

Employment and Financial Security Principles and Priorities

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. SMA community principles and priorities 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 experience, 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 support for individuals with SMA through federal and state employment programs 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 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 asset or other eligibility requirements, that could unintentionally disincentivize 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 ABLE accounts and address harmful policies, including the Supplemental Security Income asset limit, that create barriers to financial independence.*