



# MAKE AIR TRAVEL MORE ACCESSIBLE FOR INDIVIDUALS WITH SMA

*Support the Air Carrier Access Amendments Act (H.R. 1696 / S. 642)*

## DID YOU KNOW?

- More than 40 million (12.6%) of U.S. residents have a disability, including about 20 million who report having a mobility disability (ambulatory) that significantly impairs their ability to walk or climb stairs. ([Source: U.S. Disability Statistics](#))
- The federal legislation that makes it illegal for airlines to discriminate against passengers because of their disability is the Air Carrier Access Act (ACAA), not the Americans with Disabilities Act (ADA). ([Source: U.S. Department of Transportation](#))
- A federal study found that air passengers with disabilities face infrastructure, information, and customer service barriers at U.S. airports. ([Source: U.S. Government Accountability Office](#))
- Access to accessible transportation, including air travel, was among the top priorities identified by individuals with spinal muscular atrophy (SMA). ([Source: Cure SMA](#))

## WHY CONGRESS SHOULD ACT

Nearly 35 years ago, President Ronald Reagan signed into law the Air Carrier Access Act of 1986 ([Public Law 99-435](#)) to prohibit discrimination in air travel based on disability. Despite improvements over the last three decades, individuals with SMA and other disabilities continue to face barriers and unequal experiences related to air travel. Individuals with SMA who use wheelchairs, especially power chairs, often avoid travel or experience unpleasant, sometimes unsafe, air travel due to inaccessible air cabins and other challenges related to their equipment. These barriers make it difficult for individuals with disabilities to fulfill travel responsibilities for their jobs or to explore parts of the country or world. Congress has an opportunity to modernize existing law to better meet the needs of air travelers with disabilities.

## CURE SMA POSITION

To make air travel more accessible and equal for individuals with SMA and other disabilities, Cure SMA urges Congress to pass the Air Carrier Access Amendments Act.

The bipartisan legislation ([H.R. 1696 / S. 642](#)) improves the air travel experience and ensures equal access for all travelers, including those with disabilities, by:

- Requiring air carriers to provide their goods, services, and facilities in the most integrated setting appropriate and by making reasonable modifications in policies, practices, or procedures to improve air travel use and accessibility.
- Strengthening the air travel complaint process for people with disabilities to include additional air carriers responsibilities and greater federal oversight, including the use of civil penalties for violations.
- Directing the U.S. Access Board to set minimum standards for airlines to ensure the accessible design of aircraft, including lavatories, seating accommodations, video displays, and boarding and deplaning equipment.
- Improving the overall safety of air travel for passengers with disabilities.



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# PROMOTE EMPLOYMENT OPPORTUNITIES FOR INDIVIDUALS WITH SMA

*Support the Disability Employment Incentive Act (S. 630 / H.R. 3765) and funding for the Vocational Rehabilitation Services Program*

## DID YOU KNOW?

- The unemployment rate for individuals with disabilities is regularly twice as high than for individuals without disabilities. ([Source: U.S. Bureau of Labor Statistics](#))
- People with disabilities live in poverty at more than twice the rate of people without disabilities, and more than 65 percent of working-age adults with disabilities participate in at least one safety net or income support program. ([Source: National Council on Disabilities Report](#))
- Nearly 20% of adults with spinal muscular atrophy (SMA) who seek full-time employment are either unemployed or working only part-time. Most part-time employees with SMA choose to work only part-time due to SMA health-related complications (33%) or to stay below an income threshold to qualify for or retain public healthcare (i.e., Medicaid) or other community benefits (27%). ([Source: Cure SMA Community Survey](#)).
- Adults with SMA are highly qualified and educated, with 30% earning a bachelor's degree and 20% completing a master's degree. ([Source: Cure SMA Community Survey](#))

## WHY CONGRESS SHOULD ACT

Many working-age individuals with SMA struggle to find employment or are underemployed even though employment was among the highest priorities identified by adults and young adults with SMA. Individuals with SMA and other disabilities represent an untapped talent resource for employers seeking qualified, reliable, loyal, and productive workers.

