocates, CDP has worked tirelessly to ensure that our clients have access to SSI benefits, health insurance, and special education, despite the arcane and counterproductive restrictions of the dedicated account.

The Disability Law Center (DLC) is the Protection and Advocacy (P&A) system for the Commonwealth of Massachusetts. DLC provides free legal services to people with disabilities throughout the state. A key mission of the DLC is to help ensure that people with disabilities are able to access the services they need to live and work independently in the community. Access to cash disability benefits and the associated medical coverage is crucial for many to achieve this goal. DLC's Disability Benefits Project (DBP) provides back up and support to legal services advocates in Massachusetts.

The Boston Center for Independent Living (BCIL) was founded in 1974 as the nation's second independent living center (ILC), and annually provides services to over 3,000 people with disabilities in Greater Boston. BCIL is a civil rights organization led by people with disabilities, and it advocates to eliminate discrimination, isolation and segregation. BCIL advocates for the civil rights of people with disabilities for improved access to public transportation, housing, employment, healthcare, personal care services, government services, and public accommodations.

II. Introduction to the Issue of Dedicated Accounts

The Social Security Administration (SSA) administers the SSI program for adults and children with disabilities. If an applicant for disabilities benefits is approved, she will begin to receive a monthly benefit check. In the usual case, the applicant was disabled at the time of her initial application. Recognizing this, the SSA also issues retroactive (past due) benefits covering the period from the date of the application to the date of the first monthly payment. These retroactive

³ “[H]aving a child with a disability places financial and other stresses on families and may increase the chances of a family being poor...Households with children with chronic health conditions face higher costs for caring for the children as well as decreased household income when parents leave the workforce or decrease their paid workload to care for a child with a disability...Families with children with disabilities are also more likely to incur increased out-of-pocket expenses, for example, for childcare or transportation to locations with specialized medical care.” Nat’l Acad. of Scis., Eng’g, and Med, *Mental Disorders and Disabilities Among Low-Income Children* 119–21 (Thomas F. Boat & Joel T. Wu, Eds., 2015) Washington, DC: The National Academies Press, <https://doi.org/10.17226/21780>.

benefits are often quite significant, as appeals can take up to several years to process because of SSA understaffing and backlogs. Unlike with adults, who are issued their retroactive benefits directly, when a child claimant is awarded SSI benefits, her retroactive benefits are placed in a separate account (“dedicated account”) with rigid spending rules. Funds in this account cannot be used for food, shelter, clothing, transportation or most of the things a poor family with a disabled child might need. Any misstep from the parent (who is usually the representative payee, that is, responsible for managing the child’s funds) results in serious consequences, such as repayment or investigation or removal as the child’s representative payee.

These extreme restrictions on the use of the dedicated account were the last version of a complex legislative process that began with Congress wanting to pay SSI benefits only to children who were institutionalized or at risk of institutionalization. When President Clinton vetoed that legislation, Congress’s reply was the mandatory dedicated account for back payments. It is probably no accident that the restrictions on the dedicated account track the needs of a child at grave risk of institutionalization: housing modifications, personal needs assistance, special equipment, etc. However, these restrictions bear little relationships to the needs of the many children who are not at risk of institutionalization, but nonetheless qualify for SSI. This mismatch, combined with ambiguous and confusing rules, means that often, these funds will not be released even for the legitimate needs of disabled children.

The purpose of the childhood SSI benefits program is to ameliorate the extra expenses incurred by low-income families who care for children with special health care needs. As the Institute of Medicine made clear in its 2015 report to the Commissioner of Social Security,⁴ the SSI program improves the health of highly vulnerable children and has the potential to lift families out of poverty. The dedicated account rule directly undermines this important goal by creating insurmountable barriers for many children with disabilities who are simply trying to access lump sum funds that they are legally owed—funds which only come in a lump sum in the first place because of delays in awarding benefits that are a direct result of understaffing at the SSA. These restrictions are counter to the goal of the SSI program in the best of times; now, faced with the COVID-19 pandemic, poor families must be granted full and complete access to these retroactive SSI funds. A forward-thinking approach is needed in order to allow families to purchase basic necessities such as food, diapers, toilet paper, educational tools, and other items associated with being confined at home with a disabled child and little or no resources.

The problems posed by dedicated accounts even outside of this crisis are already well known to the SSA, thanks to advocacy from GBLS-CDP and others. In 2019, after reviewing CDP’s webpage, the Social Security’s Advisory Board (SSAB) contacted CDP for our community education materials on the dedicated account. After discussion with the SSAB, on March 29, 2019, CDP, DLC and Professor Mary O’Connell filed recommendations to the SSAB regarding the elimination of the dedicated account and alternative incremental solutions on decreasing barriers to accessing the funds.⁵ In the SSAB’s 2019 “Statement on the SSI Program,” the SSAB

⁴ *Id.* at 121.

⁵ We recommended: eliminating the mandatory dedicated account entirely, or making it optional for families who want and are able to save funds for their child’s educational or other needs. Incremental recommendations included: offer information on ABLE Accounts (voluntary) to families who want to save; increase the spend down period for

asked the SSA to discuss the dedicated account program, stating “[d]edicated accounts are complex and burdensome for both payees and SSA.”⁶ The SSAB intended to “further explore dedicated accounts and their varied impacts on SSI recipients, payees, and SSA.” *Id.* On September 17, 2019, the Office of Inspector General (OIG), issued an audit report of the SSA,⁷ concluding, “SSA improperly withheld approximately \$78 million in dedicated account underpayments from approximately 14,000 recipients. Of these, approximately 3,000 recipients were identified in our 2010 audit and were due approximately \$12.6 million in underpayments.”⁸

III. The Limits Imposed by Dedicated Accounts

After years of collaborating with the CDP, Professor Mary E. O’Connell of the Northeastern University School of Law authored a comprehensive article explaining the workings of the dedicated account, explaining why Congress enacted the mandatory dedicated account in the first place and describing its negative impact on the children subject to it.⁹

As discussed in Professor O’Connell’s article and below, “[u]nlike past-due funds paid to an adult beneficiary, funds in a dedicated account are subject to extremely severe restrictions.”¹⁰ Representative payees for children have been barred from using dedicated account funds for food, shelter, clothing or transportation for the beneficiary child.

SSA’s guidelines for implementing dedicated accounts are set out in their Program Operations Manual System (POMS).¹¹ According to SSA:

retroactive awards from 9 months to 12 months, allowing families to thoughtfully plan how to spend the funds; Field office (FO) staff training; for any remaining dedicated accounts, expand the list of approvable educational and disability-related expenditures; and all funds repaid by the representative payee in connection with misapplication allegations should be returned to the child’s dedicated account and not to the Department of the Treasury.

⁶ The report adds, “While empirical data evaluating the utility of dedicated accounts are not available, bipartisan recommendations to eliminate the accounts made by former Commissioners of Social Security, presidents, practitioners, the advocacy community, and those directly impacted by dedicated account policy point to the complexity and confusion generated by existing account provisions. Since dedicated accounts were created in 1996, and despite consistent and bipartisan calls for their elimination starting shortly thereafter, there has been no legislative action on the provision. Meanwhile, the existing literature suggests that the administration of dedicated accounts impose burdens on both the agency and the people who the agency serves. The Board intends to further explore dedicated accounts and their varied impacts on SSI recipients, payees, and SSA.” *Id.*

⁷ Office of the Inspector General, *Dedicated Accounts Underpayments Payable to Children Receiving Supplemental Security Income* (A-04-18-50607) (2019), <https://oig.ssa.gov/sites/default/files/audit/full/pdf/A-04-18-50607.pdf>.

⁸ “Moreover, SSA improperly withheld the dedicated account underpayments payable to 63 (38 percent) of the 166 recipients we identified in 2010. Of the 100 sampled recipients with dedicated account underpayments in our current audit, SSA improperly withheld underpayments, totaling \$363,052, to 65 recipients.” *Id.*

⁹ Mary E. O’Connell, “Supplemental Security Income’s ‘Dedicated Account’: A Debunked Urban Legend and Twenty Years of Waste” (May 3, 2017), <http://dx.doi.org/10.2139/ssrn.2962370>. Attached, please find a copy of the article (I will not repeat the details set out in the article).

¹⁰ *Id.*

¹¹ The POMS is the operational reference used by SSA staff to conduct SSA’s daily business.

This law and its restrictions represent a significant departure from the traditional approach to the use of SSI benefits by representative payees. The dedicated account restrictions drastically limit a payee's discretion in using dedicated account funds. Funds in a dedicated account can be used only for medical treatment, education, job skills training, or *expenditures related in some other way to a consequence of the child's impairment*. 42 U.S.C. §1383(a)(2)(F)(ii)(II), Program Operations Manual System (POMS) GN 00602.140 [effective 12/04/12 – present], “Permitted Expenditures from Dedicated account.” Funds in a dedicated account can be used only for:

[E]ducation or job skills training; personal needs assistance; special equipment; housing modification; medical treatment; therapy or rehabilitation; or *any other item or service that the Commissioner [of Social Security] determines to be appropriate; provided that such expense benefits such individual and...is related to the impairment (or combination of impairments) of such individual*.

Id. (emphasis added). While SSA does not *require* payees to obtain SSA’s approval before making expenditures in the “other” category, SSA staff encourages them to do so. Id. According to SSA, the “payee should explain how or why the ‘other items and services’ relate to the child’s impairment.” Id. Field Office (FO) staff are advised to “approve or deny requests promptly because many families depend on a quick response to a request to use funds.” Id.

Requiring parents to appear before Social Security FO staff to request access to dedicated account funds, and then proving that the child’s need matches the above categories, is burdensome both to families and the SSA. Like many federal agencies, SSA is understaffed, leading to frequent delays in processing requests for the release of the child’s funds. In her article, Professor O’Connell, through her research and case studies, describes in great detail how the dedicated account, in its current form and administration, effectively frustrates Congress’s goal in enacting this program to aid children with disabilities.

