

Appendix B: Brief Description of Legislation on the NFXF Research Funding & Legislative Priorities grid

Note all bill numbers are from the prior (118th) Congress.

Accelerating Kids' Access to Care Act (H.R.4758 /S.2372)

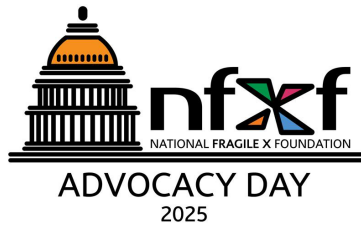
Helping reduce the time it currently takes children covered by Medicaid or Children's Health Insurance Program (CHIP) to access specialized care when providers in their home state cannot address their needs.

We ask you to support this legislation to ensure delays are eliminated to improve better outcomes. Every child deserves the best care – regardless of who they are, where they live, or their family's income.

SSI Savings Penalty Elimination Act (S.2767 /H.R.5408)

This bill aims to address the regressive, anti-savings asset limits for the Supplemental Security Income (SSI) program. Specifically, the bill would increase the asset limits that were established in 1984 from \$2,000 to \$10,000 for individuals and from \$3,000 to \$20,000 for married couples.

We ask that you support this proposed legislation that will empower the most financially vulnerable Americans to take financially responsible steps to prepare for the future without worrying they will reduce or lose benefits.



Ensuring Nationwide Access to a Better Life Experience Act (ENABLE Act) H.R.9614/S.4539**

This bill would make permanent three tax provisions relating to ABLE (Achieving a Better Life Experience) accounts established to assist disabled individuals, specifically provisions allowing increased contributions to such accounts, the allowance of a retirement savings contribution tax credit of up to \$1,000 (\$2,000 per married couple filing jointly) for contributions to an ABLE account, and allowing a tax-free rollover from a qualified tuition program (529 plan) to an ABLE account.

We ask that you support this proposed legislation ...This is a priority, as this would permanently protect ABLE account provisions set to expire in 2025.

***This has been recently re-introduced by Senator Eric Schmitt from Missouri.*

Creating Hope Reauthorization Act of 2025 (H.R.7384/S.4583)

This bill aims to extend until FY2029 a Food and Drug Administration program that awards priority review vouchers to manufacturers of drugs that treat rare pediatric disease. (A priority review voucher entitles the voucher holder to priority review of a single human drug application). This act incentivizes the development of medications for conditions, like Fragile X syndrome, having already led to the creation of numerous medications.



We ask you to support this legislation to continue to incentivize the development of critical medications. Currently, there are no targeted treatments available for Fragile X-associated conditions. This bill will help foster innovation and improve access to impactful treatments for individuals with Fragile X syndrome and other rare conditions.

***This bill passed the House in the 118th Congress but did not make the final continuing resolution and expired December 20, 2024.*

Home and Community-Based Services (HCBS) Relief Act of 2023 (H.R.6296/S.3118)

This bill would temporarily (for two years) increase the Federal Medical Assistance Percentage (i.e. federal matching rate) under Medicaid for certain approved home and community-based services. This could provide dedicated Medicaid funds to stabilize the HCBS delivery networks. Recruit and retain direct care workers and meet the long term service and support needs of individuals eligible for Medicaid home and community-based services.

We ask you to support this legislation that could help decrease or eliminate the waiting list for HCBS in the states.



Alleviating Barriers for Caregivers (ABC) Act (H.R.8018/S.3019)

This bill aims to require the Administrator of the Centers for Medicare & Medicaid Services (CMS) and the Commissioner of Social Security to review and simplify the processes, procedures, forms and communications for family caregivers to assist individuals in establishing eligibility for, enrolling in, and maintaining and utilizing coverage and benefit under the Medicare, Medicaid, CHIP, and Social Security programs and for other purposes.

We ask you to support this legislation to simplify the complex process of Medicare, Medicaid, CHIP, and Social Security for family caregivers. This will make it easier to access essential coverage and benefits, allowing caregivers to focus more on providing care.

Credit for Caregiving Act (H.R. 7165/S.3702)

This bill aims to create a new, non-refundable federal tax credit of up to \$5,000 for eligible working family caregivers to help address the significant financial impact of caregiving. The credit would help offset the cost of caregiving expenses such as home care aides, adult day services, home modifications, assistive technology, respite care, transportation, and other supports.

We ask you to support this legislation to help offset the financial impact of caregiving responsibilities. This would ease the financial burden on caregivers and enable them to focus on providing care.



Transformation to Competitive Integrated Employment Act (TCIEA)(H.R.1263 /S.533)

This bill addresses employment standards for people with disabilities.

