

AMENDMENTS TO LB376

Introduced by Health and Human Services.

1 1. Strike the original sections and insert the following new
2 sections:

3 Section 1. The Legislature finds and declares that:

4 (1) The family is vital to the fundamental development of each
5 person in the State of Nebraska;

6 (2) A growing number of families are searching for ways to provide
7 supports for disabled family members in the home rather than placing them
8 in state or private institutional or residential facilities;

9 (3) The informal support of family caregivers is the backbone of the
10 system of long-term care services, and the assistance provided to a
11 person with a disability is critical to the financial well-being of the
12 state, particularly when such assistance helps to defer a more costly
13 institutional or residential placement;

14 (4) Necessary services should be available to families caring for a
15 disabled family member so that disabled persons may remain in the home;

16 (5) The State of Nebraska should make every effort to preserve each
17 family unit having a child with disabilities, to ensure that decisions
18 regarding a child with disabilities are based on the best interests of
19 the child and the family, and to ensure that services are provided that
20 promote independent living, family-centered care, and individual choices;

21 (6) The State of Nebraska should promote cost-effective health care
22 alternatives for disabled persons and should maximize state, federal, and
23 private funding to ensure adequate health care supports and services are
24 available for children with disabilities and their families;

25 (7) Early intervention (a) has been shown to help a child with a
26 developmental delay, or at risk of a developmental delay, to acquire
27 skills during the most critical period of growth, (b) is a recognized

1 public health approach that helps to ensure that a child has access to
2 services and supports to help the child acquire living skills and
3 increase the likelihood that the child will be self-sufficient or have
4 less dependency on state services, and (c) is a less costly approach for
5 the use of limited state and federal resources;

6 (8) A child with disabilities often needs support after school and
7 during the evening, weekend, and summertime or other school breaks in
8 order to maximize the opportunities for socialization and community
9 integration and to allow family caregivers the ability to work, focus on
10 self-care, socialize, and participate in community integration;

11 (9) A family support waiver as proposed under section 2 of this act
12 will supplement the continuum of developmental disability services and
13 other state programming for children with disabilities, remediate current
14 program gaps, and offer a pathway for children with disabilities to gain
15 access to the medical assistance program and capped long-term services
16 and supports; and

17 (10) Providing support to family caregivers allows them to remain in
18 the workforce which in turn allows the state to benefit from the family
19 caregivers' private health insurance as a first payer.

20 Sec. 2. (1) The Department of Health and Human Services shall apply
21 for a three-year medicaid waiver under section 1915(c) of the Social
22 Security Act to administer a family support program which is a home and
23 community-based services program as provided in this section.

24 (2)(a) The Advisory Committee on Developmental Disabilities created
25 in section 83-1212.01 shall assist in the development and guide the
26 implementation of the family support program. The family support program
27 shall be administered by the Division of Developmental Disabilities of
28 the Department of Health and Human Services.

29 (b) It is the intent of the Legislature that any funds distributed
30 to Nebraska pursuant to section 9817 of the American Rescue Plan Act of
31 2021, Public Law 117-2, be used to eliminate unmet needs relating to home

1 and community-based services for persons with developmental disabilities
2 as much as is possible.

3 (c) If funds are distributed to Nebraska pursuant to section 9817 of
4 the American Rescue Plan Act of 2021, it is the intent of the Legislature
5 that such funds distributed to Nebraska should at least partially fund
6 the family support program if doing so is in accordance with federal law,
7 rules, regulations, or guidance.

8 (3) The family support program shall:

9 (a) Offer an annual capped budget for long-term services and
10 supports of ten thousand dollars for each eligible applicant;

11 (b) Offer a pathway for medicaid eligibility for disabled children
12 by disregarding parental income and establishing eligibility based on a
13 child's income and assets;

14 (c) Allow a family to self-direct services, including contracting
15 for services and supports approved by the division; and

16 (d) Not exceed eight hundred fifty participants.

17 (4) The department, in consultation with the advisory committee,
18 shall adopt and promulgate rules and regulations for the implementation
19 of the family support program to be set at an intermediate care facility
20 institutional level of care to support children with intellectual and
21 developmental disabilities and their families. Such rules and regulations
22 shall include, but not be limited to:

23 (a) Criteria for and types of long-term services and supports to be
24 provided by the family support program;

25 (b) The method for allocating resources to family units
26 participating in the family support program;

27 (c) Eligibility determination, including, but not limited to, a
28 child's maximum income and assets;

29 (d) The enrollment process;

30 (e) Limits on benefits; and

31 (f) Processes to establish quality assurance, including, but not

1 limited to, measures of family satisfaction.

2 (5) The division shall administer the family support program within
3 the limits of the appropriations by the Legislature for such program.