IV. Jordan, Sandra, Deidre, and Kamira’s Stories: Case Studies on the Drawbacks of Dedicated Accounts

Below are the stories of four GBLS-CDP clients whose struggle to gain access to necessary funds illustrate how the restrictions of the dedicated account harm families by thwarting their efforts to meet the critical housing, educational and health needs of a disabled child.¹²

Jordan’s Story: Jordan is a 7-year-old boy who qualifies for SSI benefits because he suffers from a brain injury stemming from a stroke. Despite having a legal right to over \$16,000 in retroactive SSI benefits, Jordan and his family are at risk of homelessness during the COVID-19 pandemic. His family is unable to access dedicated account funds to pay rent arrears to prevent homelessness (a permissible emergency expense) because of SSA’s rigid

¹² Other compelling examples can be found in Professor O’Connell’s work, including the case of an infant with a disability whose mother was barred from using his dedicated account for infant formula, diapers and a snowsuit. Had the SSA not delayed payments to this child for over a year, his benefits could have been used to meet these essential needs. *See O’Connell Article, pp. 3-9.*

and extreme dedicated account rules. Jordan's story is the perfect example of "bureaucratic disentanglement."

Jordan, a 7-year-old boy who lives with his parents and two siblings, suffers from brain injury caused by a stroke. Despite unquestionably being entitled to over \$16,000 in retroactive SSI benefits from the SSA, Jordan and his family currently face eviction in the middle of the COVID-19 crisis over less than \$3,600 in past-due rent. SSA rules make it clear that preventing homelessness is a permissible use of these retroactive funds, but the byzantine restrictions placed on dedicated accounts make it impossible for his parents to actually access this money in their time of need.

As a result of his brain injury, Jordan has coordination problems and limited mobility of his right hand. His condition causes serious functional limitations, including the inability to shower, dress, groom and feed himself without assistance, as well as emotional issues as he struggles with being "different" from his peers. In May 2019, the SSA approved Jordan's SSI claim. He was awarded monthly SSI benefits. Because his claim took several years to be approved, he was also due \$16,494 in retroactive benefits. Per SSA rules, this retroactive SSI is held by SSA and released in installments to a dedicated account. Currently, one installment has been released.

Jordan's father, Carlos, is an Uber driver. His mother, Maria, is not able to work because she has to care for Jordan and her other children. Jordan's younger brother also has health conditions which requires additional trips to the doctors and Early Intervention services. The family qualifies for a small amount of food stamps (Supplemental Nutrition Assistance Program), and has been on a waiting list for subsidized housing for several years. They currently live in a small apartment, paying \$1,800 per month in rent. Jordan's monthly SSI benefits helped to pay for some of his needs, allowing Carlos' income as an Uber driver to keep the rest of the family afloat and in housing. However, due to an error by SSA, Jordan did not receive his regular monthly SSI payments for January, February, and March of this year. As a result of this unexpected and erroneous loss of Jordan's SSI benefits, the family fell behind on rent, because money that had been dedicated to rent was suddenly required for Jordan. In March 2020, Carlos received a "14 Day Notice to Quit for Non-Payment of Rent." He owes his landlord \$3,600 in rental arrears for February and March.

Carlos came to CDP-GBLS seeking legal assistance with getting SSA to reinstate Jordan's monthly SSI benefits. Carlos informed CDP about the family's struggles to meet basic needs. Despite a current lump sum of \$2,000 in the dedicated account (representing an installment), Carlos had not touched any of this money to help with rent, because he feared repercussions from SSA if he withdrew from the dedicated account without specific written SSA approval. Due to SSA Field Office (FO) staff shortages and the challenges with getting a FO worker to approve the expense request, Carlos worried that this long, complex approval process would not help his family in time. He was unaware that Jordan has a legal right to use dedicated account funds to prevent homelessness.

On March 12, 2020, days before our offices closed because of COVID-19, CDP intervened, immediately calling and sending a letter to the FO explaining the urgency of the matter. CDP outlined the dedicated account rules and requested that SSA deposit another installment in Jordan's dedicated account in order to cover the full amount of the rent arrears. We explained that the rules are clear, specifically noting that using dedicated account funds on rent is permissible in situations where the child is at risk of homelessness. We have not heard back from SSA because of the challenges COVID-19 presents. However, based on years of assisting families with navigating SSA as they struggle to get access to dedicated account funds prior to this pandemic, we are not hopeful that SSA will even review our request.

Carlos consistently complies with all of SSA's rules, including income reporting requirements. He has always provided for his wife and three children and never expected his family to be at risk of losing their home. However, with the loss of Jordan's SSI benefits (due to SSA error), they are facing that very risk in the middle of a pandemic. Even though Jordan is legally entitled to more than enough money to cover the rent arrears, we are unsure about the outcome of Jordan's family's housing crisis, all because their ability to access his money has been so restricted by complex rules.

Jordan's story presents compelling reasons why now, more than ever, poor families need immediate access to their money to pay for food, shelter, medicine and other necessities.

Sandra's Story: Sandra is a 12-year-old girl who was born with sickle cell anemia, a potentially life-threatening disease. After an eight-year legal battle, starting when she was 6 months old, she was finally awarded SSI benefits. Four years after being awarded these benefits, she is still not allowed to make permissible purchases with her dedicated account funds because of SSA's rigid rules.

Sandra is a 12-year-old girl who was born with sickle cell anemia, a potentially life-threatening disease. Throughout her young life, Sandra endured many episodes of sickle cell pain crises requiring hospitalization and potent narcotics. Her sickle cell disease is complicated and compounded by chronic middle ear issues, hearing loss, and sleep apnea. On September 10, 2008, when Sandra was 6 months old, her mother, Sheila, applied for SSI benefits on behalf of Sandra. After Sheila's applications for benefits were denied twice, she reached out to CDP-GBLS for help with what would become an eight-year legal battle for her daughter's SSI benefits. During the period that her claim was on appeal, Sheila found a job at a Head Start program which allowed her to care for her children and provide services for other families. She also managed to go back to school and became a Licensed Social Worker. However, Sandra was not able to keep any job for long because would miss too many days of work to care for Sandra, who was frequently ill.

By the time Sandra's SSI benefits were awarded, in 2016, she was 8 years old. Sandra was awarded monthly SSI benefits and she was legally entitled to a large sum of retroactive benefits. Her retroactive benefits were held by SSA and designated for her dedicated account. With the help of CDP, in 2016 Sheila obtained permission to make

necessary and permissible purchases for Sandra's health and well-being using this money. However, despite our assistance, and even though Sheila is well-versed in the dedicated account rules, she continues to struggle with navigating SSA and getting FO staff to release funds for permissible purchases under the rules. For example, Sandra continues to require hospitalization for treatment of her sickle cell condition. In 2018, her pain crises spiked and she missed school. Her teachers and treating sources recommended that she get an iPad for schoolwork use while in the hospital or at home due to pain crises. Sheila tried to get SSA to release money into the dedicated account and grant her permission to make this purchase. However, she was unsuccessful, and eventually gave up pursuing this money because she knew her efforts would fail.

Sheila is a single mother with 3 young children. Her family lives in subsidized housing and they qualify for food stamps (Supplemental Nutrition Assistance Program). She does not have the extra money needed to purchase an iPad or the equivalent. Even though Sandra is still owed thousands of dollars in SSI retroactive benefits, because she is unable to access this money due to the SSA's strict rules, she cannot acquire the educational tools she needs to keep up while being stuck at home due to her disability. During the COVID-19 pandemic, Sandra's family will undoubtedly have numerous unmet needs stemming from poverty that would be alleviated if they could access this money.

Deidre's Story: Deidre is young woman who received SSI as a child, but when she graduated from high school, Social Security failed her by not releasing Deidre's dedicated account funds to help with her college tuition, books and school supplies. In addition to these necessary education expenses, Deidre had continuing health-related expenses stemming from her atopic dermatitis and psoriasis. Eight years elapsed from Deidre's being approved for SSI benefits until funds were finally released for Deidre's continuing education. And this result would almost certainly not have occurred but for Deidre's having legal representation.

Deidre is a 22-year-old young woman who began receiving SSI benefits in October 2010, when she was 13. Her disabilities included depression, atopic dermatitis, psoriasis, obesity and learning disabilities. When Deidre's claim was finally processed by SSA, she was owed approximately 31 months of retroactive benefits. Deidre's mother, Brenda, served as Deidre's representative payee until Deidre was 21. Brenda also has disabilities including depression, anxiety, bipolar disorder and a learning disability, and currently receives Social Security Disability Insurance (SSDI) benefits.

In 2010, CDP successfully represented Deidre on her SSI claim. Six years later, Brenda contacted CDP. Although Deidre was receiving monthly SSI benefits, she had only received one disbursement of \$2,113.20 from her dedicated account funds, which totaled over \$10,000. The story of why Deidre had been denied access to her funds lays bare the complexities and limitations of the dedicated account system.

In 2011, an initial disbursement of \$2,113.20 was made from the dedicated account. Prior to this disbursement, Brenda had signed a "Statement of Claimant or Other Person," a standard one-page description of the dedicated account. Brenda understood the agreement

to mean that she could use the dedicated account money for any expenses related to Deidre's impairments, so she used the money for necessary items for Deidre such as larger clothing, low calorie food for weight loss, hair treatments, and school supplies. However, after she timely reported her use of funds to the FO, Brenda received a notice from SSA alleging she had misapplied the funds. Brenda contacted the SSA and was told she must repay the \$2,113.20, even though she provided receipts showing all of it had been spent for Deidre's needs. Brenda paid SSA \$50 per month until she could no longer afford the payment. As per SSA rules, all of these repayments were returned to the U.S. Treasury and not to Deidre's dedicated account.

After she graduated from high school, Deidre wanted to attend Quincy College (QC) to study business. Brenda asked SSA to release funds from the dedicated account for Deidre's tuition and school supplies, but SSA refused, citing the former "misapplication" of funds by Brenda. At her mother's urging, Deidre nonetheless registered for classes and attended QC with some student aid, while Brenda struggled to purchase books with Deidre's monthly SSI and Brenda's SSDI benefits. In June of 2016, Brenda contacted CDP for help with accessing Deidre's dedicated account. Together, we contacted the SSA. Despite their claim of overpayment and misapplication of funds, after speaking with a district manager, we were able to get SSA to release funds for books, a laptop, and tuition for Deidre's upcoming college semester. However, by that time, Deidre's first semester had ended, and she had failed her classes because she did not have the books and supplies she needed to keep up with the assigned work.