## CURE SMA POSITION

To increase employment opportunities, and breakdown workplace barriers that exist for individuals with SMA and other disabilities, Cure SMA urges Congress to pass the Disability Employment Incentive Act (S. 630/H.R. 3765) that incentivizes hiring of people with disabilities and support funding for the State Vocational Rehabilitation Services Program that provides job training and employment services to jobseekers with disabilities:

- The Disability Employment Incentive Act would incentivize the hiring of individuals with SMA and other disabilities by expanding tax credits for employers who hire individuals with disabilities and for businesses who make their workplaces more accessible for their employees with disabilities.
  - Increases the Work Opportunity Tax Credit from \$2,400 to a maximum of \$5,000 for employers who hire an eligible person with a disability.
  - Increases the Disability Access Expenditures Tax Credit from \$5,000 to a maximum of \$10,000 for small businesses who incur an expense for making their workplaces accessible for employees with disabilities.
  - Increases the Architectural and Transportation Barrier Tax Credit from \$15,000 to a maximum of \$30,000 for expenses during a single year to remove a physical barrier, such as making a building entrance or vehicle accessible.
- The Vocational Rehabilitation (VR) Services Program provides formula funds to all states and U.S. territories to help transition-age youth and adults with disabilities find and retain competitive integrated employment and to achieve economic self-sufficiency.
  - Fully fund the VR Services Program at no less than \$3,719,121,000 in fiscal year 2022, as recommended in the President's FY 2022 budget.



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# PROMOTE INDEPENDENT LIVING, EMPLOYMENT, AND ECONOMIC SELF-SUFFICIENCY

*Create a National Medicaid for Workers with Disabilities Program that Removes Asset and Income Eligibility Limits and Expands Eligibility to Allow Workers with Disabilities Over 65 Years Old*

## DID YOU KNOW?

- Medicaid is the primary payer of long-term care services—such as attendant care or home health aides—that allow individuals with disabilities and others to maintain their health and independence. These services are not typically covered by Medicare or private health insurance. ([Source: Centers for Medicare & Medicaid Services](#))
- Most states allow individuals with disabilities who qualify for Medicaid due to their disability to work and earn above traditional Medicaid income and asset thresholds while still maintaining their Medicaid healthcare and home and community-based services. ([Source: U.S. Department of Health and Human Services](#))
- State Medicaid for Workers with Disabilities Programs sometimes include very low income and asset thresholds that significantly limit the earnings and career potential of workers with disabilities. In addition, these programs cap participation at age 65, preventing older adults with disabilities from working past 65 and retaining their essential Medicaid coverage. ([Source: Urban Institute](#))
- Nearly 30% of adults with spinal muscular atrophy (SMA) who work part-time said they maintain their part-time employment status to stay below an income threshold to maintain their eligibility for Medicaid, which provides essential attendant care and other home and community-based services. ([Source: Cure SMA Community Survey](#)).

## CURE SMA POSITION

To promote employment and economic self-sufficiency, and to remove existing work disincentives, Cure SMA urges Congress to adopt the **Bipartisan Policy Center** recommendations for the Medicaid Workers with Disabilities Program.

### This will:

- Create a single Medicaid Workers with Disabilities Program across all states to simplify the program and allow working-age individuals with disabilities to pursue careers and accept promotions that may require relocation to other states.
- Remove income and asset limits to allow all eligible workers with disabilities, regardless of income level, to maintain their Medicaid care and supports using a reasonable sliding premium scale.
- Remove the age cap in Medicaid for Workers with Disabilities Programs to allow individuals with disabilities over the age of 65 years to stay employed and maintain their Medicaid benefits.

