Prevention Program Policies and Procedures

Effective
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Children and Family Services Branch
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Prevention Program Policies and Procedures

I. Overview

This document provides the policies and procedures for the Prevention Program. Budget trailer bill language (2009-10 Statutes, Assembly Bill Fourth Extraordinary Session, Chapter 9) directs the Department of Developmental Services (DDS) to establish "…a prevention program for at-risk babies" and to "establish policies and procedures for implementation of the prevention program by regional centers." This new regional center program is charged to provide, for eligible children ages birth through 35 months, the following services:

A. Intake services,
B. Assessment,
C. Case management, and
D. Referral to generic agencies.

Children eligible for this program will receive these services through the regional centers. These are children who are at substantially greater high risk for a developmental disability but who would otherwise be ineligible for services through the California Early Intervention Program Services Act pursuant to Title 14 (commencing with Government Code, Section 95000) or services provided under the Lanterman Developmental Disabilities Services Act (Lanterman Act) (commencing with Welfare and Institution Code, Section 4500).

Regional centers shall implement the Prevention Program on October 1, 2009. DDS will allocate specific funding to each regional center for this program, with the regional center's total expenditures for purchasing or providing services not to exceed funding allocated in its contract for this purpose. Regional centers will partner with parents and families to ensure parents remain an integral part of the Prevention Program planning process for each child. These program guidelines were developed by DDS with the input of regional center directors and clinical staff, advocacy groups, family resource centers (FRCs), and parents.

II. Priorities

A. Primary Purpose: The purpose of the Prevention Program is to provide intake services, assessment, case management, and referral to generic agencies for those children who are:

1. At high risk for developmental delay or disability (as defined in Section III, B) but have yet to manifest delays. These children exhibit various risk factors (see "Determination of Eligibility" section below) or,

2. Children aged 24 through 35 months of age and who have a developmental delay in one domain of 33% - 49% (as defined in Section III(B)(3).

The regional center case manager will monitor the progress of these children. Should a child begin to exhibit developmental delays, the child will be referred for evaluation. The purpose of the evaluation will be an eligibility review for Early Start or Lanterman Act services.

B. Primary Focus: The Prevention Program will focus primarily on providing intake, assessment, case management, and referral to generic agencies for infants, toddlers, and their families.

III. Required Prevention Program Components For Regional Centers

Regional centers will: 1) implement the Prevention Program in their respective service area in accordance with these guidelines; 2) insure that the services mandated in WIC (Welfare and Institutions Code) 4435 are provided; 3) conduct necessary documentation and data reporting; and, 4) inform DDS of any implementation problems with WIC 4435.

A. Intake and Assessment: All infants or toddlers potentially eligible for any regional center program will enter through a single point of entry at the regional center to determine eligibility for services. The regional center shall determine the assessment tools it will use for determination of eligibility.

B. Determination of Eligibility: The regional center shall serve all eligible infants and toddlers. An infant or toddler is eligible for the Prevention Program when:
    1. The regional center determines that an infant or toddler has a combination of two or more of the following factors:
        a) Prematurity of less than 32 weeks gestation and/or low birth weight of less than 1500 grams.
        b) Assisted ventilation for 48 hours or longer during the first 28 days of life.
        c) Small for gestational age: below the third percentile on the National Center for Health Statistics growth charts.
        d) Asphyxia Neonatorum associated with a five minute Apgar score of 0 to 5.
        e) Severe and persistent metabolic abnormality, including but not limited to hypoglycemia, acidemia, and hyperbilirubinemia in excess of the usual exchange transfusion level.
        f) Neonatal seizures or nonfebrile seizures during the first three years of life.
        g) Central nervous system lesion or abnormality.
        h) Central nervous system infection.

i) Biomedical insult including, but not limited to injury, accident or illness which may seriously or permanently affect developmental outcome.
j) Multiple congenital anomalies or genetic disorders which may affect developmental outcome.
k) Prenatal exposure to known teratogens.
l) Prenatal substance exposure, positive infant neonatal toxicology screen or symptomatic neonatal toxicity or withdrawal.
m) Clinically significant failure to thrive, including, but not limited to weight persistently below the third percentile for age on standard growth charts or less than 85 percent of the ideal weight for age and/or acute weight loss or failure to gain weight with the loss of two or more major percentiles on the growth curve.
n) Persistent hypotonia or hypertonia, beyond that otherwise associated with a known diagnostic condition.