4 (6) The division shall submit an annual report electronically to the
5 Legislature on the family support program. The report shall include:

6 (a) The distribution of available funds, the total number of
7 children and families served, and the status of the waiting list for the
8 comprehensive waiver and other applicable waivers;

9 (b) A summary of any grievances filed by family units pertaining to
10 the family support program, including any appeals and a description of
11 how such grievances were resolved;

12 (c) The number and demographics of children with disabilities and
13 their families who applied under the family support program but who were
14 not found eligible and the reason such children and their families were
15 not found eligible;

16 (d) Quality assurance activities and the results of annual measures
17 of family satisfaction; and

18 (e) Recommendations to innovate the family support program, improve
19 current programming, and maximize limited funding, including, but not
20 limited to, the potential utilization of other medicaid pathways or
21 medicaid waivers that could help increase access to medicaid and long-
22 term services and supports for children with disabilities or special
23 health care needs.

24 Sec. 3. In order to be eligible for services and support under
25 section 2 of this act:

26 (1) The child shall reside in the State of Nebraska;

27 (2) The income and assets of the child shall not exceed the maximum
28 established under subsection (4) of section 2 of this act;

29 (3) The child shall have a medically determinable physical or mental
30 impairment or combination of impairments that (a) causes marked and
31 severe functional limitations and (b) can be expected to cause death or

1 has lasted or can be expected to last for a continuous period of not less
2 than twelve months; and

3 (4) The child shall be determined to meet the intermediate care
4 facility institutional level of care criteria as set forth in subsection
5 (4) of section 2 of this act.

6 Sec. 4. The Department of Health and Human Services shall allocate
7 medicaid waiver benefits under section 2 of this act based on
8 appropriations by the Legislature for such waiver and give priority
9 status in the following order:

10 (1) First, to disabled children and family units in crisis
11 situations in which the disabled child tends to self-injure or injure
12 siblings and other family members;

13 (2) Second, to disabled children who are at risk for placement in
14 juvenile detention centers, other institutional settings, or out-of-home
15 placements;

16 (3) Third, to disabled children whose primary caretakers are
17 grandparents because no other family caregivers are available to provide
18 care;

19 (4) Fourth, to families who have more than one disabled child
20 residing in the family home; and

21 (5) Fifth, based on the date of application under the family support
22 program.

23 Sec. 5. The Department of Health and Human Services shall
24 collaborate with a private, nonprofit organization with expertise in
25 developmental disabilities for an independent evaluation of the family
26 support program set forth in section 2 of this act if private funding is
27 made available for such purpose. The evaluation shall be completed by
28 December 15, 2023, and shall be submitted electronically to the
29 department and to the Health and Human Services Committee of the
30 Legislature.

31 Sec. 6. Section 83-1212.01, Revised Statutes Cumulative Supplement,

1 2020, is amended to read:

2 83-1212.01 (1) There is hereby created the Advisory Committee on
3 Developmental Disabilities. The advisory committee shall consist of a
4 representative of a statewide advocacy organization for persons with
5 developmental disabilities and their families, a representative of
6 Nebraska's designated protection and advocacy organization, a
7 representative of the Nebraska Planning Council on Developmental
8 Disabilities, a representative of the University Center for Excellence in
9 Developmental Disability Education, Research and Service as defined in
10 section 68-1114, and not more than fifteen additional members. At least
11 fifty-one percent of the members shall be persons with developmental
12 disabilities and family members of persons with developmental
13 disabilities.

14 (2) The members shall be appointed by the Governor for staggered
15 terms of three years. Any vacancy shall be filled by the Governor for the
16 remainder of the term. One of the members shall be designated as
17 chairperson by the Governor. Members shall be reimbursed for expenses as
18 provided in sections 81-1174 to 81-1177.

19 (3) The advisory committee shall advise the department regarding all
20 aspects of the funding and delivery of services to persons with
21 developmental disabilities.

22 (4) The advisory committee shall (a) provide sufficient oversight to
23 ensure that persons placed in the custody of the department under the
24 Developmental Disabilities Court-Ordered Custody Act are receiving the
25 least restrictive treatment and services necessary, ~~and~~ (b) oversee the
26 design and implementation of the quality management and improvement plan
27 described in section 83-1216.01, and (c) assist, provide feedback, and
28 guide the implementation of the family support program under section 2 of
29 this act.

30 (5) The department shall inform the advisory committee of proposed
31 systemic changes to services for persons with developmental disabilities

1 at least thirty days prior to implementation of the changes so that the
2 advisory committee may provide for a response to the proposed changes. If
3 the director determines that circumstances require implementation of the
4 changes prior to such notice, the department shall inform the advisory
5 committee as soon as possible. The advisory committee, in partnership
6 with the director, shall establish criteria for the process of providing
7 the information and receiving the response.

8 Sec. 7. Original section 83-1212.01, Revised Statutes Cumulative
9 Supplement, 2020, is repealed.