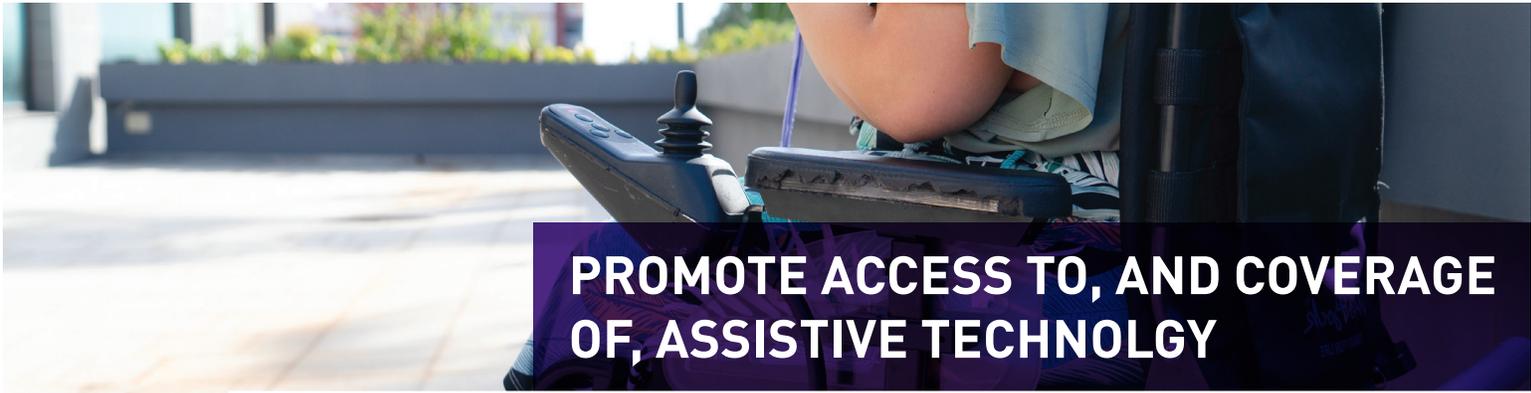
## WHY CONGRESS SHOULD ACT

Some individuals with disabilities work only part-time or remain out of the workforce completely to maintain eligibility for Medicaid and other supports that are essential for their health and independence. In the 1990s, Congress helped to address systematic work disincentives for individuals with disabilities by providing [increased flexibility](#) to states to provide Medicaid coverage to higher income-earning workers with disabilities. Many states have established Medicaid Workers with Disabilities Programs (also referred to as Medicaid buy-in programs) to help individuals with disabilities earn a living while maintaining their Medicaid services. However, income and asset caps that exist in some state programs force individuals with SMA to choose between a meaningful career and independence. In addition, the state-by-state patchwork requires workers with disabilities to restart the eligibility process if they relocate or are transferred to a work location in a different state.



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## PROMOTE ACCESS TO, AND COVERAGE OF, ASSISTIVE TECHNOLOGY

*Support the reauthorization of the Assistive Technology Act and funding for the Assistive Technology Act Programs*

### DID YOU KNOW?

- Assistive technology (AT) devices and services, such as mobility aides, voice recognition programs, screen readers, robotic arms, and adaptive pencils and utensils, greatly increase functional capabilities and enhance work participation for individuals with disabilities when they are properly prescribed, and the user receives proper training. ([Source: National Academy of Sciences](#))
- Every state and U.S. territory receives federal funding to operate a statewide AT program focused on awareness and access to AT. ([Source: Administration on Community Living](#))
- During the last program year, more than 37,000 AT devices were loaned and nearly 40,000 individuals with disabilities participated in an AT device demonstration through state AT programs. ([Source: Center for Assistive Technology Act Data Assistance](#))
- Access to, and coverage of, AT devices and services were among the top priorities identified by individuals with spinal muscular atrophy (SMA). ([Source: Cure SMA](#))

### WHY CONGRESS SHOULD ACT

Technological advances in devices and services have helped individuals with SMA and other disabilities to achieve greater independence and to live, work, and learn in their communities. Recognizing the significant impact IT devices and services can have on individuals with disabilities, Congress provided states with funding to create statewide AT programs to: evaluate the AT needs of their residents; provide education, training, and technical assistance; and establish device borrowing and reutilization programs. However, barriers remain for individuals with disabilities in accessing these life-changing AT devices and services. A [National Academy of Sciences](#) report found that barriers to IT are due to coverage restrictions and how AT discoveries are advancing at a much faster rate relative to education, regulations, and reimbursement systems.

### CURE SMA POSITION

Congress should meet the AT needs of individuals with disabilities by updating and extending Assistive Technology Act programs and increasing program funding to address current demand for AT devices and services.

- The Assistive Technology Act needs to be modernized and improved to collect data to measure AT gaps, promote collaboration among state disability-focused agencies, and expand access to assistive technology devices through increased funding and expansion of eligibility criteria for AT devices services. We support the reauthorization of the Assistive Technology Act.
- The State Grant for Assistive Technology Program provides formula funds to states and U.S. territories to provide a continuum of services to expand knowledge of and access to AT devices and services for individuals with disabilities. We support funding for AT Act programs, which includes the AT State Grant Program, at no less than \$50,000,000 in fiscal year 2022.