The bill directs the Department of Labor to award grants to states and certain eligible entities to assist them in transforming their business and program models to support people with disabilities by:

- Providing competitive integrated employment.
- Assisting such individuals in finding and retaining work in such employment.
- Providing integrated employment and integrated community participation and wraparound services for such individuals.
- Ensuring that such services comply with federal regulations for individuals receiving home and community-based services.
- Prohibits the issuance of new special certificates that allow payment of subminimum wages to people with disabilities and phases out existing certificates over a five-year period.

We ask that you support this proposed legislation to help lower unemployment and poverty rates for people with disabilities but also foster equality in the workplace, highlighting the true abilities and job skills of all individuals.



Disability Employment Incentive Act (DEIA) (S.3076)

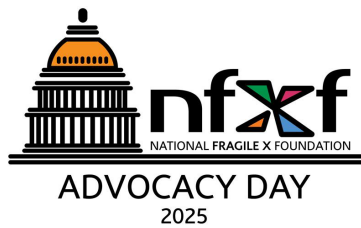
This bill aims to encourage employers to hire and retain employees with disabilities. It expands tax credits and deductions for employers who hire and retain individuals with disabilities. The key provisions include:

- Expansion of Tax Credits to include employees receiving disability insurance benefits under the Social Security Act
- Increased monetary amount of tax incentives for businesses and raises size and revenue limits for small businesses.
- Amends the Internal Revenue Code to include individuals receiving Social Security disability benefits under the work opportunity credit and enhances the disabled access credit.

We ask you to support this legislation that is designed to encourage and support the hiring of our loved ones by providing financial incentives to employers.

Retaining Access and Restoring Exclusivity Act (RARE ACT) (H.R.7383/S.1214)

This bill aims to enhance the Federal Drug Administration's (FDA's) authority to grant seven-year orphan drug exclusivity to manufacturers who develop new treatments for rare diseases. This exclusivity period prevents the approval of the same drug for the same disease or condition by other manufacturers. This ACT is designed to incentivize the



development of treatments for rare diseases by ensuring that companies can recoup their investments without immediate competition.

We ask you to support this legislation to incentivize the development of treatments for rare conditions and diseases. Currently, there are no targeted treatments available for Fragile X-associated conditions. By extending the orphan drug exclusivity, this bill will encourage companies to invest in critical medications, ensuring access to future targeted treatments for rare conditions.

Providing Realistic Opportunity to Equal and Comparable Treatment for Rare Act (PROTECT) (H.R. 6094)

This bill aims to provide coverage under the Medicare prescription drug benefit, Medicaid, and private health insurance for certain drugs that are used to treat rare diseases or conditions. Such drugs must be supported by peer-reviewed research or medical expert and must not have been reviewed unfavorably or used in a way that conflicts with the approved label.

We ask you to support this legislation to help reduce costly barriers to treatments and allow the medical expert to determine the most appropriate care.



Better Empowerment Now to Enhance Framework and Improve Treatments Act of 2023 (BENEFIT ACT) (H.R.1092 /S.526)

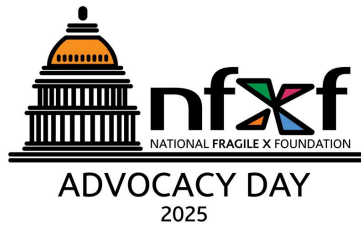
This bill aims to require the Federal Drug Administration (FDA) to consider relevant patient experience data in the risk-benefit assessment framework used in the process of approving new drugs. After a new drug application has been approved, the FDA's public statement about how it used patient experience data shall include a description of how such data was considered in the risk-benefit assessment framework.

We ask you to support this legislation to help ensure that as treatments are developed, that the patient experience is included in the approval process to foster a deeper understanding of the impact on patients.

KEEP Telehealth Options ACT of 2023 ([H.R.1110](#))

This bill requires the Centers for Medicare & Medicaid Services to report on telehealth expansion under Medicare, Medicaid, and the Children's Health Insurance Program (CHIP) during the COVID-19 public health emergency and through December 31, 2024.** The report must include information relating to the types of services available, the utilization of services, and the effects on public health.

We ask that you support this proposed legislation to ensure that everyone can access the necessary expertise and care without the barriers associated with travel, including the financial burden and potential challenges faced by individuals living with Fragile X-associated conditions.



***Congress passed the American Relief Act of 2025 preserving applicable flexibilities through March 31, 2025.*

Charlotte Woodward organ Transplant Discrimination Prevention Act (H.R. 2706/S.1183)

This bill aims to prohibit discrimination on the basis of mental or physical disability in the cases of organ transplants.

We ask you to support this legislation to ensure that individuals with disabilities are treated equally and have the same access to life-saving organ transplants as others.