

Like all Americans, individuals with spinal muscular atrophy (SMA) rely on transportation for all aspects of their lives, from accessing healthcare, education, and employment to fully participating in and contributing to their communities. However, accessibility across all modes of transportation remains a significant barrier for individuals with disabilities, who are much more likely to face inadequate transportation than individuals without disabilities. Transportation inequity among people with disabilities negatively impacts all aspects of their lives.

Cure SMA Transportation Principles and Priorities:

Cure SMA is committed to expanding accessible and equitable transportation options for individuals with SMA. Our principles and priorities in the 118th Congress include:



Promote Accessible Air Travel for Individuals with SMA: All individuals with SMA should have the right to travel by air with dignity and respect, including being able to roll onto the aircraft with their own power wheelchair for those who utilize a mobility device. *Cure SMA will support efforts to achieve fully accessible air travel for individuals with SMA and other disabilities.*



Preserve Access to Non-Emergency Medical Transportation: Reliable, affordable, and accessible community transportation options must be available for individuals with SMA who do not drive and who rely on public transportation options for activities of daily living, including everything from school and work to medical appointments and social events. *Cure SMA will support efforts to improve and expand accessible public transportation options, including disability-focused training and technical assistance, to enhance the mobility of individuals with SMA and other disabilities.*



Enhancing the Mobility of Individuals with SMA in Public Transportation: Reliable, affordable, and accessible community transportation options must be available for individuals with SMA who do not drive and who rely on public transportation options for activities of daily living, including everything from school and work to medical appointments and social events. *Cure SMA will support efforts to improve and expand accessible public transportation options, including disability-focused training and technical assistance, to enhance the mobility of individuals with SMA and other disabilities.*



Mandate Accessible Design and Prevent Discrimination in Innovative Transportation Options: Accessible transportation standards must be included in all new and future transportation technologies and advancements (e.g., autonomous vehicles) to promote mobility and prevent discriminate against individuals with SMA. *Cure SMA will support efforts to incentivize and standardize accessibility in the design and deployment of new transportation-related technologies and innovations that could improve transportation for individuals with SMA.*

Children and adults with spinal muscular atrophy (SMA) can experience unique and complex medical needs from complications associated with SMA, such as respiratory failure, difficulty swallowing, severe scoliosis, and upper and lower extremity contractures. In addition, individuals with SMA may require ongoing treatments and care, including therapies and equipment, to maintain their health and independence and for support in their activities of daily living. Federal programs (i.e., Medicaid) and laws (i.e., Affordable Care Act) have increased the ability for individuals with SMA to access essential care.

Cure SMA Healthcare Principles and Priorities:

Cure SMA is committed to expanding and improving access to healthcare for individuals with SMA and their families. Our principles and priorities during the 118th Congress include:



Do No Harm: Healthcare reforms and modifications to health-related programs should improve the lives of children and adults with SMA. *Cure SMA will view all proposals through the lens of whether the changes would benefit or harm individuals with SMA and their ability to access essential treatments and care.*



Protect Individuals with SMA From Discrimination: Individuals with SMA should not be discriminated against due to their SMA or related health conditions in accessing treatments and care that can help maintain and improve their health and independence. *Cure SMA supports the healthcare protections under current law that promote affordable access, prevents discrimination, and bans annual and lifetime limits. In addition, Cure SMA opposes efforts to ration care, under any circumstances, for individuals with SMA.*



Promote Access to SMA Treatments: Advances in medicine and science make it possible for individuals with SMA to halt the progression of the disease, improve function and muscle strength, and achieve unprecedented developmental gains. *Cure SMA will work to remove any barriers that take away from personal choices or delay access to treatment and care. In addition, we will support the ability of individuals with SMA to access available treatments done in sequence or combination with other treatments.*



Expand Home- and Community-Based Services: Individuals with SMA may utilize home-based care and related services and equipment to assist in their health and independence. *Cure SMA supports expansions of home and community-based services for individuals with SMA through Medicaid and other programs.*



