

Overall, individuals with disabilities may 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 2020 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 117th 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.*



Strengthen Financial Security Tools: All individuals with SMA should have access to savings tools that allow them to save for their future without jeopardizing eligibility to healthcare or other essential services and supports. *Cure SMA will support efforts to expand access to ABLER accounts, which currently limits eligibility to individuals with SMA whose SMA symptom onset occurred before age 26 years.*