Even worse, after the 2016 release of funds, the local SSA office experienced a staff change. The new claims representative assigned to Deidre's case refused to release any further tuition payments until the alleged overpayment and misapplication issues were resolved. This staff change and subsequent refusal to release further funds is a clear example of FO staff's subjective and inconsistent interpretation and application of the dedicated account rules, which only adds more confusion to an already difficult process.

CDP, representing Deidre, eventually appeared before an Administrative Law Judge (ALJ) to challenge SSA's actions in Deidre's case and to request that SSA be ordered to release all of the remaining funds in her dedicated account (approximately \$8,000 in retroactive SSI) for payment of her tuition, books, school supplies and other necessary expenses. In his decision, the ALJ waived the full amount of the alleged overpayment, finding that Brenda and Deidre were not at fault. He also found that no misapplication had occurred, as all monies spent on items for Deidre had been necessary and within SSA's rules. The ALJ ordered that the balance in the dedicated account be released.

Deidre's case illustrates the many pitfalls associated with administering the dedicated account. According to the ALJ, SSA staff 1) did not properly apply the concept of "other" allowable expenses such as hair treatments and larger clothing, 2) did not do enough to insure that the representative payee had a clear understanding of the many restrictions on the use of dedicated account, and 3) failed to timely release funds.

Though she was entitled to the funds in her dedicated account, the restrictions and the bureaucracy surrounding that account meant that the system profoundly failed Deidre. Her funds were not released until eight years after she first tried to access them—and then only by court order. By the time she finally had access to this money, Deidre had abandoned her dream of attending college. Most children receiving SSI cannot access legal advocates. For them, the dedicated account often means that funds which are supposed to be used to accommodate their disabilities are, in essence, forfeited. Cases like Deidre’s—which, sadly, are commonplace—prove that the dedicated account rule needs change.

Kamira’s Story: Kamira is a 16-year-old girl who was born in a refugee camp in Ethiopia. She suffers from bladder exstrophy, a serious condition causing urine leakage. She was awarded SSI benefits and is owed over \$9000 in retroactive benefits. Her mother, Adera, is not able to navigate SSA’s complex dedicated account rules and she does not speak English, which presents other challenges. Therefore, Kamira is prevented from making a permissible purchase with her dedicated account funds because of SSA’s rigid rules.

Kamira is a 16-year old girl who lives with her mother and four siblings in Section 8 Housing in Roxbury, Massachusetts. Kamira was born in a refugee camp in Ethiopia. She was born with bladder exstrophy, a condition where the opening of her bladder makes it impossible for her body to store urine, causing her bladder to constantly leak urine all over her body. Being born in a refugee camp made it impossible for Kamira to have initial bladder reconstructive surgery which is recommended within the first two to three days of life. Instead, Kamira did not receive her initial bladder reconstructive surgery until she was five years old. During her young life, Kamira spent months in the hospital undergoing multiple reconstructive surgeries to address her bladder and catheterization issues. Following these invasive surgeries, Kamira and her mother, Adera, learned how to catheterize and irrigate her. She requires catheterization five times a day at home and at school, as well as other invasive medical procedures on a daily basis. Adera has been unable to work since Kamira was born because she must attend to Kamira’s health issues.

In 2017, Adera, with the help of a social worker who spoke Somali, filed a claim for SSI benefits. CDP secured SSI benefits for Kamira in 2019. Kamira was awarded monthly SSI benefits and is entitled to almost 3 years of retroactive SSI benefits. Her retroactive SSI is held by SSA and designated for her dedicated account. Kamira is currently in 10th grade and needs a laptop for her classes. This is a permissible education related expenditure under the dedicated account rules. In February 2020, CDP-GBLS began working with Adera and Kamira to pursue permission from SSA for this allowable expenditure of dedicated account funds. Her family is low-income and not able to make this purchase while SSA holds over \$9,000 in dedicated account funds that legally belong to Kamira. Adera does not speak English and she is fearful to use any of the dedicated account funds.

The rules are complex, and obtaining permission for each purchase is difficult and time-consuming. During this COVID-19 pandemic, Kamira, unlike many of her peers, will not have a laptop. Navigating SSA’s rigid dedicated account rules is particularly challenging

for non-English speakers, like Adera, who struggle to even begin the process of trying to access dedicated account funds.

V. Conclusion

The dedicated account process hurts the people it is supposed to protect: disabled children. In our cases, we have found that most misapplications of funds by representative payees are unintentional and for the benefit of the child, as was the case with Deidre and Brenda. We have also found that usually, the restrictions on the account mean these funds just sit there, helping no one. Ever since the dedicated account statute was passed, and consistently for more than a decade, the Commissioners of Social Security have asked Congress to do away with the dedicated account. They have argued that 1) the account's strictures are not needed to prevent fraud, 2) SSA field office employees have urged that the account be abolished because of the enormous time and effort involved in overseeing it, and 3) changing the rules and eliminating the dedicated account would save millions of dollars in taxpayer money which could be diverted to other uses in the badly over-taxed SSA.¹³ Now, during the COVID-19 pandemic, families deep in poverty need the SSA to set a moratorium lifting the burdensome restrictions and allow families to make full use of their children's dedicated account funds for basic necessities.

We understand that changing the mandatory dedicated account rule, including proposal for its elimination, demands more discussion and legislative action. However, given this current, serious health crisis, when more than ever poor families need money to pay for food, shelter, medicine and other necessities, we urge you to request that SSA lift their rigid rules and allow families to access the funds for whatever the child needs.

We thank you for consideration of our recommendations.

Sincerely,

/s/Taramattie Doucette

Taramattie Doucette, Esq.

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¹³ O'Connell, *supra* note 9, at 2 ("Based on the testimony of prior Commissioners of Social Security, there is reason to believe that monitoring these accounts costs the SSA roughly \$7,000,000 per year").

/s/William Henning

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November 17, 2020

Emma Tatem
Lead Policy Analyst
Social Security Advisory Board
400 Virginia Ave, SW Suite #625
Washington, DC 20024

Re: Barriers to Accessing SSI Dedicated Account Funds

Dear Emma:

We are looking forward to participating in the November 19, 2020 SSAB Roundtable on the challenges of the SSI dedicated account. Below, please find the stories that we sent to Congressman Neal. As I was reviewing CDP's case files, I found that the stories below are representative of issues and challenges faced by CDP's clients. In some of CDP's new cases, where children were awarded SSI in 2020 and now have dedicated accounts, parent payees are trying to secure permission to purchase desks, chairs, lamps, storage bins, computers, and printers for remote school due to COVID-19. Although these items should be permitted education-related expenditures,¹ based on CDP's past experience advocating for similar requests, we anticipate that these children with new dedicated accounts will need CDP's legal assistance to get their expenditures approved.

We sent you Deidre's story in 2019, but it is worth sharing again along with the other stories since they capture the range of barriers representative payees encounter when navigating SSA's burdensome and restrictive SSI dedicated account rules.

¹ POMS GN 00602.140 Permitted Expenditures from Dedicated Accounts.
<https://secure.ssa.gov/poms.nsf/lnx/0200602140>

Jordan, Sandra, Deidre, and Kamira's Stories²: Case Studies on the Drawbacks of Dedicated Accounts

Below are the stories of four GBLS-CDP clients whose struggle to gain access to necessary funds illustrate how the restrictions of the dedicated account harm families by thwarting their efforts to meet the critical housing, educational and health needs of a disabled child.³

Jordan's Story⁴: Jordan is a 7-year-old boy who qualifies for SSI benefits because he suffers from a brain injury stemming from a stroke. Despite having a legal right to over \$16,000 in retroactive SSI benefits, Jordan and his family are at risk of homelessness during the COVID-19 pandemic. His family is unable to access dedicated account funds to pay rent arrears to prevent homelessness (a permissible emergency expense) because of SSA's rigid application of the restrictive dedicated account rules. Jordan's story is the perfect example of "bureaucratic disentanglement."

Jordan, a 7-year-old boy who lives with his parents and two siblings, has a severe brain injury caused by a stroke. Despite unquestionably being entitled to over \$16,000 in retroactive SSI benefits from the SSA, Jordan and his family currently face eviction in the middle of the COVID-19 crisis over less than \$3,600 in past-due rent. SSA rules make it clear that preventing homelessness is a permissible use of these retroactive funds, but the byzantine restrictions placed on dedicated accounts make it impossible for his parents to actually access this money in their time of need.

As a result of his brain injury, Jordan has coordination problems and limited mobility of his right hand. His condition causes serious functional limitations, including the inability to shower, dress, groom and feed himself without assistance, as well as emotional issues as he struggles with being "different" from his peers. In May 2019, the SSA approved Jordan's SSI claim. He was awarded monthly SSI benefits. Because his claim took several years to be approved, he was also due \$16,494 in retroactive benefits. Per SSA rules, this retroactive SSI is held by SSA and released in installments to a dedicated account. To date, one installment has been released.

Jordan's father, Carlos, is an Uber driver. His mother, Maria, is not able to work because she has to care for Jordan and her other children. Jordan's younger brother also has health conditions which require additional trips to his doctors and Early Intervention services. The family qualifies for a small amount of food stamps (Supplemental Nutrition

² All names in the stories are changed to pseudonyms.

³ Other compelling examples can be found in Professor O'Connell's work, including the case of an infant with a disability whose mother was barred from using his dedicated account for infant formula, diapers and a snowsuit. Had the SSA not delayed payments to this child for over a year, his monthly benefits could have been used to meet these essential needs. Mary E. O'Connell, "Supplemental Security Income's 'Dedicated Account': A Debunked Urban Legend and Twenty Years of Waste" (May 3, 2017), <http://dx.doi.org/10.2139/ssrn.2962370>.

⁴ This story was drafted in April 2020. Due to the COVID-19 closures and the housing moratorium this family's immediate housing crisis was placed on hold. Later in July 2020, as a result of CDP's advocacy, the use of dedicated account funds for the rental arrears was permitted. The story has been re-written as "Omar's Story" with updated facts and was sent to you on November 14, 2020.