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## ENSURE EMERGENCY DISASTER RESPONSE MEETS NEEDS OF PEOPLE WITH SMA

*Support the Real Emergency Access for Aging and Disability Inclusion for Disasters Act and Disaster Relief Medicaid Act*

### DID YOU KNOW?

- U.S. weather-related events that resulted in more than \$1 billion in damages are on the rise, averaging 10 or more annually for six consecutive years and totaling nearly 300 since 1989. ([Source: National Oceanic and Atmospheric Administration](#))
- State and local officials of areas impacted by recent hurricanes identified barriers for people with disabilities in accessing food and water, medication and medical care, emergency shelter, and transportation during an emergency. ([Source: U.S. Government Accountability Office](#))
- Eligibility for Medicaid home and community-based services (HCBS) differs by state and services are not transferable. If a person with a disability who relies on a personal care attendant or other HCBS support relocates to another state—whether displaced by a natural disaster or by choice—the individual must meet eligibility requirements for the new state, which may have HCBS waiting lists. ([Source: Centers for Medicare & Medicaid Services](#))
- Inclusive emergency preparedness was among the top priorities identified by individuals with spinal muscular atrophy (SMA). ([Source: Cure SMA](#))

### WHY CONGRESS SHOULD ACT

Despite agency initiatives, such as FEMA's [Office of Disability Integration and Coordination](#), and public awareness campaigns, such as [Ready.gov](#), state and local governments and their partners reported challenges in providing disaster-related assistance to people with disabilities and older adults, according to a [recent U.S. Government Accountability Office \(GAO\)](#) study. One adult with SMA, for example, reported having to ask for help on social media to safely evacuate from her flooded home during a recent hurricane. In addition, people with disabilities who rely on HCBS, such as personal care attendants, may also risk losing their lifeline to independence if they are displaced by a natural disaster and forced to relocate to a different state. The GAO recommended inclusive preparedness planning, additional training, and simplified disaster relief registration, among other things for government agencies to improve their disaster response for people with disabilities.

### CURE SMA POSITION

To help states and localities effectively respond to the needs of people with SMA and other disabilities during times of disaster, Cure SMA supports the following emergency preparedness legislation.

- The **Real Emergency Access for Aging and Disability Inclusion for Disasters (REAADI) Act** helps states and localities plan for and respond to the health, safety, and independence of people with disabilities before, during, and after disasters. The legislation, among other things, would fund research, provide training and technical assistance, ensure uninterrupted access to Medicaid services when a recipient crosses state lines, and include oversight and accountability measures for inclusive emergency preparedness and response.
- The **Disaster Relief Medicaid Act** would ensure that individuals eligible for Medicaid who are forced to relocate due to a disaster can retain access to their Medicaid-supported services. The legislation would provide states with resources to support the Medicaid needs of individuals forced to relocate following a disaster and develop an emergency response corps to provide HCBS in emergency situations.



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# ELIMINATE MARRIAGE PENALTY FOR PEOPLE WITH SMA FACT SHEET

*Support the Marriage Access for People with Special Abilities Act (H.R. 761)*

## DID YOU KNOW?

- Supplemental Security Income (SSI) is a Federal income supplement program that helps individuals with disabilities and older adults who have little or no income. ([Source: Social Security Administration](#))
- In many states, SSI beneficiaries automatically qualify for Medicaid, the primary provider of long-term care and home and community-based supports. Approximately two-thirds of those who receive Medicaid because of their disability qualify based on SSI eligibility. ([Source: Centers for Medicaid and Medicare Services](#))
- Married couples with disabilities who both qualify for SSI receive 25% less as a married couple than they would if they were not married. ([Source: Social Security Administration](#))
- More than 60% of all adults with spinal muscular atrophy (SMA) reported having never been married. In addition, nearly 30% of adults with SMA who work part-time said they maintain their part-time employment status to stay below an income threshold to maintain their eligibility for public benefits, such as Medicaid. ([Source: Cure SMA Community Survey](#))

## WHY CONGRESS SHOULD ACT

Currently, a married couple with disabilities who both qualify for SSI will receive 25% less in SSI benefits overall than if they were unmarried, yet still living together. This marriage penalty, as it is often referred, is because the [Social Security Administration](#) calculates benefits differently for couples than for individual recipients. In addition, the [asset](#) and [income](#) levels of the applicant's spouse impact [eligibility](#) for SSI. For example, a couple must have no more than [\\$3,000](#) in countable resources to qualify for SSI. The couple's resource amount is only \$1,000 more than the level for an unmarried individual. Losing Social Security benefits may also result in a loss of healthcare given that a [majority of states](#) provide Medicaid to SSI beneficiaries. These policies are contributing toward the fact that people with disabilities live in poverty at [more than twice the rate](#) of people without disabilities.

