SNA 2021-2022 Legislation Highlights

December 2022

The SNA Public Policy work is available on the SNA website. There is a section called “Advocacy: Get Involved!” Included there are [links and tools](https://members.specialneedsalliance.org/public-policy/advocacy-get-involved/) for members to use in their own advocacy.

LEGISLATION OF NOTE:

Consolidated Appropriations Act, 2023 (CAA 23) [Public Law 117-328](https://www.congress.gov/bill/117th-congress/house-bill/2617/text) signed into law on December 29, 2022. This omnibus bill provides FY2023 funding for federal agencies as well as emergency assistance for Ukraine and disaster relief here at home. Also enacted in the law are provisions on various topics, including several of importance for the Special Needs Alliance, including:

The ABLE Age Adjustment Act – [HR 1219/S. 331](https://www.congress.gov/bill/117th-congress/senate-bill/331?q=%7B%22search%22%3A%5B%22s+331%22%5D%7D&s=7&r=1) (Cardenas/Casey) To raise the eligibility age from 26 to 46 for creating ABLE accounts. Passed as part of CAA 23.

* Read the Consortium for Constituents with Disabilities (CCD) (updated) [ABLE Adjustment Act](file:///C%3A%5CUsers%5CLaurie%20Lindberg%5CDocuments%5CBWL%20Business%5CSNA%5C2022%20SNA%5C%E2%80%A2%09https%3A%5Cwww.c-c-d.org%5Cfichiers%5CABLEAge-FactSheet2-1-2022.pdf) fact sheet.
* Read the CCD [Cost and Benefit piece](file:///C%3A%5CUsers%5CLaurie%20Lindberg%5CDocuments%5CBWL%20Business%5CSNA%5C2022%20SNA%5C%E2%80%A2%09https%3A%5Cwww.c-c-d.org%5Cfichiers%5CABLE-Age-Cost-Fact-Sheet-Draft.pdf)

Special Needs Trust Improvement Act of 2022 – S.4426/H.R.8625 (Young/Schneider) To amend the Internal Revenue Code of 1986 to modify rules relating to beneficiaries of charitable remainder trusts. This is the SNA drafted/sponsored legislation to allow a charitable organization to be named as a remainder beneficiary of a trust that is established for a person who has a disability or is chronically ill. Passed as part of the CAA 23.

Enhancing American Retirement Now (EARN) Act - S. 4808 (Wyden) introduced on 9/8/2022 and reported/passed by the Committee on Finance. See [S. Report 117-142](https://www.congress.gov/congressional-report/117th-congress/senate-report/142). SNA’s Special Needs Trust Improvement Act and the ABLE Age Adjustment Act are included in the bill and report language approved by the Finance Committee. Passed as part of CAA 23

* [CCD Finance Committee hearing statement](https://www.c-c-d.org/fichiers/Statement-for-the-Record_Senate-Finance-Hearing_EARN-Act.pdf)

Securing a Strong Retirement Act of 2021 (SECURE 2.0) [– H.R.2954](https://www.congress.gov/117/bills/hr2954/BILLS-117hr2954rfs.pdf) (Neal) This bill makes various changes with respect to employer-sponsored retirement plans, including providing for the automatic enrollment of employees in certain plans and increasing the age at which participants are required to begin receiving mandatory distributions. Passed by the House on 3/29/22 and sent to the Senate where it was referred to the Committee on Finance. The Senate Finance Committee version is called the EARN Act (above). Passed as part of the CAA 23 (found in Division T of the bill).

* [Bipartisan Policy Center Article](https://bipartisanpolicy.org/blog/house-passes-secure-2-0-would-bolster-retirement-security-for-millions-of-americans/?_cldee=zvzoed6HMSaT6ZF8byhlntjJ6qD3_Q4i3m-JFrA3UXznqHza3rPZeSAh1D7u5L5a&recipientid=contact-78d561141dc7e3119e3d6c3be5a82168-a40652b205c34e0cbd5ce723fc7ebba5&utm_source=ClickDimensions&utm_medium=email&utm_campaign=Project%20Update%20%7C%20Economic%20Policy&esid=3926957b-c8b9-ec11-983f-002248317e7b)

Support for Electroshock Device Ban

The Autistic Self Advocacy Network and other advocates have successfully gotten the Congress to recognize the FDA’s authority to ban electric shock for behavior modification in the CAA 23. Now advocates are urging the FDA to pass the rule to make the ban final.