Expand Access to Comprehensive Healthcare: All working-age individuals with SMA who rely on comprehensive healthcare and services available only through Medicaid should be able to gain Medicaid coverage without limiting their ability to work, earn, and save for their future. *Cure SMA supports federal and state efforts to guarantee access to Medicaid while not disincentivizing work and hampering financial independence.*



Remove Healthcare Measurements That Minimize Patient Perspective: Health-related decisions that impact individuals with SMA may rely on healthcare measurements that often discount or fail to accurately assess patient perspective. *Cure SMA does not support quality adjusted life year (QALY) or similar assessments that fail to accurately capture the perspective of individuals with SMA related to their health, quality of life, and independence.*

Individuals with spinal muscular atrophy (SMA) need accessible, affordable housing options to achieve independent living and full participation in life—goals set forth in the landmark Americans with Disabilities Act (ADA). However, a lack of accessible and affordable housing remains a significant barrier to independence and community living for all individuals with disabilities.

Cure SMA Housing Principles and Priorities:

Cure SMA is committed to expanding safe, accessible, and affordable housing options for individuals with SMA. Our principles and priorities in the 118th Congress include:



Increase Funding for Accessible and Affordable Housing: Individuals with SMA need access to affordable and accessible housing to help live independently in their communities. *Cure SMA will support efforts to increase funding for affordable housing programs, including the Section 811 Project Rental Assistance and the Housing Choice Voucher Program, that could assist individuals with SMA in accessing housing.*



Prevent Discrimination in Housing: Individuals with SMA should not be discriminated against in housing and housing-related transactions because of disability. *Cure SMA will support efforts to strengthen the enforcement of nondiscrimination protections aimed at preventing discrimination based on disability in housing programs or housing-related activities and transactions.*



Promote Full Community Integration and Participation: Individuals with SMA may need access to housing supports and community services to help them remain in, and thrive in, their communities. *Cure SMA will support efforts to expand and mandate housing supports and community living services for individuals with SMA and other disabilities.*



Expand Tax Credits to Expand Affordable Housing Options: Individuals with SMA benefit from increased options for affordable accessible housing. *Cure SMA will support efforts to expand tax credits to help incentivize the construction and rehabilitation of affordable and accessible housing, and to help retrofit existing housing to improve accessibility and functionality for individuals with SMA and other disabilities.*



Remove Asset Limitations in Program Eligibility: Strict asset limitations in public programs may restrict the ability of an individuals with a disability to save for a deposit or down payment required for affordable housing. *Cure SMA will support efforts to remove asset building restrictions and expand opportunities for individuals with SMA and other disabilities to save without jeopardizing their healthcare and community supports.*

Many individuals with disabilities struggle to find work, with unemployment rates often twice as high as for individuals without disabilities. Adults with spinal muscular atrophy (SMA) identified flexible work schedule and financial assistance as two of their top unmet needs, according to a Cure SMA survey. Individuals with SMA who receive their health care and long-term support services through Medicaid and other public programs may also be subjected to strict asset restrictions and earnings limitations, creating the counter effect of reducing their financial security and economic independence.

Cure SMA Employment and Financial Security Principles and Priorities:

Cure SMA is committed to expanding employment opportunities and promoting financial security for individuals with SMA. Our principles and priorities in the 118th Congress include:



Expand Job Training and Employment Supports: Transition-age youth and working-age adults with SMA can benefit from on-the-job training, job shadowing, pre-employment transition services, work experiences, benefit counseling, and other employment supports to improve their employment success. *Cure SMA will support efforts to increase funding and expand access to job training and employment supports for individuals with SMA through federal and state employment program and services.*



Encourage Businesses to Hire and Rehire Individuals with SMA: Working-age individuals with SMA represent an untapped resource for public and private employers looking for skilled and reliable workers. Yet far too many individuals with disabilities, including those with SMA, are underemployed or unemployed. *Cure SMA will support efforts to expand tax credits and other incentives—such as federal contractor hiring goals and grants to improve workplace accessibility— and to promote the hiring, retention, and promotion of individuals with SMA and other disabilities.*