Assistance Program), and has been on a waiting list for subsidized housing for several years. They currently live in a small apartment, paying \$1,800 per month in rent. Jordan's monthly SSI benefits helps to pay for some of his needs, allowing Carlos' income as an Uber driver to keep the rest of the family afloat and in housing. However, due to an error by SSA, Jordan did not receive his regular monthly SSI payments for January, February, and March of this year. As a result of this unexpected and erroneous loss of Jordan's SSI benefits, the family fell behind on rent, because money that had been available for rent was suddenly required for Jordan's needs. In March 2020, Carlos received a "14 Day Notice to Quit for Non-Payment of Rent." He owed his landlord \$3,600 in rental arrears for February and March.

Carlos came to CDP-GBLS seeking legal assistance with getting SSA to reinstate Jordan's monthly SSI benefits. Carlos informed CDP about the family's struggles to meet basic needs. Despite a current lump sum of \$2,000 in the dedicated account (representing an installment), Carlos had not touched any of this money to help with rent, because he feared repercussions from SSA if he withdrew from the dedicated account without specific written SSA approval. Due to SSA Field Office (FO) staff shortages and the challenges with getting a FO worker to approve the expense request, Carlos worried that this long, complex approval process would not help his family in time. He was unaware that Jordan has a legal right to use dedicated account funds to prevent homelessness.

On March 12, 2020, days before our offices closed because of COVID-19, CDP intervened, immediately calling and sending a letter to the FO explaining the urgency of the matter. CDP outlined the dedicated account rules and requested that SSA deposit another installment in Jordan's dedicated account in order to cover the full amount of the rent arrears. We explained that the rules are clear, specifically noting that using dedicated account funds on rent is permissible in situations where the child is at risk of homelessness. We have not heard back from SSA because of the challenges COVID-19 presents. However, based on years of assisting families with navigating SSA as they struggle to get access to dedicated account funds prior to this pandemic, we are not hopeful that SSA will even review our request.

Carlos consistently complies with all of SSA's rules, including income reporting requirements. He has always provided for his wife and three children and never expected his family to be at risk of losing their home. However, with the loss of Jordan's SSI benefits (due to SSA error), they are facing that very risk in the middle of a pandemic. Even though Jordan is legally entitled to more than enough money to cover the rent arrears, we are unsure about the outcome of Jordan's family's housing crisis, all because their ability to access his money has been so restricted by complex rules.

Jordan's story presents compelling reasons why now, more than ever, poor families need immediate access to their money to pay for food, shelter, medicine and other necessities.

Sandra's Story: Sandra is a 12-year-old girl who was born with sickle cell anemia, a potentially life-threatening disease. After an eight-year legal battle, starting when she was 6 months old, she was finally awarded SSI benefits. Four years after being awarded these

benefits, she is still not allowed to make permissible purchases with her dedicated account funds because of SSA's rigid rules.

Sandra is a 12-year-old girl who was born with sickle cell anemia, a potentially life-threatening disease. Throughout her young life, Sandra endured many episodes of sickle cell pain crises requiring hospitalization and potent narcotics. Her sickle cell disease is complicated and compounded by chronic middle ear issues, hearing loss, and sleep apnea. On September 10, 2008, when Sandra was 6 months old, her mother, Sheila, applied for SSI benefits on behalf of Sandra. After Sheila's applications for benefits were denied twice, she reached out to CDP-GBLS for help with what would become an eight-year legal battle for her daughter's SSI benefits. During the period that her claim was on appeal, Sheila found a job at a Head Start program which allowed her to care for her children and provide services for other families. She also managed to go back to school and became a Licensed Social Worker. However, Sandra was not able to keep any job for long because would miss too many days of work to care for Sandra, who was frequently ill.

By the time Sandra's SSI benefits were awarded, in 2016, she was 8 years old. Sandra was awarded monthly SSI benefits and she was legally entitled to a large sum of retroactive benefits. Her retroactive benefits were held by SSA and designated for her dedicated account. With the help of CDP, in 2016 Sheila obtained permission to make necessary and permissible purchases for Sandra's health and well-being using this money. However, despite our assistance, and even though Sheila is well-versed in the dedicated account rules, she continues to struggle with navigating SSA and getting FO staff to release funds for permissible purchases under the rules. For example, Sandra continues to require hospitalization for treatment of her sickle cell condition. In 2018, her pain crises spiked and she missed school. Her teachers and treating sources recommended that she get an iPad for schoolwork use while in the hospital or at home due to pain crises. Sheila tried to get SSA to release money into the dedicated account and grant her permission to make this purchase. However, she was unsuccessful, and eventually gave up pursuing this money because she knew her efforts would fail.

Sheila is a single mother with 4 young children. Her family lives in subsidized housing and they qualify for food stamps (Supplemental Nutrition Assistance Program). She does not have the extra money needed to purchase an iPad or the equivalent. Even though Sandra is still owed thousands of dollars in SSI retroactive benefits, she is unable to access this money due to the SSA's strict rules, and she cannot acquire the educational tools she needs to keep up while being stuck at home due to her disability. During the COVID-19 pandemic, Sandra's family will undoubtedly have numerous unmet needs stemming from poverty that would be alleviated if they could access this money.

Deidre's Story: Deidre is young woman who received SSI as a child, but when she graduated from high school, Social Security failed her by not releasing Deidre's dedicated account funds to help with her college tuition, books and school supplies. In addition to these necessary education expenses, Deidre had continuing health-related expenses stemming from her atopic dermatitis and psoriasis. Eight years elapsed from Deidre's

being approved for SSI benefits until funds were finally released for Deidre's continuing education. And this result would almost certainly not have occurred but for Deidre's having legal representation.

Deidre is a 22-year-old young woman who began receiving SSI benefits in October 2010, when she was 13. Her disabilities included depression, atopic dermatitis, psoriasis, obesity and learning disabilities. When Deidre's claim was finally processed by SSA, she was owed approximately 31 months of retroactive benefits. Deidre's mother, Brenda, served as Deidre's representative payee until Deidre was 21. Brenda also has disabilities including depression, anxiety, bipolar disorder and a learning disability, and currently receives Social Security Disability Insurance (SSDI) benefits.

In 2010, CDP successfully represented Deidre on her SSI claim. Six years later, Brenda contacted CDP. Although Deidre was receiving monthly SSI benefits, she had only received one disbursement of \$2,113.20 from her dedicated account funds, which totaled over \$10,000. The story of why Deidre had been denied access to her funds lays bare the complexities and limitations of the dedicated account system.

In 2011, an initial disbursement of \$2,113.20 was made from the dedicated account. Prior to this disbursement, Brenda had signed a "Statement of Claimant or Other Person," a standard one-page description of the dedicated account. Brenda understood the agreement to mean that she could use the dedicated account money for any expenses related to Deidre's impairments, so she used the money for necessary items for Deidre such as larger clothing, low calorie food for weight loss, hair treatments, and school supplies. However, after she timely reported her use of funds to the FO, Brenda received a notice from SSA alleging she had misapplied the funds. Brenda contacted the SSA and was told she must repay the \$2,113.20, even though she provided receipts showing all of it had been spent for Deidre's needs. Brenda paid SSA \$50 per month until she could no longer afford the payment. As per SSA rules, all of these repayments were returned to the U.S. Treasury and not to Deidre's dedicated account.

After she graduated from high school, Deidre wanted to attend Quincy College (QC) to study business. Brenda asked SSA to release funds from the dedicated account for Deidre's tuition and school supplies, but SSA refused, citing the former "misapplication" of funds by Brenda. At her mother's urging, Deidre nonetheless registered for classes and attended QC with some student aid, while Brenda struggled to purchase books with Deidre's monthly SSI and Brenda's SSDI benefits. In June of 2016, Brenda contacted CDP for help with accessing Deidre's dedicated account. Together, we contacted the SSA. Despite their claim of overpayment and misapplication of funds, after speaking with a district manager, we were able to get SSA to release funds for books, a laptop, and tuition for Deidre's upcoming college semester. However, by that time, Deidre's first semester had ended, and she had failed her classes because she did not have the books and supplies she needed to keep up with the assigned work.

Even worse, after the 2016 release of funds, the local SSA office experienced a staff change. The new claims representative assigned to Deidre's case refused to release any further tuition payments until the alleged overpayment and misapplication issues were resolved. This staff change and subsequent refusal to release further funds is a clear example of FO staff's subjective and inconsistent interpretation and application of the dedicated account rules, which only adds more confusion to an already difficult process.

CDP, representing Deidre, eventually appeared before an Administrative Law Judge (ALJ) to challenge SSA's actions in Deidre's case and to request that SSA be ordered to release all of the remaining funds in her dedicated account (approximately \$8,000 in retroactive SSI) for payment of her tuition, books, school supplies and other necessary expenses. In his decision, the ALJ waived the full amount of the alleged overpayment, finding that Brenda and Deidre were not at fault. He also found that no misapplication had occurred, as all monies spent on items for Deidre had been necessary and within SSA's rules. The ALJ ordered that the balance in the dedicated account be released.

Deidre's case illustrates the many pitfalls associated with administering the dedicated account. According to the ALJ, SSA staff 1) did not properly apply the concept of "other" allowable expenses such as hair treatments and larger clothing, 2) did not do enough to insure that the representative payee had a clear understanding of the many restrictions on the use of dedicated account, and 3) failed to timely release funds.

Though she was entitled to the funds in her dedicated account, the restrictions and the bureaucracy surrounding that account meant that the system profoundly failed Deidre. Her funds were not released until eight years after she first tried to access them—and then only by an administrative court order. By the time she finally had access to this money, Deidre had abandoned her dream of attending college. Most children receiving SSI cannot access legal advocates. For them, the dedicated account often means that funds which are supposed to be used to accommodate their disabilities are, in essence, forfeited. Cases like Deidre's—which, sadly, are commonplace—prove that the dedicated account rule needs change.

Kamira's Story: Kamira is a 16-year-old girl who was born in a refugee camp in Ethiopia. She suffers from bladder exstrophy, a serious condition causing urine leakage. She was awarded SSI benefits and is owed over \$9000 in retroactive benefits. Her mother, Adera, is not able to navigate SSA's complex dedicated account rules and she does not speak English, which presents other challenges. Therefore, Kamira is prevented from making a permissible purchase with her dedicated account funds because of SSA's rigid rules.