2. High risk for a developmental disability also exists when the regional center determines that the parent of the infant or toddler is a person with a developmental disability.
3. A toddler is also eligible for the prevention program when the regional center determines that a toddler between the ages of 24 - 35 months and has a developmental delay in one domain of 33 percent through 49 percent. The developmental domains a regional center must consider are communication, cognitive, social/emotional, self help/adaptive, and physical.

C. Appeal for Denial of Eligibility: A process is available for parents who disagree with the Prevention Program eligibility determination. Eligibility is the only action or decision of the regional center that may be appealed within the Prevention Program. The regional center will provide a written notice of the denial of eligibility to the parent. The notice will state the reason(s) for the denial. The written notice will provide a copy of the eligibility factors and will inform the parent of the appeal process. A parent may submit a written request to the regional center stating the reason for their disagreement and submitting any additional information that supports their position. A review panel will be convened consisting of at least three persons, including at least two regional center staff, including one clinician, and one external person selected by the regional center director. None of the regional center staff members on the panel can have directly participated in the original eligibility determination. The panel will review all available information and the regional center will issue a written decision within 30 days of receipt of request. The regional center panel‘s decision will be final.

D. Prevention Program Case Management: A critical component in the success of the Prevention Program is case management provided by the regional centers to ensure children and families are effectively served during this critical period

in the child's life. The principal intent of this program is to provide intake services, assessment, case management, and referral to generic agencies. It is anticipated that the case manager will access regional center clinical expertise for support and guidance concerning assessing child progress and the appropriate utilization of generic resources. Because case management is the main feature of the Prevention Program, it is essential that case managers have the knowledge, skills, and abilities to guide families in the early childhood development of their infant or toddler, identify and navigate generic services, and monitor the developmental progress of the infant or toddler.

The following are tasks and responsibilities of the regional center:

1. Case record documentation
    a) Factors which support eligibility for the Prevention Program;
    b) Summary of findings and recommendations from the planning team;
    c) Periodic updates of the child's progress through periodic contact with the parents and family;
    d) Any required data collection forms;
    e) Maintaining the prevention program plan (PPP);
    f) Services received through generic services and Purchase of Services, and
    g) Transition data including eligibility for Early Start, Lanterman Act Services, and/or Local Education Agency (LEA) Services.

2. Prevention Program Plan Development
    a) Upon determining eligibility for the Prevention Program, and in collaboration with the child's parents and family, the regional center shall prepare a written PPP. The written PPP will be developed and a copy given to the parent within 60 days of the initial referral to the Prevention Program and shall include the following information:
        i. Factors supporting eligibility for the Prevention Program;
        ii. Date of PPP development and the date the PPP was provided or sent to the parent;
        iii. Case manager's name;
        iv. Frequency of contact. At minimum, each family must be contacted within 90 days after development of the PPP and every six months, thereafter;
        v. Identification of resources and referral;
        vi. Type and frequency of monitoring and screening;
        vii. Type and frequency of assessment;
        viii. Referrals to community resources or intervention services as appropriate, and,
        ix. Additional services the child will receive.
    b) Providing family support and education
        i. Assisting and partnering with families in problem solving strategies;

ii. Recognizing and building on family strengths, natural supports, and existing community resources;
iii. Considering cultural preferences, values, and lifestyle of families;
iv. Providing information about the child's developmental status and developmental activities that enhance development;
v. Assisting the parents in educating and supporting siblings;
vi. Providing information about resources currently available in the community; and
vii. Providing educational materials to parents and families regarding potential reasons they might be concerned about their child's development.

