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ABSTRACT

This report responds to a North Dakota legislative mandate to study the state's early childhood tracking system for children who are at risk for developmental delays. Introductory sections summarize critical definitions and relevant federal legislation (specifically Part H of Public Law 99-457). The North Dakota program is then reviewed. Nineteen medical or biological risk factors, three developmental risk indicators, and eleven environmental risk factors are listed. Briefly considered are the tracking processes of monitoring and referral. The North Dakota tracking system is reported to involve 35 interagency teams throughout the state and current tracking of 984 children. Ten concerns are identified (e.g., locating children who need services, dealing with confidentiality, and developing a statewide data management system). The most urgent concern is seen to be the continued financing of early intervention services. The legislative resolution authorizing this study is attached. (DB)

Prepared by the North Dakota
Legislative Council staff for
the Special Education Committee
June 1991

NORTH DAKOTA EARLY CHILDHOOD TRACKING SYSTEM BACKGROUND MEMORANDUM

INTRODUCTION

House Concurrent Resolution No. 3054 (copy attached) directs the Legislative Council to study the North Dakota early childhood tracking system and to focus on its current and future roles in the tracking of children who are at risk for developmental delays and in providing essential assistance to such children and their families. The Council was also directed to study ways in which the early childhood tracking system could, through appropriate tracking and early intervention, help the state minimize the long-term education and care costs for at risk children.

"Early childhood intervention means discovering that a child between birth and school age has or is at risk of having a handicapping condition or other special need that may affect his or her development and then providing services to the child and family to lessen the effects of the condition. Early intervention can be remedial or preventive in nature--remedying existing developmental problems or preventing their occurrence. Early intervention may focus on the child alone or on the child and the family together." (Implementing Early Intervention Services for Infants and Toddlers with Disabilities, NCSL, May 1991, at p. 2.)

"Crack" babies, low birth weight infants, toddlers with developmental delays, and children with conditions such as Down's Syndrome and cerebral palsy, just to mention a few, clearly face lifetimes filled with both physical and emotional challenges. The states in which these children reside also face challenges, particularly economic challenges, stemming from the need for special education, institutionalization, and the prevention or remediation of developmental problems later in life. Studies indicate that for every dollar invested in early intervention, $3 to $7 dollars are saved due to a reduced need for governmental intervention.

FEDERAL LEGISLATION

In 1986 Congress added Part H of Public Law 99-457 to the Education of the Handicapped Act. Part H authorizes the Secretary of Education to provide formula grants to states to plan and implement statewide coordinated, comprehensive, interagency, early intervention services for infants and toddlers with disabilities and their families. Part H provides federal dollars for a five-year planning period in which participating states can develop and implement early intervention services.

Part H requires a significant level of coordination regarding the delivery of services and funding sources. It focuses on the child within the context of the family and requires that the family actively participate in the child's assessment and treatment. State policymakers retain the primary responsibility to create and shape the programs. State legislation provides the policy framework for the development and expansion of the programs. To date, at least 15 states have passed legislation to implement Part H. Most of the statutes are modeled after the federal legislation with adoptions to reflect each state's unique circumstances and decisions about program parameters.

Primary responsibility for Part H planning and implementation is located in a single state agency designated by the Governor. (In North Dakota the Department of Human Services is the lead agency.) Another Part H requirement is that the lead agency is accountable for the entire program. Other state agencies that currently fund and provide services for handicapped infants and toddlers continue their responsibilities and work with the lead agency to design an integrated service-delivery system.

In addition, each state is required to establish an Interagency Coordinating Council to advise and assist the lead agency in identifying funding sources and delegating financial responsibility to the appropriate agency.

THE NORTH DAKOTA PROGRAM

Although the Department of Human Services is the lead agency with respect to Part H responsibilities and requirements, the North Dakota early childhood tracking system is a joint project of the North Dakota Department of Health and Consolidated Laboratories, Department of Human Services, and Department of Public Instruction. Its purpose is to monitor or "track" the development of children from birth to age 5 who are "at risk" for developmental delays. Children may be "at risk" if any of the following medical or biological factors, developmental factors, or environmental factors are present:

Medical or Biological Risk Factors

1. Gestational age less than 37 weeks, neonatal intensive care unit (NICU) graduate.

2. Low birth weight - under 2,000 grams or 4.4 pounds.

3. Respiratory distress requiring mechanical ventilation greater than 24 hours.

4. Apgar score (a numerical expression of an infant's condition) of four or less at five minutes after birth.

5. Major congenital (birth) anomalies.

6. Delayed development of suck and swallow that persists beyond 28 days.

7. Intracranial hemorrhage.

8. Neonatal seizures.

9. Clinically known or suspected evidence of central nervous system infection or trauma (congenital or postnatal).

10. Microcephaly (abnormal smallness of the head) or macrocephaly (excessive size of the head).

11. Hyperbilirubinemia (excessive bile pigment in the blood) requiring an exchange transfusion.

12. Hypoglycemia (diminished glucose content in the blood) - serum glucose under 35 mg/dl.

13. Severe chronic illness or condition.

14. Maternal phenylketonuria, diabetes, hypothyroidism, and other maternal metabolic disorders critical to the infant. (Phenylketonuria is an inborn error of metabolism attributable to a deficiency of or a defect in the enzyme that catalyzes the conversion of phenylalanine to tryosine. It can result in mental retardation or neurologic manifestations such as epilepsy and microcephaly.

15. Maternal use of anticonvulsants (agents that prevent or relieve convulsions), antineoplastic (agents that prevent the development of new and abnormal tissue growth), or anticoagulant drugs (agents that inhibit normal blood clotting) during pregnancy.