Kamira is a 16-year old girl who lives with her mother and four siblings in Section 8 Housing in Roxbury, Massachusetts. Kamira was born in a refugee camp in Ethiopia. She was born with bladder exstrophy, a condition where the opening of her bladder makes it impossible for her body to store urine, causing her bladder to constantly leak urine all over her body. Being born in a refugee camp made it impossible for Kamira to have initial bladder reconstructive surgery which is recommended within the first two to three days of life. Instead, Kamira did not receive her initial bladder reconstructive surgery

until she was five years old. During her young life, Kamira spent months in the hospital undergoing multiple reconstructive surgeries to address her bladder and catheterization issues. Following these invasive surgeries, Kamira and her mother, Adera, learned how to catheterize and irrigate her. She requires catheterization five times a day at home and at school, as well as other invasive medical procedures on a daily basis. Adera has been unable to work since Kamira was born because she must attend to Kamira's health issues.

In 2017, Adera, with the help of a social worker who spoke Somali, filed a claim for SSI benefits. CDP secured SSI benefits for Kamira in 2019. Kamira was awarded monthly SSI benefits and is entitled to almost 3 years of retroactive SSI benefits. Her retroactive SSI is held by SSA and designated for her dedicated account. Kamira is currently in 10th grade and needs a laptop for her classes. This is a permissible education related expenditure under the dedicated account rules. In February 2020, CDP-GBLS began working with Adera and Kamira to pursue permission from SSA for this allowable expenditure of dedicated account funds. Her family is low-income and not able to make this purchase while SSA holds over \$9,000 in dedicated account funds that legally belong to Kamira. Adera does not speak English and she is fearful to use any of the dedicated account funds.

The rules are complex, and obtaining permission for each purchase is difficult and time-consuming. During this COVID-19 pandemic, Kamira, unlike many of her peers, will not have a laptop. Navigating SSA's rigid dedicated account rules is particularly challenging for non-English speakers, like Adera, who struggle to even begin the process of trying to access dedicated account funds.

Please let me know if you have any questions about the stories.

Sincerely,

/s/Taramattie Doucette

Taramattie Doucette, Esq.

Project Director

Children's Disability Project

Greater Boston Legal Services

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Omar's Story¹

A family at risk of being homeless while \$14,000 was in a Dedicated Account

Omar is a 7-year-old boy who had a stroke and now suffers from several long-term functional limitations, including the inability to use his right arm and hand. He requires help with grooming, hygiene, and other activities of daily living, such as showering, dressing, and feeding himself. Omar is often frustrated because he is not able to engage in many activities that his same age peers are able to do. Omar began receiving SSI benefits in 2018 after his father, Jacob, applied and appealed his claim. Jacob, is an Uber driver and earns about \$500 per week to care for his family (wife and three kids). Jacob came to CDP-GBLS for legal assistance in March 2, 2020 shortly before the state ordered closures due to the COVID-19 pandemic. Jacob came to CDP because SSA had stopped Omar's SSI benefits in January 2020 stating that he had medically improved and SSA was preparing to perform a Continuing Disability Review (CDR). Although, Jacob had timely appealed the notice in January for the SSI benefits to continue during the pendency of the appeal, SSA erred and failed to send checks for January, February and March. As a result, the family could not meet the full amount of their rent. The rent arrears was \$3,645 and the family received a "Notice to Quit" from their landlord, which meant that they were now at risk of becoming homeless.

It was only during the course of CDP's conversation in connection with Omar's CDR matter that we learned about the rent arrears and that \$14,000 was being held by SSA. Jacob, said that even though he knew there was a lump sum installment (already in Omar's Dedicated Account), he was told by SSA that he could never use the money for items such as rent, food, and clothing. Jacob, informed CDP that he did not know what he was going to do to keep his family in their apartment. Even working extra hours was not enough to meet the rent shortfall.

CDP immediately called and wrote to SSA requesting that Jacob use funds from Omar's Dedicated Account to pay rent arrears in the amount of \$3,645. We informed SSA that the use of Dedicated Account funds on rent is permissible in situations where the child is at risk of homelessness. See *Permitted Expenditures from Dedicated Accounts*, Program Operations Manual System (POMS), GN 00602.140. D.7., 42 USC § 1631(a)(2)(F) (housing expenditure is appropriate where "[w]ithout the expenditure approval, the child and his or her family are most likely to become homeless"); see also *id.* at B.1 ("[I]n emergency situations, where the unavailability of dedicated account funds for basic living expenses may result in the child becoming homeless . . . a payee may use dedicated account funds to prevent the child from becoming homeless . . .").

¹ All names in this story are changed to pseudonyms.

CDP informed SSA that the rent arrears occurred in part because of the unexpected and erroneous loss of Omar's SSI benefits combined with Jacob's low wages.

Due to the COVID-19 closures and the housing moratorium this family's immediate housing crisis was placed on hold. As a result of CDP's advocacy, Omar's SSI payments continued until SSA performed the CDR. Later, in July 2020, SSA found that Omar continued to be disabled and eligible for SSI. Also, Jacob was permitted to use Dedicated Account funds for the rental arrears.

Omar's story is typical of the plight of families living in poverty; one missed check and a child with a disability and his family could be at risk of homelessness. Also, Jacob's limited knowledge and lack of understanding of what is an allowable expenditure under the Dedicated Account's rules is quite common among the clients we represent. What is shocking in this story is the fact that the large lump sum of funds existed yet Jacob's fears of using the funds prevented him from even thinking about it as an option to keep his family housed. Were it not for CDP, Jacob would quite possibly never know that he could use the funds to prevent homelessness.

To: SSAB
From: Children's Disability Project (CDP-GBLS) and Disability Law Center (DLC)
Date: 11/6/2020
Re: Request to Expand and Add Pandemic Related Expenses to SSA's List of Permitted Dedicated Account Expenditures

The dedicated account rules, which prevent families from accessing funds to which their children are entitled, contradict the purpose of the childhood SSI benefits program: *to help low income families meet the needs of their children with special health care needs*. We believe a change in the statute to eliminate the dedicated account and its use reporting requirements¹ is necessary because it will have a profound, positive impact on children with disabilities, their families, and the Social Security Administration (SSA). However, we also believe that immediate action is necessary to allow better access to dedicated account funds. During the COVID-19 pandemic, low income families with lost or uncertain income and facing higher costs for food and other basic needs are in crisis and struggling to care for their children with severe disabilities. They need immediate access to cash to benefit their children and keep them safe. During this emergency situation, we propose the following:

- Ideally, given the scope of the emergency, the Social Security Administration (SSA) should suspend dedicated account restrictions, lift burdensome rules and allow families to make full use of their children's dedicated account funds for *basic necessities* such as food, rent, utilities, gloves, masks, disinfectants, and other items that the family needs to survive and care for their disabled child during this pandemic.
 - At the very least, the SSA should apply rules and emergency exception with *maximum flexibility*. Currently SSA is applying maximum flexibility for its "good cause" policy for late filings. After the pandemic emergency ends, SSA should not penalize families for their use of the funds for basic needs. In late June, SSA issued Emergency Message 20010 to staff (not made public) which reportedly states that -- while loss of income in the household is not automatically a permissible use of dedicated account funds, the emergency exception in GN 00602.140B allows use of dedicated account funds to prevent the child from becoming homeless or malnourished.² Emergency Message 20010 also instructs staff to promptly handle requests for use of dedicated account funds and allows the use of attestation in dire need situations to speed up processing.

¹ Another approach is revise the statute (42 U.S.C. 1383(a)(2)(F)) to exempt natural or adoptive parents and other approved family representative payees (i.e. grandparents, legal guardians) from dedicated account use rules. Congress recently exempted most of these representative payees from annual accountings for monthly benefits. PL 115, Section 102, codified as 42 U.S.C. 1383 (a)(2)(C)(iv).

² **Emergency Exception:** SSA determines that in emergency situations, where the unavailability of dedicated account funds for basic living expenses may result in the child becoming homeless or malnourished, a payee may use dedicated account funds to prevent the child from becoming homeless or malnourished, if otherwise appropriate. <https://secure.ssa.gov/poms.nsf/lnx/0200602140>

We appreciate this instruction but it does not go far enough to meet the need.

- The SSA's list of permitted expenditures from dedicated accounts should be clarified and expanded to accurately reflect the critical needs of children with disabilities, now more than ever during this COVID-19 pandemic. The expanded list of approved expenditures should remain in effect after the pandemic. See POMS GN 00602.140 Permitted Expenditures from Dedicated Accounts.

Lifting restrictions on dedicated account access and expanding the list of approved expenditures are in sync with SSA's goal of providing income security during this emergency. Clear guidance on this issue will help both families and SSA workers in administering the dedicated account rules during this crisis.

POMS GN 00602.140 provides SSA's guidance to field office staff on permitted expenditures from dedicated accounts. Where possible, we have expanded SSA's list to include additional items that should be approved because of increased costs and drastic changes in the lives of children and families due to the COVID-19 pandemic.

POMS GN 00602.140 Permitted Expenditures from Dedicated Accounts

B. Policy For Using Dedicated Accounts

1. Use of funds in a dedicated account

A payee must use dedicated account funds for the benefit of the child and only for any of the following expenses:

- Medical treatment,
- Education, and
- Job skills training.

If related to the child's impairment:

- Personal needs assistance,
- Special equipment,
- Housing modification,
- Therapy,
- Rehabilitation, or
- Other items and services that SSA determines appropriate.

NOTE: While we do not require payees to obtain our approval before making expenditures in the "other" category, you should encourage them to do so. The payee should explain how or why the "other items and services" relate to the child's impairment. Field office (FO) staff should approve or deny requests promptly because many families depend on a quick response to a request to use funds. For examples, see GN 00602.140D. in this section.

Approved Expenditure Example

The following are examples of **approved** requests for expenditures from dedicated accounts.

1. Personal aids to facilitate living and learning

The payee requests approval to pay for computer software that enables a blind child to hear the keyed text. The software allows the child to use the computer and to keep up with the other children in his or her class.

Rationale for approval: The expenditure relates to the child's blindness.

Expand and Add: During the current COVID-19 pandemic children are receiving their education remotely or in a hybrid format (combination of remote and in school). **Education expenses do not require a disability related showing and therefore computers, technical equipment, and other materials necessary to attend school should be allowed:** computers, iPads, printers, connection cables, charging station, internet service plan (Wi-Fi), insurance for computers, service plan for computer repairs, desks and chairs (to attend remote classes), desk lamp, storage bins, book shelves, and standard school supplies (pens, pencils, markers, crayons, pencil sharpeners, paper).