3. Accessing services
   a) Identifying generic supports and agencies to assist the family;
   b) Providing referrals to appropriate generic services;
   c) Assisting the parents as necessary in connecting and coordinating services with appropriate generic agencies;
   d) Collaborating with community resources as needed;
   e) Assisting parents in advocating for themselves;
   f) Exit planning: Facilitating a family-friendly transition to ongoing services such as
      i. Initiating a referral to Early Start, the LEA, or Lanterman Act services as appropriate based on intake services, assessment, case management and referral to generic agencies;
      ii. Making appropriate referrals to other community resources serving children three years of age and older such as preschool, Head Start, First Five-funded local programs, etc.

E. Early Start Program Transfers: The referral and subsequent transfer of an infant or toddler from the Prevention Program to the Early Start Program should be a family friendly process involving the service coordinator, appropriate regional center clinicians, and the child's family. If the child's condition changes and warrants an evaluation for the Early Start Program, a referral will be made. Whenever possible, existing information obtained during the prevention monitoring will be used to assist in determining eligibility for the Early Start Program.

F. Case Transfer between Regional Centers: When a family moves from one regional center service area to another, the sending regional center will make arrangements with the receiving regional center. Transfers will include all contact information available and available records including any evaluations and PPPs. The transfers will be handled in a timely manner. Funds will not be transferred between regional centers for Prevention Program consumers.

G. Data Tracking: Tracking infants and toddlers served in the Prevention Program is critical to program evaluation. Prevention data will be tracked

using existing data systems adapted as needed for the Prevention Program. The unique status code to be used is "P". In addition to the elements reflected in B(1), above, the following data elements will be tracked:

1. Prevention Program entry and exit date
2. Factors qualifying the infant or toddler for the Prevention Program
3. Referral source
4. Purchase of Service (POS)
5. Generic services to which the family has been referred
6. Transition data such as transition to the Early Start Program, Lanterman Act Program, or LEA services or complete exit from the regional center service delivery

H. Purchase of Direct Services: The Prevention Program is primarily a case management program. The Prevention Program is not part of the Lanterman Act or Early Intervention Services Act nor does the Lanterman Act or Early Intervention Services Act entitlement apply to children served under the Prevention Program. The amount of funding is capped and, therefore, it is anticipated that purchase of direct services for the infant/toddler and family will be limited. However, if Prevention Program funding permits, regional centers may purchase direct services for infants and toddlers served by the program. Direct services shall not be purchased unless generic services have first been pursued and determined to be unavailable or inappropriate.

I. Family Resource Centers: Regional centers may negotiate directly with local FRCs concerning roles and responsibilities of the FRC. Of the funds allocated for the purposes for the Prevention Program, each regional center shall use at least two percent of these funds to support the family resource center. The family resource centers shall only use these funds to assist families in the Prevention Program.

J. Development of Regional Center Prevention Plan: Each regional center shall submit a Regional Center Prevention Plan to DDS. This plan shall be updated annually. The first Regional Center Prevention Plan is due to DDS no later than January 1, 2010. Regional centers will develop a Prevention Plan specific to their catchment area to assist parents and family in understanding local program components and to educate new service coordinators about the overall goals of program. A written plan will also minimize inappropriate referrals from generic agencies across regional centers. The regional center's plan will be based upon provisions within DDS Prevention Program policies and procedures and will include at least the following:

1. The primary contact person at the regional center for the Prevention Program;
2. A description of the prevention program, which, at minimum, includes a description of the:

a) Intake and assessment process;
b) Case management staffing model;
c) Process by which the regional center will prioritize purchase of any direct services;
d) Minimum knowledge, skills, and abilities that must be possessed by a Prevention Program case manager;
e) Expectations of the size and mix of each case manager's caseload;
f) Template used at the regional center for each child's Prevention Program Plan;
g) Proposed liaison activities with other public and private agencies offering services to Prevention Program children, and
h) Any proposed initiative to develop, enhance or obtain additional services for Prevention Program children.

K. Fiscal
1. Claim (placeholder)
2. Fiscal Data Reporting (placeholder)

IV. Required Prevention Program Components for DDS

DDS will continue to issue policies and procedures, provide technical assistance, and monitor each regional center's implementation of the Prevention Program.