## CURE SMA POSITION

To eliminate the marriage penalty in SSI and to promote financial security for people with disabilities, including individuals with SMA, Cure SMA urges Congress to approve the [Marriage Access for People with Special Abilities Act \(H.R. 761\)](#).

### The legislation:

- Disregards marital status when calculating the SSI benefit amount for an adult with a diagnosed intellectual or developmental disability; and
- Excludes a spouse's income and resources when determining eligibility for SSI.



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## SUPPORT FAMILY CAREGIVERS OF INDIVIDUALS WITH SMA

*Expand paid family caregiving opportunities and increase access to respite care*

### DID YOU KNOW?

- Family caregivers are family members who provide paid or unpaid assistance to a person with a chronic illness or disabling condition. ([Source: Centers for Medicaid and Medicare Services](#))
- Approximately 1 in 5 Americans (or about 53 million) have reported caring for an older adult or a person with a disability during the last year. ([National Alliance for Caregiving](#))
- Family caregiving can cause a heavy emotional, physical, and financial toll, with 65% of family caregivers of older adults and people with disabilities reporting that providing care interfered with their job and 75% saying short-term help, known as respite care, would allow them to care for their loved one longer. ([Source: U.S. Department of Health and Human Services](#))
- Many individuals with spinal muscular atrophy (SMA) have reported significant challenges in finding and retaining qualified caregivers. ([Source: Cure SMA](#))

### CURE SMA POSITION

To help address the caregiving challenges and shortages in this country, Congress should help support family caregivers by:

- Funding the Lifespan Respite Program at no less than \$14.2 million in fiscal year 2022, as **recommended** by the President. The funding request will allow the U.S. Department of Health and Human Services to award more grants to states to assist them in enhancing respite programs in their states.
- Incentivize states to pay family caregivers of children and adults with SMA and other disabilities.

### WHY CONGRESS SHOULD ACT

Family members of individuals with SMA and other disabilities may take on caregiving duties to assist their loved one in their activities of daily living. Researchers have [studied](#) the emotional, physical, and financial toll caregiving can take on a family caregiver of an older adult or person with disabilities. Recognizing the enormous contributions family caregivers provide to their families and society, Congress [extended](#) respite care services through 2024. However, the [Lifespan Respite Care Program](#), which assists states in making respite care available to family caregivers, has been historically underfunded. In addition, some states [allow](#) Medicaid beneficiaries who manage their own long-term services through a [Medicaid Self-Directed Care program](#) to hire family members as caregivers. Unfortunately, not all states allow for paid family caregiving, which could help address the caregiving needs and direct care workers shortages that exist across the country.



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# ENSURE FULL AND TIMELY ACCESS TO LIFESAVING TREATMENTS

*Support the Bipartisan Safe Step Act of 2021 (H.R. 2163 / S. 464)*

## DID YOU KNOW?

- Spinal muscular atrophy (SMA) is an inherited neurodegenerative disease that affects the motor nerve cells in the spinal cord and impacts the muscles used for activities such as breathing, eating, crawling, and walking. SMA impacts 1 in 11,000 births in the U.S. ([Source: Cure SMA](#))
- The U.S. Food and Drug Administration (FDA) has approved three treatments for SMA—Spinraza (2016), Zolgensma (2019), and Evrysdi (2020)—that make it possible for individuals with SMA today to stop the progression of the disease, improve motor function, achieve developmental milestones, and live independently and contribute to their communities. ([Source: Cure SMA](#))
- Research shows that SMA treatments are most effective when delivered early, and especially when treated before symptom appear, given the rapid degeneration of the disease that affects motor neurons needed for muscle strength. Lost motor neurons cannot be restored. ([Source: National Center for Biotechnology Information](#))
- Most families of children with SMA (60%) and adults with SMA (59%) have reported that they have had to appeal an insurance denial related to SMA treatment coverage. ([Source: Cure SMA Community Survey](#))

