LEGISLATURE OF NEBRASKA

ONE HUNDRED SIXTH LEGISLATURE

SECOND SESSION

LEGISLATIVE BILL 1204

Introduced by Cavanaugh, 6.

Read first time January 23, 2020

Committee: Health and Human Services

1 A BILL FOR AN ACT relating to the Disabled Persons and Family Support Act; to amend sections 68-1501, 68-1502, 68-1503, 68-1505, 68-1506, 2 3 68-1508, 68-1510, 68-1511, 68-1512, 68-1513, 68-1515, 68-1516, 4 68-1518, and 68-1519, Reissue Revised Statutes of Nebraska, and section 83-1212.01, Revised Statutes Cumulative Supplement, 2018; to 5 6 define and redefine terms; to require submission of a waiver 7 application; to provide for a family support program; to provide 8 powers and duties; to harmonize provisions; and to repeal the 9 original sections.

10 Be it enacted by the people of the State of Nebraska,

1 Section 1. Section 68-1501, Reissue Revised Statutes of Nebraska, is

- 2 amended to read:
- 3 68-1501 Sections 68-1501 to 68-1519 <u>and section 4 of this act</u>shall
- 4 be known and may be cited as the Disabled Persons and Family Support Act.
- 5 Sec. 2. Section 68-1502, Reissue Revised Statutes of Nebraska, is
- 6 amended to read:
- 7 68-1502 The Legislature finds and declares that:
- 8 $\hspace{0.1in}$ (1) The family is vital to the fundamental development of each
- 9 person in the State of Nebraska;
- 10 (2) A growing number of families are searching for ways to provide
- 11 <u>supports</u> for disabled family members in the home rather than placing them
- 12 in state or private institutional or residential facilities;
- 13 (3) Employable disabled persons should be encouraged to engage in
- 14 employment and ultimately become self-supporting;
- 15 (4) Necessary services should be available to families caring for a
- 16 disabled family member so that disabled persons may remain in the home,
- 17 obtain employment if possible, and maintain a more independent form of
- 18 living;
- 19 (5) Families that have children with disabilities should have access
- 20 to supports and services that allow the family members to maintain
- 21 employment, including a pathway to eligibility under the medical
- 22 assistance program for the child with disabilities that does not consider
- 23 parental income and provides long-term services and supports, such as
- 24 <u>respite</u>, <u>specialized child care</u>, <u>and home modifications</u>;
- 25 (6) Necessary services should be available for a child with
- 26 <u>disabilities</u> so that the child with <u>disabilities</u> may access early
- 27 intervention services and other medically necessary services, the child
- 28 may remain in the child's home, the family unit may remain intact, and
- 29 the family caregiver may maintain employment;
- 30 (7) (5) The State of Nebraska should make every effort to preserve
- 31 the family unit, to ensure insure that decisions of providing for a

- 1 disabled person are based on the best interests of the disabled person
- 2 and the family, and to provide services to disabled persons which promote
- 3 independent living and employability; and
- 4 (8) The State of Nebraska should make every effort to preserve a
- 5 family unit with a child with disabilities, to ensure that decisions of
- 6 providing for a child with disabilities are based on the best interests
- 7 of the child and the family, and to ensure that services are provided
- 8 that promote independent living, family-centered care, and choice;
- 9 (9) (6) The State of Nebraska should promote cost-effective health
- 10 care alternatives for disabled persons and should maximize state funding
- 11 <u>to ensure adequate health care supports and services are available for</u>
- 12 <u>children with disabilities and their families;</u> -
- 13 <u>(10) The informal supports of family caregivers are the backbone of</u>
- 14 the system of long-term care services and the assistance provided by
- 15 <u>family to a family unit is critical to the financial well-being of the</u>
- 16 state because such assistance helps to defer more costly institutional or
- 17 residential placement;
- 18 (11) A child with disabilities often needs support after school and
- 19 during the evening, weekend, and summer time or other school breaks, in
- 20 order to maximize the opportunities for socialization and community
- 21 <u>integration</u> and to allow family caregivers to work and access
- 22 socialization and community integration;
- 23 (12) Early intervention (a) has been shown to help a child with a
- 24 <u>developmental delay or at risk of a developmental delay to acquire living</u>
- 25 skills, (b) is a recognized public health approach that helps to ensure
- 26 that a child has access to services and supports to help the child
- 27 <u>acquire living skills and increase the likelihood that the child will</u>
- 28 eventually be self-sufficient or have less dependency on state services,
- 29 and (c) is a least costly approach for use of limited state and federal
- 30 <u>resources; and</u>
- 31 (13) A family support waiver under the medical assistance program is