A. Monitoring: DDS monitoring will consist of a review of available records in making the eligibility determination. This review will ensure that children are being served in the appropriate program. The monitoring will also consist of a review of the PPP and if the family contacts and case management activities are occurring according to the PPP. DDS monitoring will also include reviewing documentation to ensure that referrals to generic agencies are occurring in accordance with the PPP.

B. Allocation, Claims, and Fiscal Audits
(Placeholder)

Appendix A

Early Start Eligibility Categories

California Code of Regulations
Title 17, Division 2
Chapter 2 - Early Intervention Services
SubChapter 1 - General Provisions
Article 2 - Eligibility for California's Early Start Program
§52022 Eligibility Criteria

(a) Developmental Delay
A developmental delay exists if there is a significant difference pursuant to 52082 between the infant's or toddler's current level of functioning and the expected level of development for his or her age in one or more of the following developmental areas:
(1) Cognitive;
(2) Physical: including fine and gross motor, vision, and hearing;
(3) Communication;
(4) Social or emotional; and
(5) Adaptive.

(b) Established Risk
(1) An established risk condition exists when an infant or toddler has a condition of known etiology which has a high probability of resulting in developmental delay; or
(2) An established risk condition exists when an infant or toddler has a solely low incidence disability.

Appendix B

Welfare and Institutions Code Section 4435
Prevention Program

4435. (a) The department shall establish a prevention program for at-risk babies. For purposes of this section, "at-risk baby" means a child under 36 months of age who is otherwise not eligible for the California Early Intervention Program pursuant to Title 14 (commencing with Section 95000) of the Government Code or services provided under the Lanterman Developmental Disabilities Services Act (Division 4.5 (commencing with Section 4500)) and whose genetic, medical, developmental, or environmental history is predictive of a substantially greater risk for developmental disability than that for the general population, the presence of which is diagnosed by qualified clinicians.

(b) This program shall provide intake, assessment, case management, and referral to generic agencies. For purposes of this section, "generic agency" means any agency that has a legal responsibility to serve the general public and that is receiving public funds for providing these services.

(c) The department shall allocate to each regional center, subject to appropriation, specific funding for this program. A regional center's total expenditures for purchasing

or providing services under the prevention program shall not exceed the funding allocated in its contract for this purpose.

(d) The department shall establish policies and procedures for implementation of the prevention program by regional centers. These policies and procedures shall define other services included in this program and the process for appealing denial of eligibility for the prevention program.

Glossary

- **Assessment** – Formal and informal procedures used by qualified personnel including clinicians and case managers as appropriate to determine an infant's or toddler's present levels of development, their strengths and needs and eligibility for the Prevention Program.

- **At high risk for developmental disability** – Exists when an infant or toddler whose genetic, medical, developmental or environmental history is predictive of a substantially greater risk for developmental disability than that for the general population as determined by qualified clinicians.

- **Established risk** – Exists when an infant or toddler has a solely low incidence disability or a condition of known etiology which has a high probability of resulting in developmental delay.

- **Generic agency** – Any agency that has a legal responsibility to serve the general public and that is receiving public funds for providing these services.

- **Intake** – The process of gathering information, medical and developmental records, and screening data in preparation for assessment of an infant of toddler who may be "at high risk".

- **Prevention Program** – Provides an opportunity for children birth through 35 months of age to receive intake, assessment, intake services, assessment, case management and referral to generic agencies/guidance, and referrals to community resources to ensure appropriate developmental progress or if needed, referral to early intervention services.

- **Qualified clinicians** – Personnel who meet state certification, licensing, registration or other comparable requirements for the area and age group in which he or she is providing evaluation and assessment.

- **Screening** – A developmental tool designed to identify children who may be at risk for having or developing a developmental disability.

- **Service coordination/case management** – Provides documentation including a Prevention Program Plan (PPP), intake services, assessment, case management and referral to generic agencies/guidance, referrals to community services and coordination of community resources.