**SNA 2024 Advocacy Highlights**

**October 2024**

**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.**

**The following topics have been supported by SNA either by direct sign-on or by communications submitted by the Consortium for Constituents with Disabilities (CCD), SNA’s advocacy partner:**

**Accessing Medicaid Services Critical to People with Disabilities**

The Long Term Services and Supports Task Force sent a [letter](https://www.c-c-d.org/fichiers/CCD-Letter-HR-670-HR-8107.pdf) to House Energy and Commerce Committee Co-Chairs McMorris Rodger and Pallone in support of two pieces of legislation before the committee: H.R. 8107, which would remove age limits for the Medicaid Buy-In and H.R. 670, the Think Differently Database Act (H.R. 670), which would assist people with disabilities to understand more fully their caregiving options (9/18/24).

**Enforcing the Americans with Disabilities Act**

The CCD Rights Task Force sent a [letter](https://www.c-c-d.org/fichiers/Letter-From-CCD-Rights-TF-Co-Chairs-re-ADA-Investigations.pdf) of the Department of Justice supporting the DOJ’s efforts to efforts to enforce and uphold the Americans with Disabilities Act (ADA). The task force urged DOJ’s Civil Rights Division to expedite the issuance of findings and resolutions for the Department’s open ADA investigations (8/20/24).

**Support for Autism CARES Act of 2024**

Members of the CCD Autism, Developmental Disabilities, and Family Support Task Force sent a [letter](https://www.c-c-d.org/fichiers/CCD-CARES-Leadership-Letter.pdf) supporting H.R. 7213, the Autism CARES Act of 2024 which expires on September 30. This bill will help move forward critical research and training programs that will benefit the estimated 1 in 36 autistic children and 1 in 45 autistic adults in the United States (7/16/24). Note: [H.R. 7213](https://www.congress.gov/bill/118th-congress/house-bill/7213) passed the House of Representatives on 9/18/24 and was referred to the Senate Committee on Health, Education, Labor, and Pensions.

**Barriers to Workforce Participation**

The Social Security Task Force co-chairs submitted [testimony](https://www.c-c-d.org/fichiers/CCD-Senate-Testimony.pdf) to the Senate Committee on Finance for a hearing on barriers to workforce participation for Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) beneficiaries (7/2/24).

**Increasing Medicaid Access**

The Long Term Services and Supports Task Force co-chairs submitted a [statement](https://www.c-c-d.org/fichiers/Final-LTSS-Cochairs-Statement-EC-Hearing.pdf) for the hearing on Legislative Proposals to Increase Medicaid Access and Improve Program Integrity conducted by the Energy and Commerce Committee’s subcommittee on health (6/30/24).

**Ensuring Access to Medicaid Services**

The Long Term Services and Supports Task Force co-chairs published a [press release](https://www.c-c-d.org/fichiers/CCD-Press-Release-Access.pdf) to thank the Department of Health and Human Services for finalizing the “Ensuring Access to Medicaid Services” rule. This rule contains provisions that will improve access to and quality of home and community-based services (HCBS) – services that are key to achieving full integration and access to community living (6/25/24).

**Youth Residential Treatment Facilities**

The Long Term Services and Supports Task Force co-chairs submitted a [statement](https://www.c-c-d.org/fichiers/Statement-for-the-Record-PRTF-oversight-Final.pdf) for the hearing conducted by the Senate Finance Committee on [*Youth Residential Treatment Facilities: Examining Failures and Evaluating Solutions*](https://www.c-c-d.org/fichiers/Statement-for-the-Record-PRTF-oversight-Final.pdf)6/12/24).

**SSA Administrative Changes**

The Social Security Task Force co-chairs submitted [comments](https://www.c-c-d.org/fichiers/CCD-Comments-Electronic-Payroll-Data.pdf) about the proposed rule regarding the Use of Electronic Payroll Data to Improve Program Administration and various other administrative changes (4/15/24).

**Addressing Discrimination Based on Disability**

The CCD submitted this [statement](https://www.c-c-d.org/fichiers/CCD-Statement-on-HHS-504-NPRM-091423.pdf) in support of HHS’s publication of its historic proposed rule, *Discrimination on the Basis of Disability in Health and Human Service Programs or Activities*. The long-awaited proposed rule updates, clarifies, and strengthens the implementing regulation for Section 504 of the Rehabilitation Act of 1973 to address continued discrimination in medical treatment, value assessment methods, child welfare programs and activities, web and mobile accessibility, accessible medical equipment, and other situations. Published at 89 Fed. Reg. 25507 (4/11/2024).