- 1 one method of supplementing the continuum of developmental disability
- 2 services and other state programming for children with disabilities,
- 3 remediates current program gaps, decreases the state's current waiting
- 4 list for home and community-based services, and offers a pathway for
- 5 children with disabilities to gain access to the medical assistance
- 6 program and long-term services and supports.
- 7 Sec. 3. Section 68-1503, Reissue Revised Statutes of Nebraska, is
- 8 amended to read:
- 9 68-1503 For purposes of the Disabled Persons and Family Support Act:
- 10 (1) Department means the Division of Developmental Disabilities of
- 11 the Department of Health and Human Services;
- 12 (2) Disabled child means a person who is younger than twenty-two
- 13 years of age and who has a medically determinable severe, chronic
- 14 <u>disability which:</u>
- 15 (a) Is attributable to a mental or physical impairment or
- 16 combination of mental and physical impairments;
- 17 (b) Is likely to continue indefinitely;
- 18 (c) Results in substantial functional limitations in two or more of
- 19 the following areas of major life activity: (i) Self-care, (ii) receptive
- 20 and expressive language, (iii) learning, (iv) mobility, (v) self-
- 21 direction, (vi) capacity for independent living, (vii) work skills or
- 22 work tolerance, and (viii) economic sufficiency; and
- 23 (d) Reflects the person's need for a combination and sequence of
- 24 <u>special, interdisciplinary, or generic care, treatment, voca</u>tional
- 25 rehabilitation, or other services which are of lifelong or extended
- 26 duration and are individually planned and coordinated;
- 27 $\underline{(3)}$ (2) Disabled family member or disabled person means a person who
- 28 has a medically determinable severe, chronic disability which:
- 29 (a) Is attributable to a mental or physical impairment or
- 30 combination of mental and physical impairments;
- 31 (b) Is likely to continue indefinitely;

- 1 (c) Results in substantial functional limitations in two or more of
- 2 the following areas of major life activity: (i) Self-care, (ii) receptive
- 3 and expressive language, (iii) learning, (iv) mobility, (v) self-
- 4 direction, (vi) capacity for independent living, (vii) work skills or
- 5 work tolerance, and (viii) economic sufficiency; and
- 6 (d) Reflects the person's need for a combination and sequence of
- 7 special, interdisciplinary, or generic care, treatment, vocational
- 8 rehabilitation, or other services which are of lifelong or extended
- 9 duration and are individually planned and coordinated;—and
- 10 (4) Family unit means a social unit that consists of a disabled
- 11 <u>child and the parent, relative, or other caregiver who resides in the</u>
- 12 same household as the disabled child;
- 13 (5) Medical assistance program means the program established
- 14 pursuant to section 68-903; and
- 15 (6) (3) Other support programs means all forms of local, state, or
- 16 federal assistance, grants-in-aid, educational programs, or support
- 17 provided by public or private funds for disabled persons or their
- 18 families.
- 19 Sec. 4. (1) The department shall apply for the family support
- 20 waiver under the medical assistance program and establish a pilot family
- 21 <u>support program. The Advisory Committee on Developmental Disabilities</u>
- 22 established under section 83-1212.01 shall oversee the waiver and the
- 23 <u>pilot program.</u>
- 24 (2) The department, in consultation with the advisory committee,
- 25 shall adopt and promulgate rules and regulations for implementation of
- 26 the pilot family support program under the family support waiver,
- 27 including, but not limited to:
- 28 (a) Program specifications, including:
- 29 <u>(i) Criteria for services provided by the pilot family support</u>
- 30 <u>program;</u>
- 31 (ii) Methodology for allocating resources to family units within the