2. Special food for children with dietary needs: The payee requests approval for purchases of large quantities of gluten-free products for a child with celiac disease. Other residents in the group home do not commonly eat these foods.

Rationale for approval: The child could not eat a regular diet due to the impairment.

3. Attorney fees: The payee requests approval to pay for attorney fees incurred in pursuit of the child's supplemental security income (SSI) disability claim. We paid past-due benefits directly into the dedicated account; we did not pay the attorney prior to release.

Rationale for approval: Pursuit of the child's disability claim incurred the attorney fees.

4. Care-giver expenses: A parent payee requests approval from dedicated account funds for respite care expenses to enable him or her to shop and take care of personal business, and to provide a short break from care-giving responsibilities.

Rationale for approval: The expense provides care for the disabled child. Limit the expense approval to the actual cost of childcare (i.e., hourly wage of a nurse, skilled care-giver), and not the expenses associated with shopping.

5. Transportation expenses: A parent payee requests approval to pay an expense from dedicated account funds for a specially equipped van, to accommodate the child's wheelchair. The payee uses the van to transport the child to therapy sessions several times a week. In addition to providing proof of the treatment history, the payee must provide a letter from the child's doctor indicating that the treatments will continue indefinitely.

Rationale for approval: These expenses enable the child to attend impairment related therapy sessions.

Expand and Add: *Due to Covid-19 - Uber, Lyft, Cab or similar rides to and from supermarkets and laundromats for families without vehicles. In addition, reliable vehicles for families who need them to safely transport their disabled child for medical care and elsewhere in the community are approvable. We encourage including such an example so that SSA staff do not think the only approvable vehicle is a specially modified vehicle.*

6. Medical expenses: The payee requests reimbursement to sources that paid for the child's medical expenses while the child's SSI application was pending. The payee submits evidence of the expenses.

Rationale for approval: The repayment of debts for medical treatment, education, or job skills trainings, or other expenses that relate to the impairment is an appropriate expenditure.

Expand and Add: *Due to Covid-19 - Uber, Lyft, Cab or similar rides to and from the pharmacy for families without vehicles.*

7. Housing expenses: Following are examples of **approved** housing expenses.

- a. A parent payee requests approval to pay for closing costs and down payment on a used trailer and lot from dedicated account funds. The child's previous home has a contaminated water supply and lead-based paint throughout the house. The local health department requires that the family leave the house as soon as possible.

Rationale for approval: Without the expenditure approval, the child and his or her family are most likely to become homeless. In addition, the substandard housing conditions could adversely affect the child's health as it relates to the impairment.

- b. A parent payee requests approval for moving expenses from an apartment to a rented home. The payee explains that the child has frequent, noisy outbursts and as a result, the apartment manager is going to terminate the lease.

Rationale for approval: The termination of the lease is due to the autistic child's outbursts.

- c. A parent payee requests approval to pay for three months of past-due rent and utility bills. The payee is behind in their bills due to the child's hospitalization and as a result, the payee missed work. The period of past-due rent and utilities corresponds with the period of hospitalization. The landlord and utility company are now demanding payment.

Rationale for approval: The past-due debts relate directly to the child's impairment related hospitalization. For information regarding paying debts and obtaining pre-approval, see [GN 00602.030](#).

E. Other Approved Examples: Following are examples of other **approved** requests for expenditures from dedicated accounts.

1. Special clothes, such as orthopedic shoes, or adult-size pants with snap-crotch for older, incontinent children.
2. Increased electrical bills, resulting from needed mechanical devices that must frequently run.

Expand and Add: *utilities bills stemming from children attending school remotely: electric, gas, cable, and cell phone.*

3. Specialized day care and therapeutic recreation, such as special summer camps or Special Olympics.

Expand and Add: *Due to COVID-19 many day programs and camps are closed. Allow online learning/play programs (dance, cooking, art, games) and all necessary supplies and equipment.*

4. Food and veterinary care for a guide dog or other assistive animal.
5. Repair of walls, carpets or furnishings that damaged or worn by a disabled child.
6. Counseling, crisis intervention services, respite care, and therapeutic foster care, if not covered by health insurance or public service program.

Expand and Add: *Due to COVID-19 children with disabilities are stuck in their homes. Research has shown that children with ADHD and other learning and mental health conditions benefit greatly from being outdoors. Some benefits include increased attention and lower levels of stress and anxiety. Many low-income children do not have safe spaces to play. With the closing of schools, play spaces are limited. The cost of day trips to open spaces such as hiking trails and large public parks must be considered an approved expenditure.*

7. Household furnishings, appliances, and changes in utility services, related to the child's disability, such as air conditioning for an asthmatic child, a washing machine for an incontinent child, or installation and maintenance of a phone line to ensure ready access for a needed service.

Expand and Add: *As a result of remote school during Covid-19: For all kids but particularly those attending hybrid school (part home and part in school): masks, hand sanitizer, cleaning products, washing machines, dryers (most families are seeing increased laundry costs due to frequent changes of clothing when coming in after leaving the house); laundromat expenses including detergent.*

Food: *due to COVID-19 kids are spending many hours at home and food insecurity is a critical issue for many families. Many children with disabilities received breakfast, lunch and snacks at school and extended day (after school programs), now these costs fall on low-income families who are financially suffering the most during this pandemic. Food*

programs and pantries are not able to meet families' food needs. The cost of vitamins should also be included.

8. Household renovations, where the current conditions adversely affect the child's health, such as insulating a home for a child with a respiratory or cardiovascular condition aggravated by extremes of cold or heat, or a separate bedroom for a child with emotional disabilities that require a structured setting.

Expand and Add: *As a result of COVID-19, air filtration system and associated items related to cleaning the air flow in the home (house or apartment).*

9. Special play and recreation equipment related to the impairment.

Expand and Add: *Due to COVID-19 playground restrictions parents would like to purchase items for play, which can be incredibly beneficial to a child with a disability: basketball hoop, balls, bats, helmets, swing set, and other play equipment.*

F. Denied Expenditure Examples

The following are examples of **denied** requests for expenditures from dedicated accounts.

1. Clothing expenses: The payee requests approval to buy a new pair of shoes for the disabled child.

Rationale for denial: The shoes are not impairment related. The payee could receive approval if the child's impairment requires orthopedic modifications. The payee needs to get verification from the vendor that the disabled child needs regular shoes as a base shoe for performing the required modifications.

2. Medical expenses: A foster care agency payee asks for approval to repay the foster care parents for regular expenses, and for psychiatric treatment related to the child's impairment.

Rationale for denial: The first part of this request does not relate to the child's impairment. However, the psychiatric treatment is reimbursable due its impairment relationship.

The Dedicated Account: A History

Prof. Mary E. O'Connell

1. 1972: SSI becomes law

- a. Part of larger bill that increased retirement and survivors' benefits by 20% and created the COLA.
- b. To qualify for SSI, applicant must have very low income and very limited assets (with some exceptions, e.g., a house or a car). Must also be elderly or a person with a disability.
- c. Proposal to include children in SSI was controversial.
- d. Larger bill had included the FAP (Family Assistance Program), a proposed monthly benefit for all American families with children; similar to plans in many European countries.
- e. House had passed bill creating the FAP but agreed to abandon it in return for Senate's agreement to extend SSI to children with disabilities.

2. 1974-1977: SSI's early years

- a. Demographic surprises. In 1974 (year of program roll-out), most beneficiaries were elderly, not disabled. Program architects assumed this would continue, with roughly 1/3 of beneficiaries being people with disabilities. BY 1978, 4/5 OF APPLICANTS AND 2/3 OF THOSE ON SSI ROLLS HAD DISABILITIES. Drove up costs significantly.
- b. Deinstitutionalization of mentally ill began in the mid 1950's and escalated in 1960's. Institutionalized population was roughly 500,000 in 1955; by 1994 was 72,000. Many of the de-institutionalized depended on SSI.

3. 1980-1984: CDR's and purging the rolls

- a. SSI rolls grow rapidly. Congress creates the "Continuing Disability Review" (CDR) requiring periodic re-evaluation of SSI recipients with disabilities.
- b. Reagan administration ramps up CDR's dramatically. Number of beneficiaries cut from the rolls skyrockets, from roughly 22% per year in 1975-76 to 46% in 1978-1985. Beneficiary found to be no longer disabled lost benefits immediately. Was appeal process, but no benefits paid pending appeal.
- c. Appeal success rate **69%**. 23,690 separate lawsuits filed in SSI cases in 1983. SSA lost 18 separate class actions.
- d. Congress responds with DBRA (the Disability Benefits Reform Act of 1984). SSA must now demonstrate "medical improvement" or a "clearly erroneous" intimal decision to stop benefits. Benefits continue during any appeal period.

- e. “Sleeper Provision”. DBRA also directs SSA to update the listings for mental impairments.

4. 1983-1990: *Zebley*

- a. CDR debacle spawns a crop of lawyers with expertise in SSI law. Advocates for children conclude that child provisions are being incorrectly applied. Child is entitled to benefits only if he has an impairment described in the listings, or one of comparable severity. Adult gets a third bite at this apple. If adult’s impairment is not in the listings and not of comparable severity, DDS can consider whether there is any work the adult applicant can perform given his impairment, work history and education. Adult can be awarded benefits if DDS concludes there is no such work. Is no parallel third step for children.
- b. Class action lawsuit filed 7/12/1983: *Sullivan v. Zebley*. Plaintiffs are 450,000 children denied SSI benefits on or after January 1, 1980. U.S. Supreme Court finds for *Zebley* plaintiffs (7-2). SSA had argued that it was possible to assess an adult’s capacity to work, but that a functional analysis of a child’s claim was not feasible. Court disagreed. Ordered SSA to conduct “an inquiry into the impact of an impairment on the normal daily activities of a child”.
- c. *Zebley* decision (2/20/1990) explodes children’s SSI rolls. 321,600 children previously denied SSI filed for reconsideration. Pre-*Zebley*, SSI rolls included 296,000 children. Post-*Zebley*, increased to 770,500. Children now 19.9% of SSI beneficiaries.
- d. DBRA’s sleeper provision and *Zebley* interact. Pre-DBRA, mental health listings were based on DSM-II. Updated listings ordered by DBRA relied on DSM-III. DSM-III described in medical literature as “a veritable paradigm shift in psychiatry”. DSM-III moves away from psychodynamic concepts like “neurosis” to detailed and specific categories of mental disorders. DSM-III creates very specific diagnoses for mental impairments, provides detailed descriptions of symptoms, recommends tests to identify and classify mental disorders with guidelines for likely age of onset, etc. DSM-II listed 182 categories of mental disorder; DSM-III listed 265.
- e. Revised children’s listings (based on DSM-III) take effect 12/12/90. Are now 11 mental disorder categories in listings, up from 4 pre DSM-III.
- f. New procedure for child SSI applicants required by *Zebley* - the Individualized Functional Assessment (IFA) - adopted 2/1/91.
- g. Two seismic changes to children’s SSI occur in less than two months.