**Support for Implementing Observation Status Appeals**

An ad hoc coalition of organizations joined together more than a decade ago to advocate

for addressing the observation stays issue. Continuing the advocacy, we submitted a comment [letter](file:///C:\Users\Laurie%20Lindberg\Documents\BWL%20Business\SNA\2024%20SNA\Observation%20Stays%20Comment%20on%20NPRM%20Feb%2023%202024.pdf) responding to [CMS’s proposed rule](https://click.everyaction.com/k/79562194/456845841/2032578306?nvep=ew0KICAiVGVuYW50VXJpIjogIm5ncHZhbjovL3Zhbi9FQS9FQTAwMS8xLzU3NDI2IiwNCiAgIkRpc3RyaWJ1dGlvblVuaXF1ZUlkIjogIjYzOWRhZTJkLTU5ZDItZWUxMS04NWY5LTAwMjI0ODIyMzc5NCIsDQogICJFbWFpbEFkZHJlc3MiOiAibGF1cmllZ2xpbmRiZXJnQGdtYWlsLmNvbSINCn0%3D&hmac=hXC9rP6KrYczbVRo4prMLZ8dnfmD9-Mt8UJG33Vxn-w=&emci=13b14dc4-55d2-ee11-85f9-002248223794&emdi=639dae2d-59d2-ee11-85f9-002248223794&ceid=4161680) on appeal rights for Medicare beneficiaries admitted to hospitals and then reclassified as outpatients on observation status. The proposed rule establishes both standard and expedited appeals for Medicare beneficiaries who are class members in [*Alexander v. Azar*](https://click.everyaction.com/k/75639200/445294624/162170032?nvep=ew0KICAiVGVuYW50VXJpIjogIm5ncHZhbjovL3Zhbi9FQS9FQTAwMS8xLzU3NDI2IiwNCiAgIkRpc3RyaWJ1dGlvblVuaXF1ZUlkIjogIjc0YjQ5YWM2LWRmYTAtZWUxMS1iZWExLTAwMjI0ODIyM2YzNiIsDQogICJFbWFpbEFkZHJlc3MiOiAidGVkZWxtYW5AbWVkaWNhcmVhZHZvY2FjeS5vcmciDQp9&hmac=q0-6-4_Qh_ksZJC4bH2kifT6JAM8r63xIbt13Nt79bs=&emci=88adffc2-daa0-ee11-bea1-002248223f36&emdi=74b49ac6-dfa0-ee11-bea1-002248223f36&ceid=4159976#alexander-v-becerra). “The proposed rule brings Medicare beneficiaries one step closer to getting a fair shake if they are changed from inpatient to observation status.” said Alice Bers, Litigation Director of the Center for Medicare Advocacy. (2/23/2024)

**Adult Dental Health Coverage in the Marketplace**

The Consortium for Constituents with Disabilities (CCD) submitted a [comment letter](https://docs.google.com/document/d/1OmJUQZP6hCUp1ATAFipVi1CEYvfixn3U/edit?usp=sharing&ouid=109754671162208601119&rtpof=true&sd=true) , signed by SNA and others, on the Notice of Benefit and Payment Parameters (NBPP) proposed rule on changing the Essential Health Benefit (EHB) to include adult oral health coverage; this change would affect all Marketplace plans and potentially, Medicaid. “Removing the prohibition on issuers including routine non-pediatric dental services as an EHB would give states the option of adding routine adult dental services as an EHB by updating their EHB-benchmark plans without having to defray the costs of that coverage.” (1/8/2024)

**Minimum Nursing Home Staffing Standard Proposed by CMS**

A Notice of Proposed Rule Making (NPRM) was published by the Centers for Medicare and Medicaid Services on nursing home staffing. Although not an LCAO sign-on letter, a number of organizations collaborated on this letter to provide a [comment](https://docs.google.com/document/d/1ivNf9Le82d7n4OFM6ynRw5EYkgR79-z_SY-N8lODsss/edit) on the proposed rule that would, for the first time, establish a minimum staff standard for nursing homes participating in Medicare and Medicaid. (11/6/23)

The requirements would be:

* The care provided by a licensed nurse should be set at 1.4 hours per resident day (HPRD), with at least 0.75 of that provided by an RN. CMS could choose to allow the facilities to meet the remainder of the licensed nurse requirement (.65 HPRD) with LPNs or RNs, or could mandate that time be met solely by LPNs; and
* The care provided by a CNA should be 2.8 HPRD.