16. Suspected hearing impairment, suspected vision impairment, or both.

17. Diagnosed genetic disorder.

18. Serious congenitally or postnatally acquired infection.

19. Neonatal drug addiction or withdrawal syndrome.

Developmental Risk Indicators

1. Evidence of growth deficiency.

2. Failure on standard developmental or sensory screening test.

3. Identified emotional or behavioral disorders.

Environmental Risk Factors

1. Maternal age of less than 17 years.

2. Lack of routine medical care (prenatal, postnatal, and preschool).

3. Parental sensory impairment, mental retardation, learning disability, or psychiatric disorder.

4. Parental substance abuse.

5. Difficulty in parent-child bonding.

6. Difficulty in providing adequate basic parenting.

7. Lack of stable suitable housing.

8. Lack of familial and social support.

9. Significant family or socioeconomic stressors.

10. Abuse or neglect within household which may or may not include the name of the child in the 640 report.

11. Significant parental concerns about the child's development.

Of greatest concern are those children evidencing multiple risk factors.

MONITORING AND REFERRALS

The process of tracking involves two activities--monitoring and referral to services. The tracking is carried out by local interagency teams. The teams may be single or multicounty teams and consist of representatives from agencies that provide services to children and their families. Depending on the location, team members may include representatives from county social services, the Women, Infants, and Children (WIC) supplemental nutrition program, the early periodic screening, diagnosis, and treatment (EPSDT), Headstart, local hospitals, the Bureau of Indian Affairs (BIA), and other tribal agencies. Generally, team members meet on a monthly basis to review referrals and tracking information, as well as to make decisions regarding specific cases and the actions to be taken. A coordinator is then responsible for following up the activities of each team. Currently five individuals are employed as team coordinators. Each one of the state's quadrants is served by a coordinator, and the fifth coordinator serves the state's Indian reservations.

When an agency comes in contact with a child who exhibits one or more risk factors, that child is referred to the tracking system. This typically occurs during an agency's provision of services to a child and the child's family. An example might involve a parent and child coming in for a monthly WIC program visit. If the parent has concerns about the child's development, the WIC coordinator might complete a referral and ask the parent to sign an authorization form. The referral is then sent to the early childhood tracking system coordinator. The referral is shared with the other team members at the next team meeting and decisions are made regarding the tracking of the child's development. The tracking might involve a questionnaire completed by the parent for a child through two years of age, or a multiagency screening for a child between ages 3 and 5.

CURRENT STATUS

The North Dakota early childhood tracking system began as a pilot project in the Grand Forks area in 1986. Since that time, it has grown to include 35 interagency teams located throughout the state. The teams consist of 462 members and represent 328 agencies and providers on the regional, county, tribal, and local levels. Nine hundred eighty-four children are currently being "tracked" and by the time the system is fully operational, it is anticipated that 5,000 children ranging in ages from birth through five years will be tracked.

As the program has expanded, so too have the issues facing its coordinators. Of particular concern are the following:

1. Not being able to find all the children who need the services.
2. Dealing with problems created by a rural environment, e.g., travel and isolationism.
3. Dealing with confidentiality.
4. Dealing with the issue of environmental risk in the birth to five-year-old population.
5. Expanding the representation on the tracking teams.
6. Expanding the interactions with the medical community.

7. Training as a team to deal with the issues involved in tracking.
8. Continuing education about the early childhood tracking system.
9. Developing a statewide data management system.
10. Expanding the scope of the system to assist greater numbers of at-risk children.

The most significant concern for state policymakers is the continued financing of early intervention services. Part H provides a loose structure for early intervention services, but not the bulk of the financial resources necessary for service delivery. States are instead expected to assemble funding from a variety of different sources. Part H federal funds are to be used merely to plan and coordinate existing programs, mobilize financial resources, and fill in the gaps.

ATTACH: 1

Fifty-second Legislative Assembly, State of North Dakota, begun and held at the Capitol in the City of Bismarck, on Monday, the seventh day of January, one thousand nine hundred and ninety-one

HOUSE CONCURRENT RESOLUTION NO. 3054

(Representatives Oban, Kelsch, Gilmore)
(Senators Heinrich, Holmberg)

A concurrent resolution directing the Legislative Council to study the current and future role of the North Dakota early childhood tracking system.

WHEREAS, the North Dakota early childhood tracking system is a joint effort of the Department of Health and Consolidated Laboratories, Department of Human Services, and the Department of Public Instruction; and

WHEREAS, the North Dakota early childhood tracking system is a comprehensive early intervention program designed to monitor children up to age 5 who may be at risk for developmental delays; and

WHEREAS, by monitoring a young child's development, potential developmental delays can be detected and appropriate services can be offered at such times and in such ways that future difficulties for a child can be minimized or prevented; and

WHEREAS, the North Dakota early childhood tracking system began as a pilot project in Grand Forks in 1987, and as a result of its initial success, has expanded throughout the state;

NOW, THEREFORE, BE IT RESOLVED BY THE HOUSE OF REPRESENTATIVES OF NORTH DAKOTA, THE SENATE CONCURRING THEREIN:

That the Legislative Council study the North Dakota early childhood tracking system's current and future roles, not only in tracking children at risk for developmental delays and providing essential assistance to such children and their families, but also in helping the state minimize long-term education and care costs for certain children through tracking and early intervention efforts; and

BE IT FURTHER RESOLVED, that the Legislative Council report its findings and recommendations, together with any legislation required to implement the recommendations, to the Fifty-third Legislative Assembly.

Filed April 1, 1991