* [Stop the Shock article](https://autisticadvocacy.org/2022/12/congress-has-supported-the-fdas-right-to-stoptheshock/)

ALSO in CAA 23:

Note, these are not bills like the ones above, but provisions that were included in CAA 23.

* Money Follows the Person (MFP) - extended through 2027, this program provides grants to states to fund the transitional services required for Medicaid beneficiaries who wish to leave a nursing home or other institution. In general, Medicaid is required to pay for nursing home care, but not home and community-based care. MFP enables older adults and people with disabilities to live in a community setting.
* Spousal Impoverishment - extends through 2027 the provision that applies the spousal impoverishment protections to couples whose spouse lives in a community setting (in addition to the protections for a couple whose spouse lives in a nursing home).
* Mental Health – funds crisis care and community behavioral health clinics, as well as youth and maternal mental health programs.

Augmentative and Alternative Communication Centers to Establish National Training (AACCENT) Act – [S. 2](https://www.congress.gov/bill/117th-congress/senate-bill/2/text) (Casey) introduced 11/17/22 and referred to Senate HELP Committee. To support national training, technical assistance, and resource centers to ensure that all individuals with significant expressive communication disabilities have access to the augmentative and alternative communication the individuals need to interact with others to learn, work, socialize, and take advantage of all aspects of life in the United States.

Inflation Reduction Act – [Public Law 117-169](https://www.congress.gov/bill/117th-congress/house-bill/5376/text?q=%7B%22search%22%3A%5B%22Inflation+Reduction+Act%22%2C%22Inflation%22%2C%22Reduction%22%2C%22Act%22%5D%7D&r=1&s=2). A re-worked version of the Build Back Better Act, this budget reconciliation bill included climate protections, a tax hike, funding for the IRS, funding for the ACA, and provisions to allow drug price negotiation under Medicare Part D. Signed into law August 16, 2022.

Protection and Advocacy in Education Act - [H.R.9100](https://www.congress.gov/bill/117th-congress/house-bill/9100?q=%7B%22search%22%3A%5B%22disability%22%2C%22disability%22%5D%7D&s=7&r=13)/[S.5013](https://www.congress.gov/bill/117th-congress/senate-bill/5013?q=%7B%22search%22%3A%5B%22disability%22%2C%22disability%22%5D%7D&s=7&r=14) (DeSaulnier and Hassan) To authorize grants to establish a national education protection and advocacy program to enforce the rights and protections under the Individuals with Disabilities Education Act, the Americans with Disabilities Act of 1990, and section 504 of the Rehabilitation Act of 1973, and for other purposes (introduced 9/29/22).

Health Equity for People with Disabilities Act - [S. 4544](https://www.congress.gov/bill/117th-congress/senate-bill/4544/text?q=%7B%22search%22%3A%5B%22disability%22%2C%22disability%22%5D%7D&r=18&s=7) (Casey). This bill modifies certain grants available to health centers that offer primary health services to medically underserved

populations to ensure that members of such populations with disabilities receive accessible health services (introduced 07/18/2022); referred to Committee on Health, Education, Labor, and Pensions.

Social Security Expansion Act of 2022 – [H.R. 8005](https://www.congress.gov/bill/117th-congress/house-bill/8005/text) (DeFazio) enhances Social Security benefits and ensures the long-term solvency of the Social Security program through 2096.

* Read the [press release](https://defazio.house.gov/media-center/press-releases/defazio-sanders-introduce-legislation-to-expand-and-strengthen-social) by Rep. DeFazio and Senator Sanders

Equality for Families with Disabilities Act- [H.R. 8335](https://www.congress.gov/bill/117th-congress/house-bill/8335/text?q=%7B%22search%22%3A%5B%22disabilities%22%2C%22disabilities%22%5D%7D&r=47&s=7) (Langevin) To protect individuals with disabilities who are parents, legal guardians, relatives, other caregivers, foster or adoptive parents, or individuals seeking to become foster or adoptive parents from discrimination in the child welfare system (introduced 7/12/22).