**Rental Subsidy Expansion**

CCD’s Social Security Task Force submitted a [comment](https://www.c-c-d.org/fichiers/CCD-SSTF-HTF-Comments-NPRM-Rental-Subsidy.pdf) on a Notice of Proposed Rulemaking (NPRM), signed by SNA and others, supporting SSA’s proposal to expand the rental subsidy policy to make it more uniform and equitable nationwide. “SSA’s proposed rule is an urgently needed step towards ensuring that disabled people on SSI are not penalized for receiving help with housing from friends, family or other informal supports – help that is often necessary to avoid institutionalization and homelessness.” (10/22/23)

**Eliminating the SSI Savings Penalty**

SNA signed a [Letter in support](https://thearc.org/wp-content/uploads/2023/09/SSI-SPEA_Letter-of-support_2023_Final.pdf) for S. 2767/H.R. 5408  SSI Savings Penalty Elimination Act introduced by Senators Sherrod Brown (D-OH) and Bill Cassidy (R-LA) and U.S. Representatives Brian Higgins (D-NY-26) and Brian Fitzpatrick (R-PA-1), the first bipartisan, bicameral push to reform the Supplemental Security Income (SSI) program, which has not been updated in nearly 40 years and currently punishes older and disabled Americans for saving for emergencies (9/12/23).

**Increasing Medicaid Access**

SNA signed onto a [comment letter](https://docs.google.com/document/d/1tf5rXGCa2zR_WSbHzF2Zbn7TDyDIrRW7/edit) submitted to the Department of Health and Human Services (HHS) by the Disability and Aging Collaborative on the [Medicaid Access proposed rule](https://us-east-2.protection.sophos.com/?d=federalregister.gov&u=aHR0cDovL3d3dy5mZWRlcmFscmVnaXN0ZXIuZ292L2QvMjAyMy0wODk1OQ==&i=NjAwNDUwMjQ1MDRjNTA0NTdjYjRjNjdm&t=WCtZRkFzU0JoVFBFa0NVQi8wN3l3U1U5YUYxR3lMZ3pvNE96SjU1SVcyUT0=&h=bdb97174b41940d39299766f917d8cb7&s=AVNPUEhUT0NFTkNSWVBUSVb7EllAtmpnZpqU-PQtNu8xnkimkR9Ghct4cMPWqMiPAg)  to increase access to high-quality Medicaid home and community-based services and strengthening the direct care workforce for older adults and people with disabilities (6/30/23).

**Opposing Cuts Proposed by the House Appropriations Committee**

SNA signed onto this [CCD letter](https://c-c-d.org/fichiers/CCD-Fiscal-Policy-TaskForce-letter-on-Budget-Allocations-July-602023.pdf) to the U.S. House of Representatives Appropriations Committee (7/6/23) opposing the devastating cuts to the subcommittee allocations that were approved on June 15, 2023.

**Guardianship Statement**

The CCD Rights Task Force submitted a statement for the record for the Senate Special Committee on Aging hearing on Guardianships, Conservatorships, Protective Arrangements, and Alternatives (3/ 23/23). [Written Testimony on Guardianship](https://www.c-c-d.org/fichiers/CCD-Rights-Statement-on-Guardianship-and-Alternatives-(submitted-03.23.2023).pdf)

**On the Passing of Advocate Judy Heumann**

The CCD Board of Directors statement mourning the passing of Judy Heumann, a lifelong leader, and fierce local, national, and international disability rights advocate. Heumann passed away in Washington, D.C. on March 4th (3/6/23). [Judy Heumann Statement](https://www.c-c-d.org/fichiers/CCD-Board-Statement-on-Passing-of-Judy-Heumann-030623-FINAL.pdf)

**Importance of Medicaid HCBS**

The CCD’s Long-Term Services and Supports (LTSS) Task Force provided a statement for the written record for the Senate Special Committee on Aging in support of the committee’s efforts to highlight the importance of the Medicaid Home and Community Based Services (HCBS) program (3/9/23). [Written Testimony on Medicaid HCBS](https://www.c-c-d.org/fichiers/CCD-Senate-Aging-Committee-Testimony-3.9.2023.pdf)

**Proposed Rule on Prior Authorization under the ACA**

The CCD’s Health and LTSS Task Forces provided these comments on the Department of Health and Human Services’ (HHS) proposed rule on prior authorization and interoperability in Medicaid, the Children’s Health Insurance Program (CHIP), and Qualified Health Plans (QHPs) sold through the Affordable Care Act (ACA) Marketplaces (hereinafter “Prior Authorization Proposed Rule”) (3/13/23). [Download [ PDF]](https://www.c-c-d.org/fichiers/CCD_Prior_AuthorizationComments03132023.pdf)

