

STUDY OF EARLY INTERVENTION SYSTEM FOR CHILDREN FROM BIRTH TO AGE 3 WITH DEVELOPMENTAL DISABILITIES

Section 2 of 2017 Senate Bill No. 2325 ([appendix](#)) provides for a Legislative Management study of the state's early intervention system for children from birth to age 3 with developmental disabilities. The study may include a historical overview of the system; funding mechanisms, including Medicaid; the broader implications of how the state's system interfaces with other early childhood systems; and responsibilities for implementing federal law directing states participating in Part C of the federal Individuals with Disabilities Education Act to locate and evaluate children from birth to age 3.

The committee has been assigned the responsibility to conduct this study.

BACKGROUND INFORMATION

North Dakota Century Code (NDCC) Section 25-01.2-01 defines "developmental disability" as a severe, chronic disability of an individual which:

- Is attributable to a mental or physical impairment or combination of mental and physical impairments;
- Is manifested before the individual attains age 22;
- Is likely to continue indefinitely;
- Results in substantial functional limitations in three or more of the following areas of major life activity:
 - Self-care;
 - Receptive and expressive language;
 - Learning;
 - Mobility;
 - Self-direction;
 - Capacity for independent living; and
 - Economic sufficiency; and
- Reflects the individual's needs for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

North Dakota Administrative Code (NDAC) Section 75-04-01-01 defines "infant development" as a systematic application of an individualized family service plan designed to alleviate or mediate developmental delay of an individual from birth through age 2.

North Dakota Administrative Code Section 75-04-06-04 identifies that service eligibility for children from birth through age 2 is based on distinct and separate criteria designed to enable preventive services to be delivered. Young children may have conditions which could result in substantial functional limitations if early and appropriate intervention is not provided. Professional judgment must be exercised to determine whether the child is high risk or developmentally delayed, and if the child may need early intervention services. If a child, from birth through age 2, is either high risk or developmentally delayed, the child may be included on the caseload of an intellectual disabilities-developmental disabilities case manager and considered for those services designed to meet specific needs. Eligibility for continued service inclusion through intellectual disabilities-developmental disabilities case management must be redetermined by age 3 using criteria specified in NDAC Section 75-04-06-02.1. For purposes of NDAC Section 75-04-06-04:

1. "Developmentally delayed" means a child, from birth through age 2:
 - Who is performing 25 percent below age norms in two or more of the following areas:
 - Cognitive development;
 - Gross motor development;
 - Fine motor development;
 - Sensory processing (hearing, vision, haptic);
 - Communication development (expressive or receptive);
 - Social or emotional development; or
 - Adaptive development; or

- Who is performing at 50 percent below age norms in one or more of the following areas:
 - Cognitive development;
 - Physical development, including vision and hearing;
 - Communication development (expressive and receptive);
 - Social or emotional development; or
 - Adaptive development; and
2. "High risk" means a child, from birth through age 2, who:
- Based on a diagnosed physical or mental condition, has a high probability of becoming developmentally delayed; or
 - Based on informed clinical opinion documented by qualitative and quantitative evaluation information, has a high probability of becoming developmentally delayed.

Based on testimony provided by the Department of Human Services during the 2017 legislative session, the department's Developmental Disabilities Division administers the delivery of services for eligible individuals with an intellectual or developmental disability, and children birth to age 3 with developmental delays. Services administered by the division include residential and day supports, employment, family support, self-directed, corporate guardianship, infant development, and right track. The unduplicated number of individuals under the age of 3 that received developmental disabilities program management are as follows:

| Developmental Disabilities Program Management | State Fiscal Year | | | | | | |
|---|-------------------|-------|-------|-------|-------|-------|-------|
| | 2010 | 2011 | 2012 | 2013 | 2014 | 2015 | 2016 |
| Unduplicated count of individuals under the age of 3 receiving developmental disabilities program management. | 1,754 | 1,931 | 1,987 | 1,990 | 2,223 | 2,564 | 2,842 |

PREVIOUS LEGISLATIVE STUDIES 2007-08 interim

Infant Development Program

Section 9 of 2007 Senate Bill No. 2012 directed a study of infant development programs, including a review of the state's lead agency agreement, service coordination, staffing, and funding structure, including the adequacy of the funding and the equitable distribution of funds to providers.

Overview

The 2007-08 interim Human Services Committee was assigned to this study. The committee learned the Department of Human Services' infant development program provides home-based, family-focused services to families with eligible children up to 3 years of age. The program provides information, support, and training for families to assist them in meeting their child's needs. The committee learned infant development programs are not facility-based nor do they provide direct therapy for children. The infant development service delivery model provides support to the family of the eligible child and provides training to the family through natural learning opportunities that occur within home- and community-based routines. Services are provided in the family's home, child care settings, or other community programs to support the family and child.