Removing Access Barriers to Running for Elected Office for People with Disabilities Act – [S. 4597](https://www.congress.gov/bill/117th-congress/senate-bill/4597/text?q=%7B%22search%22%3A%5B%22disabilities%22%2C%22disabilities%22%5D%7D&r=51&s=7) (Casey) To allow individuals with disabilities to campaign for elected office without losing access to federally supported benefits (introduced 7/21/22).

* Read Senator Casey’s [press release](https://www.casey.senate.gov/news/releases/casey-introduces-suite-of-legislation-to-enable-americans-with-disabilities-to-run-for-and-serve-in-elected-office)

Retirement Security and Savings Act – [S.1770](https://www.congress.gov/bill/117th-congress/senate-bill/1770?q=%7B%22search%22%3A%5B%22Retirement+Security+and+Savings+Act%22%2C%22Retirement%22%2C%22Security%22%2C%22and%22%2C%22Savings%22%2C%22Act%22%5D%7D&s=3&r=1) (Cardin) Includes enhancements to the private retirement system that will encourage more small businesses to offer plans and expand access to workers without coverage. Some consider it the early Senate version of SECURE 2.0.

Autism Family Caregivers Act of 2022 – [H.R.6783/S.4198](https://www.congress.gov/bill/117th-congress/house-bill/6783) (Meng/Menendez)  Authorizes HRSA to award grants to provide caregiving training to families of children with ASD or other DDs. Referred to House Energy and Commerce/Senate HELP.

Stop Unfair Medicaid Recoveries Act of 2022 – [H.R.6698](https://www.congress.gov/bill/117th-congress/house-bill/6698/text?q=%7B%22search%22%3A%5B%22stop+unfair+medicaid+recoveries%22%2C%22stop%22%2C%22unfair%22%2C%22medicaid%22%2C%22recoveries%22%5D%7D&r=1&s=1) (Schakowsky) To repeal the requirement that States establish a Medicaid Estate Recovery Program and to limit the circumstances in which a State may place a lien on a Medicaid beneficiary’s property. The bill was referred to the Subcommittee on Health of the Energy and Commerce Committee on 2/10/22.

* Issue brief on estate recovery: [Medicaid Estate Claims: Perpetuating Poverty & Inequality for a Minimal Return](https://healthlaw.org/resource/medicaid-estate-claims-perpetuating-poverty-inequality-for-a-minimal-return/) (Jointly authored by California Advocates for Nursing Home Reform (CANHR), Justice in Aging, National Academy of Elder Law Attorneys (NAELA), National Health Law Program (NHeLP), and Western Center on Law & Poverty)

Stop the Wait Act of 2022 [– S.3575/H.R.6583](https://www.congress.gov/bill/117th-congress/house-bill/6583?q=%7B%22search%22%3A%5B%22hr+6583%22%2C%22hr%22%2C%226583%22%5D%7D&s=1&r=1) (Casey/Doggett) To eliminate the waiting period for disability insurance benefits in certain situations. The bill was referred to both the House Ways and Means and Energy and Commerce Committees and Senate Finance Committee.

* Watch the 02/03/22 hearing: <https://www.youtube.com/watch?v=gLpInSl1UHo>

Marriage Equality for Disabled Adults Act – [H.R.6405](https://www.congress.gov/bill/117th-congress/house-bill/6405?q=%7B%22search%22%3A%5B%22HR+6405%22%2C%22HR%22%2C%226405%22%5D%7D&s=2&r=1) (Panetta) eliminates marriage restriction for disabled adult children for purposes of income deeming rules, Medicaid, and other issues.

Social Security 2100: A Sacred Trust – [H.R.5723/S.3071](https://www.congress.gov/bill/117th-congress/house-bill/5723?q=%7B%22search%22%3A%5B%22Social+Security+2100%22%2C%22Social%22%2C%22Security%22%2C%222100%22%5D%7D&s=3&r=2) (Larson/Blumenthal) To increase various Old Age, Survivors, and Disability Insurance (OASDI) benefits and related taxes.