## WHY CONGRESS SHOULD ACT

Health plans that include step therapy protocols require patients to try the plan's preferred treatment before the patient can access the desired treatment originally prescribed by their physician. Step therapy protocols are aimed at controlling spending on medications and may ignore a patient's unique circumstances, medical history, and choice. For degenerative diseases such as SMA, the use of restrictive protocols and other barriers that delay access to the most clinically appropriate treatment can be harmful to the patient's overall health and well-being. For example, infants with SMA

Type 1, the most common and severe form of the disease, lose 90% of their motor neurons before reaching 6 months of age. Lost neurons can never be regenerated, leading to neuromuscular and respiratory muscle weakness that can progress to life-long medical needs and costs, as well as be fatal.

Beginning the most clinically appropriate treatment as early as possible is the only way to prevent this motor neuron loss.

## CURE SMA POSITION

To ensure individuals with SMA and others have full and immediate access to the treatment that is most appropriate to their clinical needs and goals, Cure SMA urges Congress to approve the **Safe Step Act of 2021 (H.R. 2163 / S. 464)**.

### The legislation would:

- Require a group health plan to implement a clear and transparent process for a patient or physician to request an exception to a step therapy protocol.
- Create step therapy standard exemptions when:
  - The patient has already tried the medicine without success.
  - Delayed treatment will cause irreversible consequences.
  - The treatment is contraindicated or has caused or is likely to cause an adverse reaction.
  - The treatment has, will, or is likely to prevent a participant from fulfilling their occupational responsibilities at work or performing activities of daily living.
  - The patient is stable for his or her disease or condition on the current drug or treatment.
- Require a group health plan to respond to an exemption request within 72 hours in all circumstances, and 24 hours if the patient's life is at risk
- Incentivize states to pay family caregivers of children and adults with SMA and other disabilities.



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# PROMOTE REPRESENTATION OF PEOPLE WITH RARE DISEASES

*Support the Creation of Rare Disease Advisory Councils in Every State*

## DID YOU KNOW?

- Rare diseases are defined as conditions that impact fewer than 200,000 people in the U.S. Collectively, there are approximately 7,000 rare diseases that affect 30 million Americans. Of the 7,000 rare diseases, only about 5 percent have FDA-approved treatments. ([Source: U.S. Government Accountability Office](#))
- Spinal muscular atrophy (SMA) is an inherited neurodegenerative disease that affects the motor nerve cells in the spinal cord and impacts the muscles used for activities such as breathing, eating, crawling, and walking. SMA impacts 1 in 11,000 births in the U.S. There are three treatments for SMA approved by the U.S. Food and Drug Administration. ([Source: Cure SMA](#))
- The economic burden of rare diseases in the U.S. is nearly \$1 trillion, which includes direct medical costs (57% of \$966 billion total) and indirect and nonmedical costs (43%). In addition, significant unmet need exists within the rare disease community. ([Source: EveryLife Foundation](#))
- The first Rare Disease Advisory Council was created in North Carolina in 2015 by patients, caregivers, families, and providers. ([Source: National Organization for Rare Disorders](#)).

## CURE SMA POSITION

Cure SMA urges all states to form a **Rare Disease Advisory Council (RDAC)** to give the rare disease community a stronger voice in the state and local issues that impact their lives.

The goal of a RDAC is to:

- Provide advice to the governor, legislature, and state agencies on issues that impact the rare disease community.
- Include broad membership that includes individuals with rare diseases and representatives of rare disease organizations.
- Host regular public meetings and forums to educate and advise leaders and the public on issues and proposals that impact the rare disease community.
- Develop public reports on rare disease proposals and topics, such as prevalence, unmet needs, strategies for diagnosis and care, and economic and social cost.

## WHY STATES SHOULD ACT

State policies and programs play a critical role in the lives of individuals with SMA and other rare diseases. The rare disease community should have a seat at the table when decisions are being considered and made that could impact them and their ability to live independently and access healthcare, educational supports, transportation, and other community services. In addition, state leaders and agency officials would benefit from a regular forum where stakeholders across government, healthcare, and the rare disease community could discuss opportunities and challenges and provide feedback on policy and program proposals.



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