- 1 appropriations for the pilot family support program;
- 2 (iii) Eligibility determinations and enrollment; and
- 3 (iv) Limits on benefits;
- 4 (b) Coordination of the pilot family support program and the use of
- 5 available funds equitably throughout the state, with other publicly
- 6 funded programs, including other resources of the medical assistance
- 7 program;
- 8 (c) Resolution of any grievance filed by a family unit pertaining to
- 9 actions of the pilot family support program, including appeals;
- 10 <u>(d) Quality assurance; and</u>
- 11 (e) Annual evaluation of services, including consumer satisfaction.
- 12 (3) The department shall administer the pilot family support program
- 13 within the limit of the appropriation for the program. The department
- 14 <u>shall establish annual benefit levels for family units.</u>
- 15 (4) Any person contracting with the department to provide any
- 16 service or support under the pilot family support program shall report
- 17 information gathered regarding the family units served to the department
- 18 on at least a quarterly basis in the manner required by the department.
- 19 (5)(a) Eligibility requirements for the pilot program shall include
- 20 the requirements of sections 68-1505 and 68-1506 as modified by the
- 21 <u>family support waiver</u>. Program eligibility shall be determined by the
- 22 assets of the disabled child and the child's eligibility for the medical
- assistance program and eligibility for the family support waiver.
- 24 <u>(b) A family may self-direct services under the pilot program as</u>
- 25 authorized by the family support waiver, including contracting for
- 26 services and supports approved by the department.
- 27 (c) The maximum support allowable under the family support waiver
- 28 shall be twelve thousand dollars annually.
- 29 <u>(d) The department shall review the needs of each family unit</u>
- 30 annually or upon the showing of a change in circumstances of the disabled
- 31 child or the family unit.

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- 1 (e) From July 1, 2020, through July 1, 2024, the department shall 2 provide support on a priority basis to disabled children and family units eligible to receive support pursuant to the pilot program. The department 3 4 shall allocate waiver slots based on appropriations for the waiver and 5 give priority status to (i) disabled children and family units in crisis situations in which the disabled child tends to self-injure or provides 6 injury to siblings and other family members, (ii) disabled children who 7 are at risk for placement in juvenile detention centers, other 8 9 institutional settings, or out-of-home placements, (iii) disabled 10 children whose primary caretakers are grandparents because no other family caregiver is available to provide care, (iv) families who have 11 more than one disabled child residing in the family home, and (v) other 12
- (6) The provisions of the Disabled Persons and Family Support Act
 shall apply to applicants under the pilot program except as otherwise
 specifically provided in this section and the family support waiver.

family units based on the date of application under the pilot program.

- Sec. 5. Section 68-1505, Reissue Revised Statutes of Nebraska, is amended to read:
- Disabled Persons and Family Support Act sections 68-1501 to 68-1519 if the family (1) resides in the State of Nebraska, (2) has a family member who is disabled and is (a) living at home or (b) residing in a state or private institutional or residential facility but could return home under the act sections 68-1501 to 68-1519, and (3) has insufficient income to provide for the total cost of care for the disabled family member.
- Sec. 6. Section 68-1506, Reissue Revised Statutes of Nebraska, is amended to read:
- 68-1506 A disabled person in an independent living situation may be eligible to receive support pursuant to the Disabled Persons and Family

 Support Act sections 68-1501 to 68-1519 if the person (1) is a resident of the State of Nebraska, (2) requires care to remain within an

- 1 independent living situation, and (3) has insufficient income to provide
- 2 for the total cost of such care.
- 3 Sec. 7. Section 68-1508, Reissue Revised Statutes of Nebraska, is
- 4 amended to read:
- 5 68-1508 The department may allocate costs for programs and services
- 6 between the department and the family or the disabled person in an
- 7 independent living situation. Such cost allocation shall be based on the
- 8 need for support pursuant to the Disabled Persons and Family Support Act
- 9 sections 68-1501 to 68-1519 and shall not be based on income guidelines
- 10 or fee schedules established for other programs administered by the
- 11 department.
- 12 Sec. 8. Section 68-1510, Reissue Revised Statutes of Nebraska, is
- 13 amended to read:
- 14 68-1510 The support available under the Disabled Persons and Family
- 15 Support Act sections 68-1501 to 68-1519 shall be supplemental to other
- 16 support programs for which the family or disabled person is eligible and
- 17 is not intended to reduce the responsibility for the provision of
- 18 services and support by such other programs. The department shall (1)
- 19 determine whether any request under the act sections 68-1501 to 68-1519
- 20 is appropriate to and available from other support programs, (2) deny any
- 21 request if the requested assistance is appropriate to and available from
- 22 other support programs, and (3) provide information and referral to all
- 23 families and disabled persons whose request for assistance was denied
- 24 pursuant to this section on the procedure for applying for other
- 25 appropriate and available support programs.
- Sec. 9. Section 68-1511, Reissue Revised Statutes of Nebraska, is
- 27 amended to read:
- 28 68-1511 The department may, by agreement with the head of the family
- 29 or disabled person, provide support pursuant to the Disabled Persons and
- 30 Family Support Act sections 68-1501 to 68-1519 (1) directly to the family
- 31 or the disabled person, or (2) directly to qualified programs and