* Watch the [hearing](https://waysandmeans.house.gov/legislation/hearings/social-security-subcommittee-hearing-fierce-urgency-now-social-security-2100)
* Read the [fact sheet](https://larson.house.gov/sites/evo-subsites/larson.house.gov/files/Social%20Security%202100%20-%20Fact%20Sheet%20117th.pdf).

Work Without Worry Act – [S.2108/H.R.4003](https://www.congress.gov/bill/117th-congress/senate-bill/2108?q=%7B%22search%22%3A%5B%22work+without+worry%22%2C%22work%22%2C%22without%22%2C%22worry%22%5D%7D&s=5&r=1) (Wyden/Larson) To amend the Social Security Act to eliminate work disincentives for childhood disability beneficiaries. This bill allows individuals to retain eligibility for such benefits regardless of the amount of earnings after age 22. Additionally, individuals who apply for SSDI benefits on a parent's record and also independently qualify for Social Security benefits on their own record will receive the larger of the two benefit amounts.

Protection of Social Security Benefits Restoration Act – [S.3177/H.R.5866](https://www.congress.gov/bill/117th-congress/senate-bill/3177) (Wyden/Grijalva) To restore protections for Social Security, Railroad retirement, and Black Lung benefits from Administrative offsets; referred to the Committee on Finance.

* Read the [press release](https://grijalva.house.gov/sen-wyden-and-reps-grijalva-larson-reintroduce-the-protection-of-social-security-benefits-restoration-act/)

Build Back Better Act – 117th Congress [H.R.5376](https://www.congress.gov/bill/117th-congress/house-bill/5376?q=%7B%22search%22%3A%5B%22Medicaid%22%2C%22Medicaid%22%5D%7D&r=8&s=5) (Yarmuth) (passed as the Inflation Reduction Act) To provide funding for a broad array of areas including Medicaid home and community-based services, energy and climate change, prescription drug reform, etc.

* Senate Finance Committee [version](https://www.finance.senate.gov/chairmans-news/finance-committee-releases-updated-build-back-better-text) 12/11/21

Guardianship Accountability Act of 2021 – 117th Congress [S.2881/H.R.5600](https://www.congress.gov/bill/117th-congress/senate-bill/2881/text?q=%7B%22search%22%3A%5B%22guardianship%22%2C%22guardianship%22%5D%7D&r=1&s=1) (Collins/Soto) To assist states in improving guardianship oversight and data collection and create a national resource center on guardianship; referred to the Senate Committee on Health, Education, Labor, and Pensions/ House Committee on the Judiciary.

Recognizing the importance of independent living for individuals with disabilities made possible by the Americans with Disabilities Act – 117th Congress [H.Res.552/S.Res.348](https://www.congress.gov/bill/117th-congress/house-resolution/552?q=%7B%22search%22%3A%5B%22disabilities%22%2C%22disabilities%22%5D%7D&s=7&r=1) (Hoyer/Casey)

Freedom and Right to Emancipate from Exploitation (FREE) Act – 117th Congress [H.R.4545](https://www.congress.gov/search?q=%7B%22congress%22%3A%5B%22117%22%5D%2C%22source%22%3A%22all%22%2C%22search%22%3A%22Freedom%20and%20Right%20to%20Emancipate%20from%20Exploitation%20Act%22%7D) (Crist) To protect the rights of legally incompetent adults who are the subject of a guardianship or conservatorship; referred to the Committee on the Judiciary, subcommittee on the Constitution, Civil Rights, and Civil Liberties.

Special Needs Tax Credit Act – 117th Congress [H.R.3819](https://www.congress.gov/bill/117th-congress/house-bill/3819/text?q=%7B%22search%22%3A%5B%22guardianship%22%2C%22guardianship%22%5D%7D&r=2&s=1) (Deutch) This bill allows an income-based tax credit, up to $5,000 in a taxable year, for legal expenses paid to establish a legal guardianship of a disabled family member; referred to Committee on Ways and Means.

