

# **WEST VIRGINIA LEGISLATURE**

## **2025 REGULAR SESSION**

**Introduced**

### **Senate Bill 654**

By Senator Takubo

[Introduced March 3, 2025; referred  
to the Committee on Health and Human Resources;  
and then to the Committee on Finance]

A BILL to amend the Code of West Virginia, 1931, as amended, by adding a new article, designated §9-11-1, §9-11-2, §9-11-3, §9-11-4, and §9-11-5, relating to the creation of the West Virginia ALS Care Services Act; listing findings and purpose; requiring Department of Human Services to provide care services coordination and support; providing access to assistive technology, medical equipment, and ramp loan programs; facilitating access to multidisciplinary ALS clinics; appropriating funds from the General Revenue Fund to support this act; and establishing an effective date.

*Be it enacted by the Legislature of West Virginia:*

**ARTICLE 11. WEST VIRGINIA ALS CARE SERVICES ACT.**

**§9-11-1. Short title.**

This act shall be known as the "West Virginia ALS Care Services Act".

**§9-11-2. Legislative findings and purpose.**

(a) The Legislature finds that individuals living with Amyotrophic Lateral Sclerosis (ALS) face significant financial and medical burdens, requiring targeted state support to improve their quality of life and to help them remain in their homes under family-based care.

(b) The purpose of this act is to establish programs that provide funding for ALS care services, assistive technology, durable medical equipment, and other essential resources to residents of West Virginia living with ALS and their caregivers.

(c) ALS clinics reduce the cost of care for Medicaid and other insurers by consolidating multidisciplinary services into a single location, thereby minimizing the need for repeated specialist visits and emergency room visits. By providing comprehensive, coordinated care, these clinics improve patient outcomes, reduce hospital admissions, and decrease reliance on costly long-term care facilities. Additionally, ALS clinics facilitate access to clinical trials and advanced treatment options, potentially slowing disease progression and reducing overall healthcare expenditures.

(d) The Ramp Reutilization Loan Program reduces burdens to West Virginia families living

15 with ALS and reduces demand for in-patient institutionalized care by providing cost-effective,  
16 reusable ramps that enable individuals with ALS to safely enter and exit their homes. Installing  
17 ramps can cost many thousands of dollars and is not typically covered by insurance, leaving many  
18 West Virginia families living with ALS unable to pay. Unable to pay for ramps, many individuals  
19 with ALS may be forced out of their homes and into institutionalized care or require emergency  
20 services for preventable falls and injuries. By allowing people to remain in their homes longer and  
21 reducing or delaying the need for assisted living arrangements, the program ultimately helps delay  
22 or eliminate the need for ALS patients to enroll in Medicaid, saving taxpayer money and reducing  
23 strain on state-funded healthcare and housing assistance programs.

24 (e) As the disease progresses, the needs of individuals living with ALS increase, making it  
25 critical to keep patients in their homes with family-based care. Home-based care improves patient  
26 outcomes, enhances emotional well-being, and reduces overall healthcare costs by preventing  
27 unnecessary hospitalizations and delaying or eliminating the need for long-term institutional care.  
28 By supporting in-home caregiving solutions, the state can ensure that individuals with ALS receive  
29 compassionate, cost-effective care in a familiar environment.

**§9-11-3. Establishment of ALS Care Services Program.**

1 (a) The Department of Human Services shall administer the West Virginia ALS Care  
2 Services Program and distribute funds to the ALS Association for implementation.

3 (b) The program shall provide funding for the following initiatives:

4 (1) Care Services Coordination and Support – Ensures that West Virginians living with ALS  
5 and their caregivers receive disease education, specialized support navigating complex systems,  
6 individualized resource linkage, and ongoing compassionate assistance. This initiative improves  
7 well-being and safety while reducing the emotional and financial burdens of ALS and enhancing  
8 overall quality of life.

9 (2) Assistive Technology, Medical Equipment, and Ramp Reutilization Loan Programs –  
10 Provides access to expensive but essential equipment for individuals with ALS and their

caregivers. These loan programs significantly enhance safety, independence, and the ability to remain in their home and community. By reducing the costs of care on state and federal programs and promoting the reuse of ramping materials and equipment, this initiative also has a positive environmental impact.

(3) Multidisciplinary ALS Clinics – Facilitates access to specialized multidisciplinary care that adheres to the highest clinical care and treatment standards. Research has demonstrated that multidisciplinary ALS clinic care extends life expectancy and improves quality of life. These clinics provide comprehensive family support, reduce the burden of care by addressing multiple needs in a single visit, and help lower healthcare costs for both individuals with ALS and state and federal programs.

**§9-11-4. Appropriation of funds.**

(a) The sum of \$250,000 shall be appropriated from the general revenue fund for Fiscal Year 2026 to implement the provisions of this act.

(b) The Department of Human Services shall ensure that funds are distributed equitably and shall provide an annual report to the Legislature detailing expenditures and program impact.

**§9-11-5. Effective Date.**

This act shall take effect upon passage.

NOTE: The purpose of this bill is to create the ALS Care Services Act.

Strike-throughs indicate language that would be stricken from a heading or the present law and underscoring indicates new language that would be added.