

LEGISLATURE OF NEBRASKA
ONE HUNDRED SEVENTH LEGISLATURE
FIRST SESSION

LEGISLATIVE BILL 376

Introduced by Cavanaugh, M., 6; Walz, 15.

Read first time January 13, 2021

Committee: Health and Human Services

- 1 A BILL FOR AN ACT relating to developmental disabilities; to amend
2 section 83-1212.01, Revised Statutes Cumulative Supplement, 2020; to
3 state intent; to authorize the application for and implementation of
4 services and supports for developmentally disabled children and
5 their families; to provide for a report; to provide duties for the
6 Advisory Committee on Developmental Disabilities; and to repeal the
7 original section.
- 8 Be it enacted by the people of the State of Nebraska,

1 Section 1. The Legislature finds and declares that:

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

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

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

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

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

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

24 (7) Early intervention (a) has been shown to help a child with a
25 developmental delay, or at risk of a developmental delay, to acquire
26 skills during the most critical period of growth, (b) is a recognized
27 public health approach that helps to ensure that a child has access to
28 services and supports to help the child acquire living skills and
29 increase the likelihood that the child will be self-sufficient or have
30 less dependency on state services, and (c) is a less costly approach for
31 the use of limited state and federal resources;

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

6 (9) A family support waiver as proposed section 2 of this act will
7 supplement the continuum of developmental disability services and other
8 state programming for children with disabilities, remediate current
9 program gaps, decrease the state's current waiting list for home and
10 community-based services, and offer a pathway for children with
11 disabilities to gain access to the medical assistance program and capped
12 long-term services and supports; and

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

16 Sec. 2. (1) The Department of Health and Human Services shall apply
17 for a waiver to administer a pilot family support program which is a home
18 and community-based services program. The Advisory Committee on
19 Developmental Disabilities created in section 83-1212.01 shall develop
20 and guide the implementation of the pilot family support program. The
21 pilot family support program shall be administered by the Division of
22 Developmental Disabilities of the Department of Health and Human
23 Services.

24 (2) The pilot family support program shall:

25 (a) Offer an annual capped budget for long-term services and
26 supports of twelve thousand dollars;

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

30 (c) Allow a family to self-direct services, including contracting
31 for services and supports approved by the division.

1 (3) The department, in consultation with the advisory committee,
2 shall adopt and promulgate rules and regulations for the implementation
3 of the pilot family support program, including, but not limited to:

4 (a) Criteria and types of long-term services and supports provided
5 by the family support program;

6 (b) Methodology for allocating resources to family units for the
7 family support program;

8 (c) Eligibility determinations and enrollment;

9 (d) Limits on benefits; and

10 (e) Processes to establish quality assurance, including family
11 satisfaction.

12 (4) The division shall administer the pilot family support program
13 within the limit of the appropriation for the program. The division shall
14 establish annual benefit levels for family units.

15 (5) The division shall submit an annual report electronically to the
16 Legislature on the pilot family support program. The report shall
17 include:

18 (a) The distribution of available funds, the total number of
19 children and families served, and the status of the waiting list;

20 (b) A summary of any grievances filed by family units pertaining to
21 actions of the pilot family support program, including appeals and
22 resolution;

23 (c) Quality assurance activities and results of annual family
24 satisfaction; and

25 (d) Recommendations to innovate the program, improve current
26 programming, and maximize limited funding.

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

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

30 (2) The income and assets of the child shall be no more than is
31 allowed to qualify under the annual benefit levels established under

1 subsection (4) of section 2 of this act; and

2 (3) The child shall be a child who has a medically determinable
3 physical or mental impairment or combination of impairments that (a)
4 causes marked and severe functional limitations and (b) can be expected
5 to cause death or has lasted or can be expected to last for a continuous
6 period of not less than twelve months.

7 Sec. 4. The Department of Health and Human Services shall allocate
8 waiver slots based on appropriations for the waiver and give priority
9 status in the following order to:

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

13 (2) Second, 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, disabled children whose primary caretakers are
17 grandparents because no other family caregivers are available to provide
18 care;

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

21 (5) Fifth, date of application under the pilot program.

22 Sec. 5. Section 83-1212.01, Revised Statutes Cumulative Supplement,
23 2020, is amended to read:

24 83-1212.01 (1) There is hereby created the Advisory Committee on
25 Developmental Disabilities. The advisory committee shall consist of a
26 representative of a statewide advocacy organization for persons with
27 developmental disabilities and their families, a representative of
28 Nebraska's designated protection and advocacy organization, a
29 representative of the Nebraska Planning Council on Developmental
30 Disabilities, a representative of the University Center for Excellence in
31 Developmental Disability Education, Research and Service as defined in

1 section 68-1114, and not more than fifteen additional members. At least
2 fifty-one percent of the members shall be persons with developmental
3 disabilities and family members of persons with developmental
4 disabilities.

5 (2) The members shall be appointed by the Governor for staggered
6 terms of three years. Any vacancy shall be filled by the Governor for the
7 remainder of the term. One of the members shall be designated as
8 chairperson by the Governor. Members shall be reimbursed for expenses as
9 provided in sections 81-1174 to 81-1177.

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

13 (4) The advisory committee shall (a) provide sufficient oversight to
14 ensure that persons placed in the custody of the department under the
15 Developmental Disabilities Court-Ordered Custody Act are receiving the
16 least restrictive treatment and services necessary, ~~and~~ (b) oversee the
17 design and implementation of the quality management and improvement plan
18 described in section 83-1216.01, and (c) develop and guide the
19 implementation of the pilot family support program under section 2 of
20 this act.

21 (5) The department shall inform the advisory committee of proposed
22 systemic changes to services for persons with developmental disabilities
23 at least thirty days prior to implementation of the changes so that the
24 advisory committee may provide for a response to the proposed changes. If
25 the director determines that circumstances require implementation of the
26 changes prior to such notice, the department shall inform the advisory
27 committee as soon as possible. The advisory committee, in partnership
28 with the director, shall establish criteria for the process of providing
29 the information and receiving the response.

30 Sec. 6. Original section 83-1212.01, Revised Statutes Cumulative
31 Supplement, 2020, is repealed.