SSI Restoration Act – 117th Congress [S.2065/H.R.3763](https://www.congress.gov/bill/117th-congress/senate-bill/2065?q=%7B%22search%22%3A%5B%22S.2065%22%2C%22S.2065%22%5D%7D&s=4&r=1) (Brown/Grijalva) To update eligibility

* Poverty estimates: <https://www.cbpp.org/blog/policymakers-can-expand-ssi-to-cut-poverty-for-seniors-and-people-with-disabilities>

SSI Savings Penalty Elimination Act – 117th Congress [S.4102](https://www.congress.gov/bill/117th-congress/senate-bill/4102) (Brown/Portman). This bill would allow recipients of SSI to have assets up to $10,000 for individuals and $20,000 for couples.

* [Read the press release](https://www.portman.senate.gov/newsroom/press-releases/portman-brown-introduce-bipartisan-legislation-reform-supplemental-security) of Senators Brown and Portman.

Trust Act - [S.1295/H.R.2575](https://www.congress.gov/bill/117th-congress/senate-bill/1295?q=%7B%22search%22%3A%5B%22trust+act%22%2C%22trust%22%2C%22act%22%5D%7D&s=10&r=6) (Romney/Gallagher):

* Sen. Romney's TRUST Act was [Amendment #803](https://www.congress.gov/amendment/117th-congress/senate-amendment/803?s=a&r=87) in Reconciliation vote-a-rama. Non-binding but passed the Senate in a [71-29 vote](http://www.senate.gov/legislative/LIS/roll_call_lists/roll_call_vote_cfm.cfm?congress=117&session=1&vote=00047)
* Analysis: <https://www.crfb.org/blogs/bipartisan-group-introduces-trust-act>

Special Needs Trust Inclusion Act – 117th Congress [H.R.2109](https://www.congress.gov/bill/117th-congress/house-bill/2109/text?q=%7B%22search%22%3A%5B%22special+needs+trust%22%2C%22special%22%2C%22needs%22%2C%22trust%22%5D%7D&r=1&s=3) (Sherrill) To authorize a person participating in the Survivor Benefit Plan to change the beneficiary to a supplemental or special needs trust for the benefit of a dependent child, to authorize a person who establishes such a trust to begin participating in the Survivor Benefit Plan; referred to the House Committee on Armed Services.

The American Rescue Plan Act of 2021 – [P.L. 117-2](https://www.congress.gov/bill/117th-congress/house-bill/1319/text/pl?overview=closed) Signed on March 11, 2021: See also SNA News You Can Use 03/16/2021

Consolidated Appropriations Act (CAA) of 2021, is a five thousand plus page measure that combines a $1.4 trillion omnibus government (appropriations) spending bill with a $900 billion COVID-19 pandemic relief package. Read all about it in [SNA News You Can Use 12/28/20](https://members.specialneedsalliance.org/wp-content/uploads/2021/01/SNA-News-You-Can-Use-December-28-2020-.pdf).

ALS Disability Insurance Access Act of 2019 - S.578/HR1407 (Whitehouse/Moulton) To eliminate the waiting period for disability benefits; signed into law on December 22, 2020; [Public Law 116-250](https://www.congress.gov/bill/116th-congress/senate-bill/578/text/pl?overview=closed)

Marriage Access for People with Special Abilities Act or the “MAPSA Act” – [H.R.761](https://www.congress.gov/bill/117th-congress/house-bill/761/text?r=1) (Katko) To repeal SSI marriage penalty, but only for people with intellectual/developmental disabilities.

FAMILY Act – [H.R.804/S.248](https://www.congress.gov/bill/117th-congress/house-bill/804?q=%7B%22search%22%3A%5B%22hr+804%22%5D%7D&s=8&r=1) (DeLauro/Gillibrand) paid family leave administered by SSA.

Fairness in Social Security Act of 2021 – [HR 1161](https://www.congress.gov/bill/117th-congress/house-bill/1161?q=%7B%22search%22%3A%5B%22HR+1161%22%5D%7D&s=9&r=1) (Neguse) To exempt lump-sum retroactive benefits from taxable income.