5. 1994: The Media and “Crazy Checks”

- a. Jan. 1994. *Washington Post* begins a series of articles targeting federal programs that, in the authors’ view, wreaked havoc with the federal budget.

- b. Feb. 4 1994. *Post* publishes “Cost Soar for Children’s Disability Program: How 26 Words Cost the Taxpayers Billions in New Entitlement Payments” by famed journalists Bob Woodward and Benjamin Weiser.
- Claims:
- (i) Dr. Nora Cook Porter, a pediatrician formerly with DDS, says that children who curse teachers, fight with classmates, perform poorly in school or are rebellious are being diagnosed with behavioral disorders and given SSI benefits. Woodward and Weiser report that Dr. Porter’s claims are echoed by many others working in DDS. Are also reports that benefits are often not spent on the children. Parents are reported to be buying cars and televisions with children’s SSI payments.
 - (ii) Thomas Joe, an assistant at HEW during the drafting of the SSI statute, tells Woodward and Weiser that he is the author of the “26 words”, which he tucked into the 697 page bill to “sneak it through”. No public hearings were held.
 - (iii) Beverly Smith, parent of an 11 year old child described as “hyperactive”. Member of the *Zebley* class. Child received a \$13,000 back payment - more than 1 ½ times his mother’s annual income. Amount exceeds the asset limit for SSI. If the family had this asset in 6 months, the child would lose his SSI benefits and his Medicaid. Woodward and Weiser describe a “spending spree” by Ms. Smith. She used the money to repair her leaky roof; replace floors that had collapsed because of the water damage; buy a new stove with a number of safety features because her son liked to set fires; purchased a washer and dryer, a used car, a television and a computer.
 - (iv) Woodward and Weiser end by quoting a psychologist who sometimes worked with DDS: “parents are receiving a cash award for having achieved the problem.”
 - (v) Copies of the Woodward and Weiser article are distributed to all members of Congress.
- c. Oct. 13, 1994: ABC’s *PrimeTime Live* airs segment called “Crazy Checks”, hosted by Chris Wallace, Diane Sawyer and Sam Donaldson.
- (i) Same pediatrician as in Woodward and Weiser article tells interviewer that “fewer than 30% of the children on SSI deserve their benefits” which are so generous that a family with several disabled children could “buy a Mercedes”.
 - (ii) Remaining interviews take place in Arizona. State legislator there had taken an interest in the children’s SSI program. Spoke with *Arkansas Democrat-Gazette* whose reporters made inquiries. Were told by a number of teachers and school counselors that parents were coaching their children to act disturbed so that they could collect “crazy checks”.
 - (iii) “Crazy Checks” episode screened for members of Congress.

6. 1994-1995: Congressional Efforts to Cut SSI and the Adoption of the Dedicated Account.

- a. Bill Clinton elected President 1992. Promises to “end welfare as we know it”. Reference is to AFDC (not SSI).
- b. Republicans are minority in House but are focused on cutting both AFDC and SSI.
- c. Sept. 1994: Newt Gingrich introduces the “Contract with America.” Promises voters that if a Republican House is elected they will pay off the federal deficit, cut taxes and end welfare.
- d. Oct. 1994: Crazy Checks airs.
- e. Nov. 1994: Republicans take control of the House. One focus is children’s SSI and its large back payments (*Zebley*). *Zebley* counsel had asked SSA for some adjustment to pay down rules in light of the large back payments. SSA declined.
- f. Senators Robert Dole and John Heinz also worried about *Zebley* payments. Had introduced the “SSI Independence Act for Elderly and Disabled Americans” in Sept. 1990 (seven months post *Zebley*.) Bill would have excluded any assets held in a trust for an SSI beneficiary from the beneficiary’s countable resources. Bill disappears, but Dole’s and Heinz’s staffs investigate possibilities further. Learn that trusts drafted and managed by private attorneys would be prohibitively expensive.
- g. Republicans in House pursue their agenda.

7. First Bill: (House) “The Personal Responsibility Act of 1995”: March 1995

- a. Includes drastic cuts to children’s SSI.
- b. Cash benefits terminated for all children except those residing in institutions and children who would have to be placed in an institution if benefits were terminated (because of the cost of required personal assistance).
- c. All other children with disabilities would become the responsibility of the states. States would receive block grants equal to 75% of what the terminated beneficiaries had been receiving. States would decide which children qualified for benefits and what benefits would be available, but statute bars states from making any cash payments to children’s representatives.
- d. Eliminates the IFA.
- e. Requires CDR every three years.

8. Second Bill: (Senate Response to Personal Responsibility Act of 1995) “Work Opportunity Act of 1995”: August 1995 (Note: As is the case with all of the legislation discussed here, major focus was AFDC. “Work Opportunity Act of 1995” had over 250 sections; 3 addressed children’s SSI.)

- a. Act adopts a new definition of disability unique to children. Child must show “a medically determinable physical or mental impairment, which results in marked and severe functional limitations” and can be expected to last at least twelve months.
- b. Like House bill, eliminates IFA.
- c. Follows House on CDRs.
- d. Requires representative payee to demonstrate at each CDR that the child is receiving medical treatment “to the extent medically necessary and available”.
- e. Final section is titled: “Additional Accountability Requirements: Tightening of Representative Payee Requirements”. Focus is on the payee, not the child. Directs SSA to advise payees of specific examples of appropriate expenditures. Adds a documentation requirement. Payee to “document expenditures and keep contemporaneous records of transactions made using such payment.”
- f. **Adds a “dedicated savings account”.** This is the first iteration of this idea. It is markedly different from what was ultimately enacted. Intended as a solution to the problems created by the six month pay-down rule, the **“dedicated savings account” is a cost-free device** (payee simply opens a bank account) **that a representative payee may elect if she wishes. Money in the dedicated savings account would not be a countable asset for SSI eligibility purposes. There would be no need to spend down.**
- g. **Money in the dedicated savings account could be used only for**
 - (i) **Education and job skills training**
 - (ii) **Special equipment or housing modifications...specifically related to and required by the nature of, the child’s disability or**
 - (iii) **Appropriate therapy and rehabilitation.**
- h. Goal is to empower the representative payee. No dedicated savings account would be established unless the representative payee so elected.

9. Third Bill (House): “The Balanced Budget Act of 1995”: October 1995.

House worked on this bill and the Personal Responsibility Act of 1995 simultaneously. Goal of the Balanced Budget Act was to balance the federal budget by 2002 and to enact substantial tax cuts. House is searching for spending cuts to offset these revenue losses. This drove the effort to cut AFDC and SSI.

- a. Balanced Budget Act takes major step back from the Personal Responsibility Act. Block grants disappear; cash benefits return, but the two tiers of disability remain. Full benefits restricted to children under 6 who “without special personal assistance would require specialized care outside the home” and children over 6 who require personal care assistance, continual 24 hour monitoring, or the administration of medical treatment and who, without this, would need full or part-time specialized care outside the home.
- b. Other children’s benefits would be cut by 25%.

- c. Final section of bill addresses representative payees and their responsibilities. Radical shift in tone from Senate's "Work Opportunity Act". Like the Work Opportunity Act, bill directs payees to insure that beneficiaries are receiving appropriate medical care. But bill includes rules for removing any payee who fails to comply. Focus is not on informing and guiding the payee, but on rules to prevent the payee's "disposal of resources for less than market value", a provision taken from Medicaid law. Unclear that representative payees of children on SSI dispose of resources (?)
- d. Includes a "**Requirement to Establish Account.**" This is the first appearance of the mandatory dedicated account. States that whenever a child is owed past due benefits in excess of 6 times FBR, the representative payee "**shall establish on behalf of such individual an account in a financial institution into which such benefits shall be paid.**"
- e. Statute slightly expands the list of permitted uses for dedicated savings accounts that had been set out in the Work Opportunity Act, adding "**personal needs assistance**" and "**medical treatment.**"
- f. Also provides that the Commissioner of Social Security may add "**any other item or service that the Commissioner determines to be appropriate; provided such expense benefits such individual...[and] is related to the impairment of such individual.**"
- g. Where did the decision to **mandate** the dedicated account come from? Not from the Personal Responsibility Act of 1995 (first House bill; see above). The mandatory dedicated account first appears in the Conference Committee Report on the Balanced Budget Act, where it is inserted with no accompanying explanation or discussion. In the Conference Committee's words, it is "follow[ing] the Senate amendment [this is Senator Dole's amendment in the "Work Opportunity Act of 1995" creating the optional dedicated account] **with modification requiring the dedicated account (instead of being optional at the request of the representative payee.)**
- h. The Conference Committee Report also notes that the permitted uses of dedicated account funds have been expanded, but nothing is offered to explain the value of or need for a mandatory provision. Given the negative media coverage and the focus on "spending sprees" one might speculate that the provision was designed to prevent such conduct. But this simply creates another mystery: why do the restrictions imposed on the dedicated account continue after the child reaches age 18, even if benefits are, at that point, paid directly to her?
- i. Balanced Budget Act also provides that a representative payee who knowingly uses dedicated account funds outside the seven permitted categories is guilty of "misuse" and must repay all funds so used to the U.S. Treasury. They are not returned to the child's account and are lost to the family.
- j. **Balanced Budget Act of 1995 VETOED by President Clinton, Dec. 6, 1995.** Clinton listed 82 specific objections to the bill, including the benefit reductions for hundreds of thousands of children with disabilities.