Remove Work Disincentives: Individuals with SMA should not have to limit their earnings or asset accumulation to maintain access to the care and services they need to work and live independently. *Cure SMA will support efforts to remove barriers to employment, such as earnings limits or other strict eligibility requirements, that could have the counter effect of disincentivizing work for individuals with SMA and other disabilities.*



Prevent Employment Discrimination: Individuals with SMA should not be discriminated against in the workplace, including related to hiring, promotions, and earnings. *Cure SMA will support efforts to prevent discrimination, enforce affirmative action requirements for federal contractors, and promote competitive integrated employment for all individuals with SMA.*

Despite the 1990 passage of the Americans with Disabilities Act (ADA), the United States has yet to fully live up to its mandate to eliminate discrimination against individuals with disabilities. While enormous progress has been achieved, the ADA's vision of equality of opportunity, full participation, independent living, and economic self-sufficiency remains out of reach for some individuals with spinal muscular atrophy (SMA).

Cure SMA Disability Rights Principles and Priorities:

Cure SMA is committed to preserving and expanding the rights of individuals with SMA in all aspects of daily and community living. Our principles and priorities in the 118th Congress include:



Prevent the Weakening of the Americans with Disabilities Act: The ADA's nondiscrimination protections and enforceable accessibility standards remain vital and must be preserved and strengthened to help remove societal and institutional barriers for all individuals with SMA. *Cure SMA will oppose efforts to remove or weaken equal opportunity and nondiscrimination protections included in the ADA for individuals with SMA and other disabilities.*



Emphasize and Enforce Nondiscrimination Protections in Healthcare: Individuals with SMA should not be discriminated against in healthcare based on disability, including under national emergencies and pandemics or through quality-of-life formulas. *Cure SMA will support efforts to emphasize, clarify, and enforce protections in federal law that protect confidentiality of individuals with SMA and prohibits any discrimination in healthcare.*



Strengthen and Enforce Physical and Electronic Accessibility Standards: Individuals with SMA should have equal opportunity to participate in, and have access to, all aspects of daily and community living. *Cure SMA will support efforts to promote and enforce accessibility standards in physical and electronic products, services, and locations to ensure full access for individuals with SMA and other disabilities.*



Protect Student Rights and Access to Accessible and Appropriate Education: Students with SMA should have full access to educational supports (i.e., accessible educational technology), learn alongside their peers, and not be subjected to discrimination in the classroom. *Cure SMA will support efforts to fulfill the federal mandate to provide all students with SMA with a free and appropriate public education that is least restrictive, meets their individual needs, and protects their rights.*



Require Disability Representation: Individuals with SMA should be represented or considered when agencies or policymakers consider changes to public services and programs that impact the SMA community. *Cure SMA will promote opportunities for individuals with SMA to serve on or provide feedback to governing boards or government agencies responsible for public programs and services that impact individuals with SMA and other disabilities.*

Individuals with spinal muscular atrophy (SMA) can benefit from assistive technology devices and services, such as mobility aides, modified driving controls, voice recognition programs, and adaptive utensils, to increase, maintain, or improve functional capabilities related to daily living. Assistive technology is helping people with SMA and other disabilities to access education and the workplace, live independently in their communities, and participate in recreational activities.

Cure SMA Technology Principles and Priorities:

Cure SMA is committed to expanding access and coverage to assistive technology devices and services for all individuals with SMA. Our principles and priorities in the 118th Congress include:



Increase Funding for Assistive Technology Act Programs: Congress established the Assistive Technology (AT) State Grants and other AT programs to promote awareness of and access to AT devices and services in all 50 state and U.S. territories. *Cure SMA will support efforts to increase funding for assistive technology programs at the Administration on Community Living (U.S. Health and Human Services) to promote greater access to these life-changing technologies and devices.*



Promote Full Coverage of Assistive Technology Services and Devices: Assistive technology devices and services are having life-changing impacts on people with SMA and other disabilities. Unfortunately, coverage restrictions and other barriers make it difficult for individuals with disabilities to access these AT devices and services. *Cure SMA will work to remove any barriers that may limit full access to the assistive technology device or service that best meets the unique and individualized needs of every person with SMA.*



Support Research and Incentives into Assistive Technology Development: Despite the amazing advances in assistive technology, gaps in need still exist for individuals with SMA and other disabilities. *Cure SMA will support efforts to further incentivize the development and production of new assistive technology devices and services, particularly those that would address the needs of individuals with rare diseases or significant disabilities.*

Access to high-quality, inclusive education and educational supports—from early education to higher education—are critical for individuals with spinal muscular atrophy (SMA). Federal law makes available a free appropriate public education for children with disabilities, requires public school accessibility and appropriate educational accommodations, and makes it illegal to discriminate against students with disabilities on the basis of disability.