- 1 services. The department shall assist each family or disabled person
- 2 receiving support under the act sections 68-1501 to 68-1519 in locating
- 3 qualified programs and services. The family or the disabled person may be
- 4 required to be responsible for contracting for those programs and
- 5 services which the department approves and shall furnish the department a
- 6 copy of each contract. The family or the disabled person may compensate
- 7 the providers of such programs and services directly. Providers of
- 8 programs and services shall be required to comply with all standards
- 9 established by the department for participation pursuant to the act
- 10 sections 68-1501 to 68-1519.
- 11 Sec. 10. Section 68-1512, Reissue Revised Statutes of Nebraska, is
- 12 amended to read:
- 13 68-1512 The maximum support allowable under the Disabled Persons and
- 14 Family Support Act sections 68-1501 to 68-1519 shall be (1) three hundred
- 15 dollars per month per disabled person averaged over any one-year period
- or (2) three hundred dollars per month per family averaged over any one-
- 17 year period for the first disabled family member plus one hundred fifty
- 18 dollars per month averaged over any one-year period for each additional
- 19 disabled family member. The department shall not provide support,
- 20 pursuant to the act sections 68-1501 to 68-1519, to any family or
- 21 disabled person whose gross income less the cost of medical or other care
- 22 specifically related to the disability exceeds the median family income
- 23 for a family of four in Nebraska, except that the department shall make
- 24 adjustments for the actual size of the family.
- 25 Sec. 11. Section 68-1513, Reissue Revised Statutes of Nebraska, is
- 26 amended to read:
- 27 68-1513 The department shall review the needs of each family or
- 28 disabled person receiving support under the Disabled Persons and Family
- 29 Support Act sections 68-1501 to 68-1519 on a regular basis, as
- 30 established by the department, or upon the showing of a change of
- 31 circumstances by the head of the family.

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1 Sec. 12. Section 68-1515, Reissue Revised Statutes of Nebraska, is

- 2 amended to read:
- 3 68-1515 The department shall adopt and promulgate rules and
- 4 regulations, as necessary, to implement the Disabled Persons and Family
- 5 Support Act sections 68-1501 to 68-1519, including:
- 6 (1) Standards and procedures for determining approval of qualified
- 7 programs and services to participate under the act sections 68-1501 to
- 8 68-1519;
- 9 (2) Identification of the need for programs and services of families
- 10 providing for a disabled family member in the home or of disabled persons
- in an independent living situation;
- 12 (3) Identification of the need for support to families and disabled
- 13 persons and procedures for the provision of support under the act
- 14 sections 68-1501 to 68-1519;
- 15 (4) Procedures for review of each family or disabled person
- 16 receiving support under the act sections 68-1501 to 68-1519;
- 17 (5) Procedures and quidelines for determining priorities,
- 18 eligibility standards, and eligibility criteria for the selection of
- 19 families and disabled persons to participate in programs pursuant to the
- 20 <u>act sections 68-1501 to 68-1519;</u>
- 21 (6) Procedures and guidelines for determining when support pursuant
- 22 to the act sections 68-1501 to 68-1519 would be a duplication of support
- 23 from other support programs or would result in excessive support to a
- 24 family or disabled person; and
- 25 (7) An annual determination of the family income guidelines
- 26 necessary to carry out the provisions of section 68-1512. Such quidelines
- 27 shall be based on population, per capita income, and other data provided
- 28 by the United States Department of Commerce, Bureau of the Census.
- 29 Sec. 13. Section 68-1516, Reissue Revised Statutes of Nebraska, is
- 30 amended to read:
- 31 68-1516 The department shall begin providing support pursuant to the