The committee learned developmental disabilities case managers employed through the regional human service centers authorize early intervention services, including infant development, family subsidy, and family support services depending on each family's needs and preferences. Other services a case manager will help families identify, access, and coordinate include physical, occupational or speech therapy, specialized medical care, child care, adaptive equipment, and other support services available within the community. Approximately 41 percent of children who receive developmental disabilities case management prior to 3 years of age continued to receive case management after their 3rd birthday. The committee learned the Department of Human Services as the lead agency entered into agreements with other service agencies to identify and provide services to eligible children and their families, including special education in schools and the Department of Public Instruction; State Department of Health; Head Start; child care, medical services, child protective services, foster care, mental health service program; tribal early childhood programs; and family support organizations. Infant development providers in the state included:

1. Northwest Infant Development Program - Williston.
2. Minot Infant Development Program - Minot.
3. Lake Region Kids Program - Devils Lake.

4. Northeast Regional Kids Program - Grand Forks.
5. Southeast Regional Kids Program - Fargo.
6. South Central Regional Kids Program - Jamestown.
7. Bismarck Early Childhood Education Program - Bismarck.
8. Standing Rock Early Childhood Infant Development Program - Fort Yates.
9. Kids Program - Dickinson.

Number Served and Staffing

The committee learned the North Dakota infant development service delivery model is a transdisciplinary primary coach model with staff that are adult educators/coaches that work with the caregivers. A total of 72.66 full-time equivalent positions were either employed or contracted for by the programs. Infant development programs were required to employ or have contracts with physical therapists, occupational therapists, speech pathologists, educators, social workers, and other early intervention consultants. The committee reviewed the following schedule, which detailed the number of infants and toddlers that were receiving infant development services by region on October 1, 2008:

| Region | Infant Development Program - Number Served as of October 1, 2008 |
|--------------------|---|
| Northwest | 39 |
| North Central | 79 |
| Lake Region | 61 |
| Northeast | 148 |
| Southeast | 207 |
| South Central | 80 |
| West Central | 224 |
| Badlands | 70 |
| Total ¹ | 908 |

¹The number of children receiving infant development services increased from 675 during July 2005 to 908 in October 2008. The increase was primarily a result of having more resources available to identify eligible infants and toddlers.

Funding

The committee learned funding for the infant development program was provided from the state general fund and federal Medicaid and federal Individuals with Disabilities Education Act, Part C, funds. Part C funds, which were used to encourage states to develop early intervention services, were used in the program for children entering the system. The funds provided reimbursement for the first partial month of service. The committee reviewed the following schedule, which detailed the legislative appropriation for the program and the projected program expenditures for the 2007-09 biennium:

| Infant Development Program | 2007-09 Legislative Appropriation | 2007-09 Projected Expenditures |
|----------------------------|-----------------------------------|--------------------------------|
| General fund | \$3,892,327 | \$3,600,395 |
| Federal Medicaid funds | 6,910,638 | 6,696,909 |
| Federal Part C funds | 82,164 | 267,840 |
| Total | \$10,885,129 | \$10,565,144 |

The committee learned private organizations provide infant development services in all human service regions. Prior to the 2007-09 biennium, four human service centers--Northwest, Northeast, Southeast, and South Central--hired staff to provide these services directly. The committee learned payment rates for infant development services were developed based on a retrospective ratesetting process. This process involved the department setting an interim rate for the upcoming year. Each provider's rate was unique and dependent on the provider's budgeted allowable costs. Providers submitted a statement of budgeted costs to the department each year that was used to establish the interim rate. The final rate was determined at the close of the fiscal year after each provider reported actual costs for the previous fiscal year. The department reviewed the reports to determine whether the reported costs were allowable, reasonable, and client-related. The actual costs were compared to the reimbursements the provider received for the year based on the interim rate. Settlement was then made at the end of the year through either a refund paid to the department by the provider if overpayment occurred or an additional payment to the provider was made by the department if the provider was underpaid for the year. The interim rates paid to providers for infant development services ranged from \$17.25 to \$29.25 per day with a daily average of \$24.24 during this study.

Other Testimony Received

The committee received other information and testimony regarding the study. Concerns expressed in testimony included:

- Current funding levels for the infant development program make it difficult for providers to hire and retain qualified professional staff.
- Computer equipment used by infant development providers was purchased and maintained by the state. However, the equipment is often outdated and difficult to use.

Recommendations

The committee made no recommendations regarding the infant development program study.

PROPOSED STUDY PLAN

The following is a proposed study plan for the committee's consideration:

1. Receive information from the Department of Human Services regarding the state's early intervention system for children from birth to age 3 with developmental disabilities, including historical overview of the system; funding mechanisms, including Medicaid; the broader implications of how the state's system interfaces with other early childhood systems; and responsibilities for implementing federal law directing states participating in Part C of the federal Individuals with Disabilities Education Act to locate and evaluate children from birth to age 3;
2. Receive information from the Department of Public Instruction regarding the efficiency and effectiveness of programs available to children reaching 3 years of age and transitioning out of the early intervention system;
3. Receive testimony from stakeholders, including representatives of providers of infant development services, families, and state and local agencies and institutions;
4. Receive comments by interested persons regarding the early intervention system for individuals with developmental disabilities study;
5. Develop recommendations and any bill drafts necessary to implement the recommendations; and
6. Prepare a final report for submission to the Legislative Management.

ATTACH: 1