

LEGISLATIVE BILL 376

Approved by the Governor April 19, 2022

Introduced by Cavanaugh, M., 6; Walz, 15; Cavanaugh, J., 9; Hansen, B., 16; Blood, 3.

A BILL FOR AN ACT relating to developmental disabilities; to amend sections 83-1201 and 83-1212.01, Revised Statutes Cumulative Supplement, 2020; to state findings and declarations; to require application for and implementation of services and supports for children with disabilities and their families as prescribed; to require reports and evaluations; to provide powers and duties; to harmonize provisions; and to repeal the original sections.

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

Section 1. The Legislature finds and declares that:

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

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

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

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

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

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

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

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

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

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

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

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

(b) It is the intent of the Legislature that any funds distributed to Nebraska pursuant to section 9817 of the federal American Rescue Plan Act of 2021, Public Law 117-2, be used to eliminate unmet needs relating to home and community-based services for persons with developmental disabilities as much as is possible.

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

(3) The family support program shall:

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

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

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

(d) Not exceed eight hundred fifty participants.

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

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

(b) The method, as provided in section 4 of this act, for allocating resources to family units participating in the family support program;

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

(d) The enrollment process;

(e) Limits on benefits; and

(f) Processes to establish quality assurance, including, but not limited to, measures of family satisfaction.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Sec. 5. If the federal Centers for Medicare and Medicaid Services denies the 1915(c) waiver required to be submitted in section 2 of this act, the family support program outlined in sections 2 to 4 of this act shall not be implemented until such waiver or other mechanism authorizing the program is approved. The Department of Health and Human Services shall submit a new waiver application or seek other mechanisms for approval if such application is denied.

Sec. 6. The Department of Health and Human Services shall collaborate with a private, nonprofit organization with expertise in developmental disabilities for an independent evaluation of the family support program set

forth in section 2 of this act if private funding is made available for such purpose. The evaluation shall be completed by December 15, 2023, and shall be submitted electronically to the department and to the Health and Human Services Committee of the Legislature.

Sec. 7. Section 83-1201, Revised Statutes Cumulative Supplement, 2020, is amended to read:

83-1201 Sections 83-1201 to 83-1227 and section 8 of this act shall be known and may be cited as the Developmental Disabilities Services Act.

Sec. 8. (1) The Department of Health and Human Services shall engage a nationally recognized consultant to provide an evaluation of the state's developmental disabilities system in order to examine how the State of Nebraska can better serve all Nebraskans with a variety of developmental disabilities.

(2) The consultant shall be independent of the Department of Health and Human Services and be a national entity that can demonstrate:

(a) Direct involvement with public and tribal developmental disabilities agencies;

(b) Partnerships with national advocacy organizations, think tanks, or technical assistance providers for persons with developmental disabilities;

(c) Collaboration with community agencies for persons with developmental disabilities; and

(d) Independent research regarding developmental disabilities.

(3) The evaluation shall analyze the array of services and programs existing in Nebraska for persons with developmental disabilities and address potential areas for improvement with an emphasis on maximizing impact, effectiveness, and cost-efficiencies. The evaluation shall consider: (a) Services offered and provided by the state through the medicaid state plan or by current medicaid waivers; (b) services offered by other states through medicaid state plans, medicaid waivers, or other mechanisms; and (c) any other areas which may be beneficial to the state in the assessment of its developmental disabilities services.

(4) The consultant shall electronically deliver a report detailing the findings and recommendations of the consultant to the Governor, the Department of Health and Human Services, the chairperson of the Health and Human Services Committee of the Legislature, and the Clerk of the Legislature on or before December 31, 2023.

Sec. 9. Section 83-1212.01, Revised Statutes Cumulative Supplement, 2020, is amended to read:

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

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

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

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

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

Sec. 10. Original sections 83-1201 and 83-1212.01, Revised Statutes Cumulative Supplement, 2020, are repealed.