- 1 <u>Disabled Persons and Family Support Act</u> sections 68-1501 to 68-1519 on
- 2 July 1, 1982. From July 1, 1982, to July 1, 1986, the department shall
- 3 provide support on a priority basis to families and disabled persons
- 4 eligible to receive support pursuant to the act sections 68-1501 to
- 5 68-1519. The department shall give priority to those families providing
- 6 for a severely or multiple disabled family member and to severely or
- 7 multiple disabled persons in independent living situations. Priority
- 8 shall also be given to those families and disabled persons (1) with the
- 9 greatest need for support to maintain the disabled person in the family
- 10 home or independent living situation, (2) who have the greatest
- 11 possibility of maintaining the disabled person in the home or independent
- 12 living situation on a continual basis, and (3) who demonstrate that
- 13 support pursuant to the act sections 68-1501 to 68-1519 will provide the
- 14 most cost-effective form of care for the disabled person.
- 15 Sec. 14. Section 68-1518, Reissue Revised Statutes of Nebraska, is
- 16 amended to read:
- 17 68-1518 The department shall file an annual report with the Governor
- 18 and the Clerk of the Legislature on or before January 1 of each year
- 19 beginning January 1, 1983. The report submitted to the Clerk of the
- 20 Legislature shall be submitted electronically. Such report shall include:
- 21 (1) The number of families and disabled persons applying for support
- 22 pursuant to the Disabled Persons and Family Support Act and the number of
- 23 families and disabled persons receiving support pursuant to the act;
- 24 (2) The types of services and programs being applied for and those
- 25 being provided through the act;
- 26 (3) The effects of the support provided under the act on the
- 27 disabled and their families;—and
- 28 (4) The status of the waiver application under section 4 of this
- 29 <u>act; and</u>
- 30 (5) (4) Any proposals for amendment of the act.
- 31 Sec. 15. Section 68-1519, Reissue Revised Statutes of Nebraska, is

- 1 amended to read:
- 2 68-1519 Any person who by means of a willfully false statement or
- 3 representation, or by impersonation or other device, obtains or attempts
- 4 to obtain, or who aids or abets any other person in obtaining support
- 5 under the Disabled Persons and Family Support Act sections 68-1501 to
- 6 68-1519 shall, upon conviction thereof, be punished pursuant to section
- 7 68-1017.
- 8 Sec. 16. Section 83-1212.01, Revised Statutes Cumulative Supplement,
- 9 2018, is amended to read:
- 10 83-1212.01 (1) There is hereby created the Advisory Committee on
- 11 Developmental Disabilities. The advisory committee shall consist of a
- 12 representative of a statewide advocacy organization for persons with
- 13 developmental disabilities and their families, a representative of
- 14 Nebraska's designated protection and advocacy organization, a
- 15 representative of the Nebraska Planning Council on Developmental
- 16 Disabilities, a representative of the University Center for Excellence in
- 17 Developmental Disability Education, Research and Service as defined in
- 18 section 68-1114, and not more than fifteen additional members. At least
- 19 fifty-one percent of the members shall be persons with developmental
- 20 disabilities and family members of persons with developmental
- 21 disabilities.
- 22 (2) The members shall be appointed by the Governor for staggered
- 23 terms of three years. Any vacancy shall be filled by the Governor for the
- 24 remainder of the term. One of the members shall be designated as
- 25 chairperson by the Governor. Members shall be reimbursed for their actual
- 26 and necessary expenses as provided in sections 81-1174 to 81-1177.
- 27 (3) The advisory committee shall advise the department regarding all
- 28 aspects of the funding and delivery of services to persons with
- 29 developmental disabilities.
- 30 (4) The advisory committee shall (a) provide sufficient oversight to
- 31 ensure that persons placed in the custody of the department under the

- 1 Developmental Disabilities Court-Ordered Custody Act are receiving the
- 2 least restrictive treatment and services necessary and (b) oversee the
- 3 design and implementation of the quality management and improvement plan
- 4 described in section 83-1216.01.
- 5 (5) The department shall inform the advisory committee of proposed
- 6 systemic changes to services for persons with developmental disabilities
- 7 at least thirty days prior to implementation of the changes so that the
- 8 advisory committee may provide for a response to the proposed changes. If
- 9 the director determines that circumstances require implementation of the
- 10 changes prior to such notice, the department shall inform the advisory
- 11 committee as soon as possible. The advisory committee, in partnership
- 12 with the director, shall establish criteria for the process of providing
- 13 the information and receiving the response.
- 14 (6) The advisory committee shall provide assistance to the
- department in administering the waiver under section 4 of this act.
- 16 Sec. 17. Original sections 68-1501, 68-1502, 68-1503, 68-1505,
- 17 68-1506, 68-1508, 68-1510, 68-1511, 68-1512, 68-1513, 68-1515, 68-1516,
- 18 68-1518, and 68-1519, Reissue Revised Statutes of Nebraska, and section
- 19 83-1212.01, Revised Statutes Cumulative Supplement, 2018, are repealed.