Cure SMA Education Principles and Priorities:

Cure SMA is committed to promoting inclusive education and the rights of students with SMA within our country's educational system. Our principles and priorities in the 118th Congress include:



Protect Student Rights and Access to Accessible and Appropriate Education: Students with SMA should have full access to educational supports, learn alongside their peers, and not be subjected to discrimination in the classroom. *Cure SMA will support efforts to fulfil the federal mandate to provide all students with SMA with a free and appropriate public education that meets their individual needs and protects their rights.*



Increase Funding for Educational Supports for Students with Disabilities: Under the Individuals with Disabilities Education Act (IDEA), the federal government committed to pay 40 percent of the average per pupil expenditure for special education and related services for individuals with disabilities, including SMA. *Cure SMA will support efforts to increase funding for IDEA programs, including state grants, preschool grants, and early intervention services, to finally meet the federal promise to children with disabilities.*



Enhance Educational Learning through Assistive Technology and Related Educational Supports: Students with SMA should have access to assistive technology that is accessible, interoperable, and usable in the school setting. *Cure SMA will support efforts to promote access to assistive technology and other educational supports and accommodations that students with SMA may need to promote learning.*



Increasing Access to Higher Education: Students with SMA who choose to pursue higher education must receive access to the educational supports and accommodations they need to succeed within their college or other post-secondary program. *Cure SMA will support efforts focused on ensuring students with SMA and other disabilities are supported in their higher education pursuits.*



Preparing Teachers of the Future: Students studying to become teachers must receive training and in-classroom experiences in their college teacher preparation programs to effectively support the educational needs of students with SMA and other disabilities. *Cure SMA will support efforts to attract new teachers in the field of special education and to train all teachers to effectively support and meet the learning needs of students with disabilities.*

Effective emergency preparedness and disaster response are a matter of life and death for people with disabilities, including individuals with spinal muscular atrophy (SMA). Existing emergency response and recovery efforts often overlook or fail to effectively meet the needs of people with disabilities and older adults who may need accessible options and specialized assistance during an emergency evacuation.

Cure SMA Emergency Management Principles and Priorities:

Cure SMA is committed to ensuring that emergency response and recovery plans in the United States meet the needs of individuals with SMA and other disabilities. Our principles and priorities in the 118th Congress include:



Enhance Disability-Focused Emergency Preparedness Resources: Emergency response and recovery efforts often overlook or fail to effectively meet the needs of people with disabilities, including individuals with SMA, who may need accessible options and specialized assistance during an emergency evacuation. *Cure SMA will support efforts, including dedicated technical assistance, resources, and disability-focused planning requirements, to improve emergency preparedness for people with SMA and other disabilities.*



Support the Post-Emergency Needs of People with Disabilities: Individuals with disabilities who are displaced from their home and community due to a natural disaster or other emergency must be supported to ensure they have full access to the services and supports they need to remain healthy and live independently. *Cure SMA will support efforts to ensure individuals with disabilities who are eligible for services and supports through Medicaid or other public programs are able to access those programs and services if they are forced to relocate to another state due to a natural disaster or national emergency.*



Promote Disability Representation on Emergency Planning Boards and Committees: Emergency response and recovery plans and efforts may lack knowledge and understanding of the needs of individuals with SMA and other disabilities in their community. *Cure SMA will support efforts to require that emergency planning boards and committees include members with disabilities or, at a minimum, collects the views and experiences of individuals with disabilities from their community as they develop and implement their emergency management strategies.*