**Unwinding Medicaid and the Continuous Coverage Requirement**

The CCD’s Health and LTSS Task Forces wrote a letter to CMS regarding the unwinding of the Medicaid continuous coverage requirement. CMS guidance has laid out a series of plans, documents and data that states are required to produce. Among these is a Renewal Redistribution Plan where a state must detail how renewals and other eligibility actions will be distributed across the 12-month unwinding period. The plan must mitigate churn, account for workforce and systems capacity limitations, and establish a sustainable renewal schedule for future years (3/9/23).  [Download [ PDF]](https://www.c-c-d.org/fichiers/CCD-letter-to-CMS-on-unwinding-plans-transparency-final.pdf)

**Congressional Leaders: Consider People with Disabilities**

The CCD letter to congressional leaders (Leader Charles Schumer, Speaker Kevin McCarthy, Chair of Senate Appropriations Patty Murray and Vice-Chair of Senate Appropriations Susan Collins, Chair of House Appropriations Kay Granger and Ranking Member of House Appropriations Rosa DeLauro) urging them to consider the needs of people with disabilities in policy and appropriations deliberations for the 118th Congress (2/22/23). [CCD Priorities Letter to Leaders](https://www.c-c-d.org/fichiers/CCD-118th-Congress-Priorities-Final.pdf)

**MISCELLANEOUS ADVOCACY NEWS**

**Center for Medicare Advocacy (CMA) Applauds VP Harris on Medicare**

CMA issued a press release voicing support for the Vice President’s proposals to improve home care under Medicare and to add needed vision and hearing benefits to traditional Medicare.

Read the [press release on Vice President Harris’s Medicare proposals](https://medicareadvocacy.org/center-for-medicare-advocacy-statement-on-vice-president-harris-proposal-re-medicare-and-home-care/) . Here’s another take on the topic from [*The Hill*](https://thehill.com/policy/healthcare/4922425-harris-adult-caregivers-medicare-benefit-at-home-care-sandwich-generation/) showcasing the family caregiver’s role in providing care in the home and how these proposals would help them (10/8/24).

**New Social Security Commissioner No Stranger to Bureaucracy**

Martin O’Malley, SSA’s new commissioner, is a lifelong public servant, having served as the Governor of Maryland, as the Mayor of Baltimore, and as an Assistant States Attorney. He even ran for president in 2015. According to the [SSA press release](https://blog.ssa.gov/martin-j-omalley-sworn-in-as-commissioner-of-social-security-administration/), “Commissioner O’Malley is a pioneer in using performance-management and customer service technologies in government and has written extensively about how to govern for better results in the Information Age by measuring the outputs of government on a real-time basis.” The Social Security Task Force of the CCD sent a [Transition Memo](https://www.c-c-d.org/fichiers/CCD-SSTF-Transition-Memo.pdf) to Commissioner O’Malley.

**CCD ANNUAL REPORTS**

The CCD issued several annual reports of its various task forces in January 2024. The reports are uncharacteristically (for an annual report) short and sweet, focusing on three issues tackled in 2023 and three issues anticipated to be worked on in 2024. A list of the reports can be found [here](https://www.c-c-d.org/rubriques.php?rub=annual.php); below are direct links to those of special interest to SNA (the Rights Task Force did not publish an annual report):

[Social Security](https://www.c-c-d.org/fichiers/CCD-2023-Task-Force-Annual-Report-Form_SSA.pdf) Task Force of the CCD Annual Report 2023

[Developmental Disabilities, Autism, Family Support](https://www.c-c-d.org/fichiers/CCD-2023-Autism-DD-Task-Force-Annual-Report.pdf) Task Force of the CCD Annual Report 2023

[Health](https://www.c-c-d.org/fichiers/CCD-2023-Health-Task-Force-FAnnual-Report.pdf) Task Force of the CCD Annual Report 2023

[Long-Term Services and Supports](https://www.c-c-d.org/fichiers/CCD-2023-Task-Force-Annual-Report-Form_LTSS.pdf) Task Force of the CCD Annual Report 2023

**Easterseals Disability Film Challenge Entry**

SNA member Stephen W. Dale forwarded this short film to SNA from the Disability Rights Bar Association listserv.

<https://www.youtube.com/watch?v=Su4wwHCuz44>