10. Fourth Bill: (House): “The Personal Responsibility and Work Opportunity Act of 1995”.

- a. Bill moved very rapidly through Congress because it was virtually identical to the Balanced Budget Act, but stripped of all but the AFDC and SSI changes.
Personal Responsibility and Work Opportunity Act of 1995 VETOED by President Clinton Jan. 9, 1996. Clinton’s veto message says “welfare reform is about moving people from welfare to work, not playing budget politics.” Clinton specifically objected to “massive structural changes to a variety of programs” including “help for disabled children”. Clinton cited a report by the Urban Institute suggesting that the statute could push 2,000,000 American children below the poverty line.

11. Fifth Bill: (House): “The Welfare and Medicaid Reform Act of 1996”.

- a. Cuts in children’s SSI are gone; cash benefits not restricted to institutionalized and at risk children. Largely tracks the original Senate bill, i.e., the “Work Opportunity Act of 1995” sponsored by Sen. Dole. Adopts the new definition of disability for children; ends IFA; mandates CDRs every three years, at age 1 for low birthweight babies and age 18 for all participants.
- b. Only one provision carried over from the vetoed bills: mandatory dedicated account with its 7 categories of permitted spending.
- c. Adds new term, “knowing misapplication”, to describe use of dedicated account funds outside the 7 permitted categories but for the benefit of the child (e.g., purchase of a winter coat.) However, penalty for “knowing misapplication” is the same as for “misuse”. All funds spent must be repaid to the U.S. Treasury.
- d. Introduces new rule for all SSI beneficiaries, child and adult, owed more than 12 months’ back payments. Back payments to be made in up to three installments, at 6 month intervals. First and second installments could not exceed 12XFBR. Final installment consists of all remaining funds due.

12. Sixth Bill: (Senate): “The Personal Responsibility, Work Opportunity and Medicaid Restructuring Act of 1996”.

- a. No changes in SSI provisions. Copies “The Welfare and Medicaid Reform Act of 1996”. Drops Medicaid provisions.
- b. Were efforts in Senate to revert to an optional dedicated account (filed by Sen. Joe Biden of Delaware). Did not succeed.

13. Seventh (and final) Bill: “The Personal Responsibility and Work Opportunity Reconciliation Act of 1996” (PRWORA).

- a. Includes the mandatory dedicated account first introduced by the conference committee working on the Balanced Budget Act of 1995.
- b. Signed by President Clinton August 26, 1996.
- c. Congress’s understanding of the mandatory dedicated account and its reasons for electing it remain a mystery.

Research and investigations of children's SSI

OIG Reports

1. Oct. 1994: HEHS OIG report: "Concerns about the Participation of Children with Disabilities in the Supplemental Security Income Program". Published by OIG but study conducted by SSA.
 - (a) Reviewed sample of 617 child SSI applicants with cases adjudicated by DDS and reviewed by SSA quality assurance staff. Sample included 325 awards and 292 denials (Oct. 1992 to July 1993.)
 - (b) All applicants claimed mental impairments: ADD, ADHD, personality disorder, conduct disorder, learning disorder, oppositional defiant disorder, anxiety disorder, developmental delay, behavior disorder, speech and language disorders, borderline intellectual functioning and adjustment disorder. Extreme disorders such as psychosis and mental retardation were excluded.
 - (c) Disorders chosen because SSA considered behavioral and learning disorders "the most susceptible to coaching and malingering".

Coaching: Reviewers considered whether "the child reported or an information source suspected that the parent or other caregiver had told the child to act or respond in a manner that would make the child appear more functionally limited than he or she actually was."

Malingering: Looked for evidence that the child deliberately answered questions incorrectly, or failed to put forth effort during testing.
 - (d) Found only 13 cases with any evidence of possible coaching or malingering (2%) *and only three of those children received awards* (.005%).
 - (e) Reports of possible coaching all came from medical personnel conducting consultative examinations. None of the cases flagged for possible coaching had resulted in awards. Cases flagged for possible malingering all focused on the child's behavior during IQ testing. Awards made in only three cases. In all three, the basis for the award was not connected to the child's IQ.
2. Jan. 1995: HEHS OIG report. "Supplemental Security Income Disability Determinations for Children with Mental Impairments"
 - (a) IG staff reviewed 553 cases decided in 1992: 298 awards; 255 denials. Focus of study was the IFA (Individualized Functional Assessment) process, but the report states that "[b]ased on its review of these cases...they had found no evidence of coaching."

New Directives and Procedures

1. June 1994: New requirement for DDS's: report to SSA's regional quality assurance office "any case with an allegation or suspicion of coaching..." Includes any case in which a teacher, physician or psychologist indicates that
 - (1) "the child's behavior was atypical of the child's customary school behavior";
 - (2) "the child was uncooperative during testing"; or
 - (3) "the child's behavior deteriorated without explanation during the 6 month period preceding the application".
- (4) By Jan. 1995, DDSs nationwide had reported 674 cases of alleged coaching. This is less than .005 percent of all childhood applications filed during the period. Fewer than 50 of these children had been awarded benefits (7%).
2. Aug. 1994: DDS's are directed to "send applicants' schools a set of questions specifically designed to elicit the teacher's views on whether the child had been coached." Each SSA regional office also established a toll-free phone number for teachers and school officials to notify the quality assurance unit of coaching allegations. Field offices and telephone service centers were directed to report any allegations of coaching received from the public to the quality insurance unit. In the two months after hotlines were first publicized, 42 calls were received with allegations concerning 54 individuals. SSA policy is to review the allegation if the child has been awarded benefits.

GAO Reports

1. March 1995: *Report to Congressional Requesters: Social Security: New Functional Assessments for Children Raise Eligibility Questions*: GAO files report strongly critical of the IFA adopted to comply with *Zebley*, but states explicitly that while "coaching cannot be ruled out and its extent is virtually unmeasurable... scant evidence exists to substantiate that coaching is a problem". In GAO's view, the problem was the IFA.
2. Mar. 1996: *"SSA Initiatives to Identify Coaching*. Report updates information on both the SSA hotline and the DDS process for identifying cases that might involve coaching. Report states that "[b]oth of these initiatives identified few cases of suspected coaching and very few of the children involved received SSI benefits". Approximately 460,000 children applied for SSI benefits during the period studied. The DDS initiative identified 1232 cases in which coaching was suspected or alleged; only 77 of the cases resulted in awards. SSA hotline and the directive to send allegations of coaching received by a field office or SSA telephone center produced 232 allegations of coaching, 119 of which involved children receiving benefits. SSA recommended a CDR or a reopening of the case in 83 instances. 66% of the DDS and hotline cases involved children with mental impairments.

National Academy of Social Insurance: Disability Policy Project (1996)

- (a) 102nd Congress (1991-1993) commissioned a “Disability Policy Project” to be carried out by the National Academy of Social Insurance. Academy accelerated its analysis, noting that the children’s disability program “was on an urgent timetable in Congress”.
- (b) Report published August 1996: *Restructuring the SSI Disability Program for Children and Adolescents*. Reviews: (1) the prevalence of childhood disability;
(2) rationale for the children’s disability program;
(3) opportunity costs of providing care for children with disabilities.
- (c) Concludes that children’s SSI program “support[s] and preserves[s] the capacity of families to care for their disabled children in their own homes.” SSI benefits meet “some of the additional disability-related costs of raising a disabled child.... Compensate for some of the income lost because of the everyday costs of caring for a disabled child; and [meet] the child’s basic needs for food, clothing and shelter.”
- (d) Directly addressed the issue of coaching: “In the childhood disability program today, evidence of such coaching or ‘gaming the system’ is extraordinarily thin – and appears to be based on anecdotes or perceptions of dubious benefit claims, which upon investigation are found to have been denied... [A]llegations of widespread abuse or inappropriate allowances have not been substantiated. Furthermore, data from administrative records show that children who receive SSI have very significant cognitive, physical or emotional disabilities.”

National Academy of Medicine (2015)

Dec. 2010: Three articles suggesting abuse of children’s SSI appear in *Boston Globe*. Author Patricia Wen asserts that many poor parents are shopping for doctors who will prescribe drugs for their child for ADHD and related disabilities. Parents believe that having the child on these drugs is likely to qualify the child for SSI. Wen states that SSI was created for children with severe physical disabilities, but “now largely serves children with relatively common mental, learning and behavioral disorders.”

Claim that most children on SSI are being medicated for disorders (71%), while children not receiving benefits were not (29%) was corrected by the *Globe* (May 2011). In fact, incidence of medication was roughly equal in both populations.

SSA Commissioner Michael Astrue responds to *Globe* articles. Travels to Boston for extensive interview with *Globe*. Announces he would ask Congress for \$10 million to fund a thorough study of the children’s SSI program, to be conducted by the National Academy of Medicine.

“Committee to Evaluate the Supplemental Security Income Disability Program for Children with Mental Disorders” is formed.

Task: to “[i]dentify past and current trends in the prevalence and persistence of mental disorders for the general population under the age of 18 and compare those trends to trends in the SSI childhood disability population.”

Goal was to determine whether mental disabilities were being over-diagnosed in the SSI population.

Response:

- (a) There is no repository of mental health diagnoses in the general population (unlike, for example, measles and rabies.) So there is no number to assign to the non-SSI population.
- (b) In addition, *“disability is more common among children living in poverty than among those not living in poverty”*. ..*“poverty is itself a risk factor for mental disorders in children.”*
- (c) The rate of SSI allowances for children based on mental health disorders *decreased* between 2004 and 2013. Rate of allowances 10% lower in 2013 than in 2004. But overall *number* of children receiving SSI for mental disabilities increased because children who join the rolls tend to stay on them.
- (d) “[H]aving a child with a disability places financial and other stress on families and may increase the chances of the family being poor... Households with children with chronic health conditions face higher costs for caring for the children as well as decreased household income when parents leave the workforce or decrease their paid workload to care for a child with a disability... Families with a child with disabilities are also more likely to incur increased out-of-pocket expenses, for example, for childcare or transportation to locations with specialized medical care.”

Report concludes that “access to Medicaid and income supports via the SSI disability program may improve the long-run outcomes for both children with disabilities and their families.” Far from supporting the claim that too *many* children are being classified as having disabilities, the Committee states that it is “highly likely that a sizeable number of [poor] families that include a child with a disabling mental disorder are not supported by SSI benefits” . In short, qualifying children are probably under-enrolled.