



# Risk factors of children who exited from an early intervention program without an identified disability and returned with a developmental disability

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## ABSTRACT

A retrospective cohort study was undertaken to identify risk factors for children at greatest risk of delayed diagnosis of developmental disability. Two thousand four hundred and thirty-nine children were selected for this study due to their participation in the California Early Start (ES) Program in 1998. Comparisons were made among children that had no break in services offered through the ES Program versus children that returned with a disability after exiting the ES Program. Factors examined include child's condition and qualifying risk factors, mother's demographic characteristics, family's risk factors, and risk scores developed for each county in which the family resided. Children with a delay in diagnosis of a disability have characteristics that fall outside the norm for the identification of a disability. It is not clear if this is related to age-specific manifestation to the appearance of a disability or to conditions difficult to diagnose.

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## 1. Introduction

The age of diagnosis of disability is an issue for states providing early intervention services to children with risk conditions or delays. Not all children with developmental disabilities who receive state early intervention services due to medical risks and/or developmental delay are diagnosed with a condition by 3 years of age, the time of transition to other appropriate services. The age of identification is complicated by the difficulty in identifying factors that will have a transient impact and those that will result in disability. A wide range of biological and environmental risk factors have been shown to influence early development. In addition, a child's stage of development and environmental resources can affect detection (Meisels, 1989). Severe developmental disabilities are usually diagnosed early, while some become apparent only after a period of normal growth (Zoghbi, 2003).

A study of special education children in urban schools found a wide range of ages when disability was identified (Palfrey, Singer, Walker, & Butler, 1987). Conditions under study came from a broad spectrum including cognition, motor, communication, and emotional disturbance. Four percent were identified at birth, 16% before age 3 years, almost 30% before age 5 years, with the remaining identified at age 5 years or later. In children referred for neurodevelopmental evaluation, the median age of diagnosis by condition was found to be 11 months for prenatal or perinatal medical disorders; 12 months for cerebral palsy; 27 months for mental retardation; communication disorder, 32 months; postnatal illness, 39 months; attention deficit disorder, 87 months; learning disability, 113 months (Lock, Shapiro, Ross, & Capute, 1986). Learning disabilities, hyperactivity, or emotional problems typically require more detailed assessment, with the diagnosis becoming

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clearer over time (Aylward, 1988). Some children with autism or children with genetic disorders are not necessarily identified at an early age (Hauser-Cram et al., 2001). Relative late identification of speech articulation and other speech problems, behavior problems, and autism becomes more apparent as children begin to interact in a group (Britain, Holmes, & Hassanein, 1995).

To identify children with a delay in diagnosis of developmental disability, this study examined the effects of child and family risks, along with category of disability. By identifying these children, who enter an early childhood intervention program at risk of developmental disability but leave before a diagnosis, services could be sustained for maximum benefit to the child and family.

## 2. Materials and methods

### 2.1. Study design and population

This retrospective cohort study included children initially at risk of developmental disability who ultimately received a diagnosis of developmental disability. Children were served by the California Department of Developmental Services (DDS) Early Start (ES) Program. The subjects came from the original cohort of 8,987 children who entered the ES Program in 1998 at high risk of developmental disability due to medical and/or clinical risk conditions and/or developmental delay (Fig. 1). Early intervention services are provided through a statewide system of 21 locally based regional centers run by nonprofit private corporations located throughout California.

The study was conducted using data collected by DDS related to characteristics of the child and family including data from: the ES Program database, Client Master File (CMF), and Client Development and Evaluation Report (CDER) database (Table 1). The CMF contains additional demographic and tracking information not provided in the Early Start database. The CDER is completed once a year for anyone receiving services related to a disability from DDS. Children transition out of the ES Program at age 3, but can continue receiving DDS services for an identified disability. Records from the ES Program, the CMF, and CDER were linked by unique identifiers in ascending age order. The final file included records on 2,439 children.

### 2.2. Outcome variable

The outcome was based on two groups of children with developmental disabilities: one group had no break in services and the other group returned with a disability after exiting the ES Program. The CDER, completed once a year for children receiving services related to a disability from DDS, was used to identify those children with a disability. The two groups were identified by linking the original cohort of 8,987 children who entered the ES Program without a categorical disability to the last available CDER record. Only children with at least one CDER record were eligible.

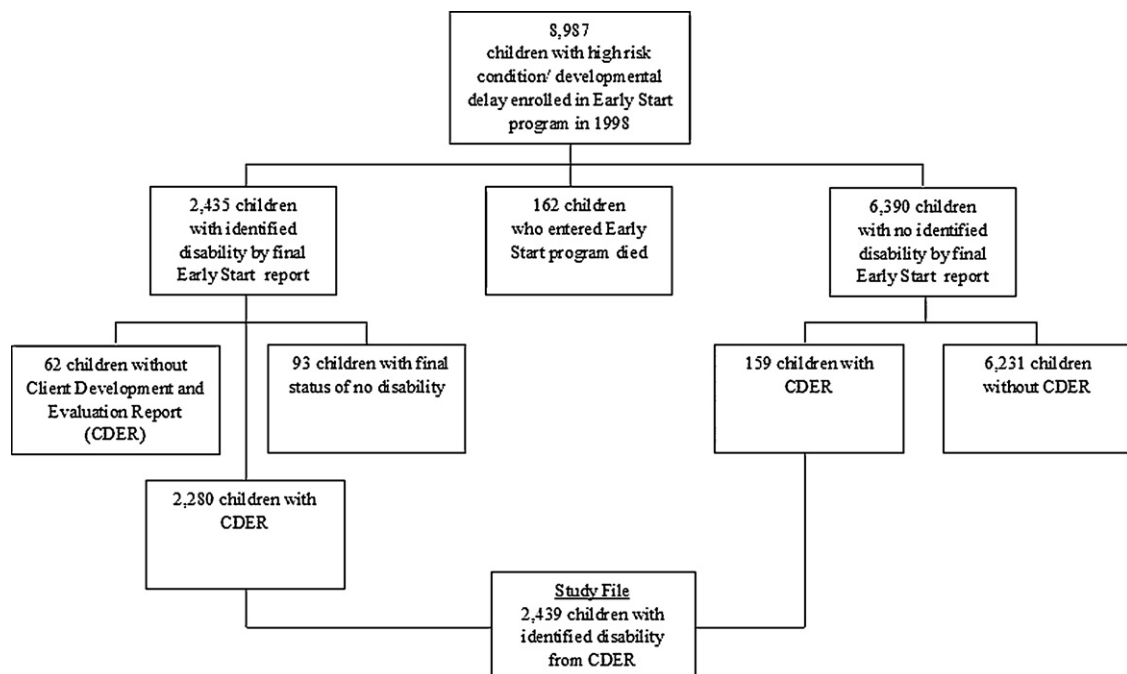


Fig. 1. Flowchart showing sources of study file from linked Early Start Program and Client Development Evaluation Report records, 1998 cohort.

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