

AT-RISK FOLLOW-UP AND TRACKING

Introduction

The Kansas Infant-Toddler Services /tiny-k does **not** provide early intervention services for infants and toddlers who are at risk of developmental delay due to biological or environmental risk and who are not experiencing a developmental delay. Infants and toddlers for whom there is a concern due to a biological or environmental risk may be referred to the Infant-Toddler Services/tiny-k network for screening to determine if the suspicion of a developmental delay is well founded. Kansas recognizes the significant brain development that occurs during a child's first three years of life. Therefore, a follow-up and tracking system for children who are at risk, but are not eligible for early intervention services, is a response to the recognition of the importance of early identification.

I. Definition of At Risk for Developmental Delay [34 C.F.R. 303.16]

Kansas Infant-Toddler Services/tiny-k criteria describes "at risk for developmental delay" as:

Children, ages birth through 2, who are at-risk* of experiencing a developmental delay because of biological or environmental reasons and are not otherwise eligible for early intervention services under the statewide Kansas Infant-Toddler Services/tiny-k.

This group of children can be provided with early intervention services, including tracking and monitoring, **based on local discretion and funding. Tracking of these children is recommended but not mandatory at this time. Kansas Infant-Toddler Services/tiny-k monies cannot be used to track or monitor the "at-risk" population.**

***NOTE: "At risk" is different from "established risk," as defined in Section IV of this manual.**

II. Tracking Mechanisms

Tracking at-risk children is not required under Kansas Infant-Toddler Services/tiny-k, but local networks are encouraged to develop a follow-up system to screen these children at appropriate intervals. Frequency of follow-up will be unique to the needs of the child and family. Communities may select varying methods based on available resources to achieve the follow-up goal.

Kansas Infant-Toddler Services/tiny-k networks are encouraged to initiate, expand, or improve collaborative efforts related to at-risk infants and toddlers, including establishing linkages with appropriate public and private community-based organizations, services, and personnel. Many infants can be enrolled in tracking systems by being identified as "at risk" in the hospital (e.g., NICUs). Referrals from hospitals to local community early intervention networks, local health departments, and primary care providers ensure that regular contacts are maintained with the family so the child can be monitored through the local ongoing screening program (see Section III on Child Find).

For children who are at risk of developmental delay, follow-up screening:

- helps parents keep their child in a primary health care system;
- promotes early identification of children requiring further evaluation;
- assists parents in becoming better observers of their child's development; and
- responds to parental concerns.

III. Local Option to Serve Children with a Biological or Environmental Risk for Developmental Delay [20 U.S.C. 1438(5); 34 C.F.R. 303.16]

Children ages birth through 2 who are at risk of developmental delay for biological or environmental reasons, or who may have been screened but are not suspected of a developmental delay, are not automatically eligible for Part C services provided by state funding. This group of children can be provided with early intervention services, including tracking and monitoring, based on local discretion and local funding. State of Kansas Part C monies cannot be used to serve, track, or monitor the "at-risk" population when there is no current evidence of a developmental delay.

There are circumstances, either environmental or biological, that place children at risk for developmental delay but may not result in an eligibility determination. Examples of such conditions include, but are not limited to:

1. Biological factors such as:

- history of prenatal, perinatal, or early developmental events suggestive of biological insults to the central nervous system
- low birth weight (less than 1,500 grams)
- prematurity (less than 34 weeks' gestation)
- asphyxia
- newborn respiratory distress

2. Environmental factors such as:

- evidence of a family history of child abuse or neglect
- lack of physical or social stimulation
- high level of family disruption

Environmental risk factors should be identified by the multidisciplinary team and cannot be based on behavior related to cultural or socioeconomic differences. For children who are at risk of developmental delay, follow-up screening is strongly recommended.

IV. Referral of Specific At-Risk Children [20 U.S.C. 1437(a)(6)]

A referral must be made for any child under the age of 3 who is involved in a substantiated case of abuse or neglect or is identified as being affected by substance abuse or withdrawal symptoms resulting from prenatal drug exposure. It would be appropriate to provide screening for these children to determine if they might have a developmental delay.

Federal Statute 2004

20 U.S.C. 1438 USES OF FUNDS. In addition to using funds provided under section 633 to maintain and implement the statewide system required by such section, a State may use such funds—

(5) in any State that does not provide services for at-risk infants and toddlers under section 637(a)(4), to strengthen the statewide system by initiating, expanding, or improving collaborative efforts related to at-risk infants and toddlers, including establishing linkages with appropriate public or private community-based organizations, services, and personnel for the purposes of— (A) identifying and evaluating at-risk infants and toddlers; (B) making referrals of the infants and toddlers identified and evaluated under subparagraph (A); and (C) conducting periodic follow-up on each such referral to determine if the status of the infant or toddler involved has changed with respect to the eligibility of the infant or toddler for services under this part.

20 U.S.C. 1437. STATE APPLICATION AND ASSURANCES.

(a)(6) a description of the State policies and procedures that require the referral for early intervention services under this part of a child under the age of 3 who—

(A) is involved in a substantiated case of child abuse or neglect; or

(B) is identified as affected by illegal substance abuse, or withdrawal symptoms resulting from prenatal drug exposure;

Federal Regulations 1997

34 C.F.R. 303.16 Infants and toddlers with disabilities.

(a) As used in this part, infants and toddlers with disabilities means individuals from birth through age two who need early intervention services because they—

(1) Are experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures, in one or more of the following areas:

(i) Cognitive development.

(ii) Physical development, including vision and hearing.

(iii) Communication development.

(iv) Social or emotional development.

(v) Adaptive development; or

(2) Have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay.

(b) The term may also include, at a State's discretion, children from birth through age two who are at risk of having substantial developmental delays if early intervention services are not provided.

(Authority: 20 U.S.C. 1432(5))

Note 1: The phrase "a diagnosed physical or mental condition that has a high probability of resulting in developmental delay," as used in paragraph (a)(2) of this section, applies to a condition if it typically results in developmental delay. Examples of these conditions include chromosomal abnormalities; genetic or congenital disorders; severe sensory impairments, including hearing and vision; inborn errors of metabolism; disorders reflecting disturbance of the development of the nervous system; congenital infections; disorders secondary to exposure to toxic substances, including fetal alcohol syndrome; and severe attachment disorders.

Note 2: With respect to paragraph (b) of this section, children who are at risk may be eligible under this part if a State elects to extend services to that population, even though they have not been identified as disabled. Under this provision, States have the authority to define who would be "at risk of having substantial developmental delays if early intervention services are not provided." In defining the "at risk" population, States may include well-known biological and environmental factors that can be identified and that place infants and toddlers "at risk" for developmental delay. Commonly cited factors include low birth weight, respiratory distress as a newborn, lack of oxygen, brain hemorrhage, infection, nutritional deprivation, and a history of abuse or neglect. It should be noted that "at risk" factors do not predict the presence of a barrier to development, but they may indicate children who are at higher risk of developmental delay than children without these problems.