SUPREME COURT

* Davis and Carr v. Saul (Whether a claimant seeking disability benefits under the [Social Security Act](https://casetext.com/statute/united-states-code/title-42-the-public-health-and-welfare/chapter-7-social-security/subchapter-i-grants-to-states-for-old-age-assistance/section-301-authorization-of-appropriations) forfeits an appointments-clause challenge to the appointment of an administrative law judge by failing to present that challenge during administrative proceedings.) NADR and NOSSCR submitted amicus briefs. [Judgment](https://www.scotusblog.com/case-files/cases/carr-v-saul/) REVERSED and case REMANDED, 9-0, April 22, 2021.
* US v. Vaello-Madero (SSI in Puerto Rico) [Judgment:](https://www.scotusblog.com/case-files/cases/united-states-v-vaello-madero/) Reversed, 8-1, in an opinion by Justice Kavanaugh on April 21, 2022. Justices Thomas and Gorsuch filed concurring opinions. Justice Sotomayor filed a dissenting opinion.

MISCELLANEOUS

[President Biden Nominates Sharon Lewis to SSA Advisory Board](https://www.whitehouse.gov/briefing-room/statements-releases/2022/01/21/president-biden-announces-2-key-nominees-2/)

[White House Fact Sheet on the National Mental Health Crisis](https://www.whitehouse.gov/briefing-room/statements-releases/2022/03/01/fact-sheet-president-biden-to-announce-strategy-to-address-our-national-mental-health-crisis-as-part-of-unity-agenda-in-his-first-state-of-the-union/)

[Senate Finance Committee Report on Mental Health](https://www.finance.senate.gov/imo/media/doc/SFC%20Mental%20Health%20Report%20March%202022.pdf)

[White House Fact Sheet on Nursing Homes](https://www.whitehouse.gov/briefing-room/statements-releases/2022/02/28/fact-sheet-protecting-seniors-and-people-with-disabilities-by-improving-safety-and-quality-of-care-in-the-nations-nursing-homes/)

[National Academies for Science, Engineering, and Medicine: The National Imperative to Improve Nursing Home Quality: Honoring Our Commitment to Residents, Families, and Staff](https://www.nationalacademies.org/our-work/the-quality-of-care-in-nursing-homes%22%20%5Ct%20%22_self)

**President Biden Nominates Rita Landgraf for Assistant Secretary for Aging, Department of Health and Human Services: She would also serve as Administrator for the Administration for Community Living, which does not need to be confirmed by the Senate:** [Read bio](https://www.whitehouse.gov/briefing-room/statements-releases/2022/03/09/president-biden-announces-key-nominees-5/)

GAO Report on Social Security Administration – Legality of Service of Acting Commissioner: The [GAO’s decision](https://www.gao.gov/products/b-333543) states that Dr. Kilolo Kijakazi can be Acting Commissioner until the President replaces her with another Acting Commissioner or someone else is confirmed by the Senate.

Chairman Brown Asks Biden to Remove Social Security Commissioner Saul: Read the [press release](https://www.brown.senate.gov/newsroom/press/release/brown-chairman-social-security-pensions-subcommittee%2C%20https%3A/waysandmeans.house.gov/media-center/press-releases/larson-davis-pascrell-call-removal-social-security-commissioner-and).

SSA Current [organizational chart](https://www.ssa.gov/org/ssachart.pdf).

SSA’s COVID-19 [response](https://www.ssa.gov/coronavirus/).

CCD Letter Regarding Exclusion of Adult Dependents in Payment: [Letter](http://www.c-c-d.org/fichiers/CCD-Financial-Security-and-Poverty-Taskforce-Co-Chair-Letter_Nutrion-and-Adult-Dependents.pdf) to Senate and House Leadership on CCD’s disappointment that once again adult dependents were excluded from economic impact payments in the latest package.

Proposed OPM rule on hiring ALJs:

* [Read the Rule](https://www.federalregister.gov/documents/2020/09/21/2020-17684/administrative-law-judges)
* Read CCD’s submitted [comments](file:///C%3A%5CUsers%5CLaurie%20Lindberg%5CDocuments%5CBWL%20Business%5CSNA%5C2022%20SNA%5C%E2%80%A2%09http%3A%5Cc-c-d.org%5Cfichiers%5CCCD-comments-on-OPM-NPRM-on-ALJ-hiring.pdf)
* Final Rule expected 12/2022

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