



**Project PRISM: A LONGITUDINAL STUDY OF  
DEVELOPMENTAL PATTERNS OF CHILDREN WHO ARE  
VISUALLY IMPAIRED**

*Executive Summary*

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**Project PRISM: A National Longitudinal Study of the Early Development of  
Children Who Are Visually Impaired**

Abstract

The University of Northern Colorado received federal support to conduct a five-year study (1991-96) examining the sequence and rate of development of children ages birth to five years who are blind or visually impaired. Measures of visual acuity, behavior, temperament, and environment were obtained in an effort to identify differences in the development of children who are blind and visually impaired based on standardized assessment norms, while examining within group variation by visual disorders, additional disability, and other factors.

The original grant was awarded to Teachers College, Columbia University in October 1991, then transferred to the University of Northern Colorado in June 1992. The University of Northern Colorado thereafter coordinated the research. Collaborators included The Lighthouse National Center for Vision and Child Development (from 10/1/91 to 5/31/92), the New York Institute for Special Education (from 6/1/92 to 6/30/94), and a consortium of agencies providing services to young children with visual disabilities and their families in Arizona (The Foundation for Blind Children), Colorado (Anchor Center for Blind Children), Kentucky (Visually Impaired Preschool Services), New Mexico (New Mexico School for the Visually Handicapped Preschool), and Texas (Dallas Services for Visually Impaired Children). Additional funding was received from the Hilton/Perkins National Program, through a grant from the Conrad N. Hilton Foundation of Reno, Nevada, which supported an additional two agencies in California (Blind Childrens Center) and Massachusetts (Perkins School for the Blind).

This report presents the analysis of data according to the seven research questions originally proposed in the grant. Results indicate that the greatest impact on developmental outcome appears to be the presence of disabilities in addition to visual impairment, although differences were also found based on gestational age at birth and some types of visual disorders. Differences were documented in the rate and sequence of acquisition of developmental milestones and developmental inventory scores, but those differences tended to disappear over time.

Limitations of the Study

The data, conclusions, interpretations, and findings included within all reports of

Project PRISM outcomes require that consumers of this research honor the objectives of the investigators and also the participant families who gave willingly of their time over the five-year period of the study. The data collected through this project represents information about one of the most vulnerable low incidence disability groups and their families possible. Given the nature of the research design, all of the data is shadowed by the process of participant selection. All of the participant children in the study were receiving specialized services from an agency specializing in serving individuals with visual impairments.

This factor was an unavoidable artifact of participant availability and the data collection procedure conducted by project-trained evaluators. In an effort to avoid (a) misinterpretation of the findings, (b) oversimplification of results, or (c) unclear generalizations about the delicate interactions between children's development and other variables under investigation, we request that at all times the conclusions be presented with the caveats listed below.

### Participants

(a) All participants in this study were receiving services from early intervention and early childhood programs.

(b) None of the children in this study were without services, although the intensity, duration, and frequency of services differed across participants.

(c) Each of the infants in the study was being served by one of seven agencies specializing in serving children and adults with visual impairments. The services differed across sites and included center-based services, home-based services, a combination of the two, consulting services to generic and/or special education service providers, and testing/evaluation services only.

(d) The investigators hope to account for differences in individual cases as an ongoing part of the research, by exploring the effects of these service variables on outcomes rather than minimizing them or controlling for them.

### Research Sites

(e) Each of the seven sites included in this study specialized in serving individuals with visual impairments.

(f) Sites were selected to represent a cross-section of geographic, cultural, ethnic, and socio-economic factors.

(g) Both urban and rural services were represented.

(h) The relative failure of this study to attribute differences in development to degree of visual loss may have occurred because the services provided by the specialized agencies minimized the effects of visual disability.

(i) Sites differed in terms of public/private funding, resources available, licensing and certification requirements for teachers in each state, and age span served.

### Diagnosis of Visual Disability

(j) Each child in the study was initially deemed visually impaired and thus eligible for services by the host agency.

(k) The seven host agencies followed guidelines in their states for definitions of vision impairment, eligibility, and additional disability. These definitions varied somewhat across sites.

#### Assessment Procedures

(l) All assessments instruments were selected for their technical soundness and to optimize efficiency of testing and ease of communicating results to broad audiences.

(m) Due to the distance between the seven research sites, inter-observer agreement was calculated at each annual training of Project Evaluators, and at annual site visits by project staff.

#### Conclusions

##### General Conclusions

A. Project Evaluators were highly skilled and their work lends great confidence to the results. Mean interobserver agreement for five standardized tests was 86.7% for annual training sessions and 92.9% for site visits in between annual trainings. Two months after the project ended, Project Evaluators had maintained interobserver agreement at a mean 83.2%.

B. Project Evaluators administered 2446 standardized tests to 202 participants during the course of the project. Three-fourths of the participants received two or more assessments. Almost one-fifth (19.8%) of the participants were only tested once during the course of the project, and seven participants received no test administrations at all.

C. Parents completed more than 2653 questionnaires over the course of the project, at response rates per age interval ranging from 57.1% to 77.8%.

D. Mean age at project entry was 8.7 months, more than 5 months later than the mean age at diagnosis of the visual disorder (3.3 mos.). The visual disorder was generally diagnosed earlier if no additional disabilities were present.

E. Participants were studied for a mean 19.1 months. The shortest length of study was 3.2 months; the longest, 46.7 months.

F. Of the 202 families who agreed to participate in the project, 78.7% (n = 159) were still active at project end.

G. The majority of the children in this study were males (58.4%).

H. The leading diagnoses for children in this study were cortical visual impairment (n = 41, 20.6%), retinopathy of prematurity (n = 38, 19.1%), and optic nerve hypoplasia (n = 33, 16.6%).

I. The frequency of visual disorders differed according by severity of additional disability. Optic nerve hypoplasia (n = 16, 20.3%) and albinism (n = 13, 16.5%) were the most frequent visual disorders for participant children without additional disabilities.

Retinopathy of prematurity (n = 16, 36.4%) and optic nerve hypoplasia (n = 7, 15.9%) were the most frequent visual disorders for participant children classified as having mild additional impairment. Cortical visual impairment (n = 29, 38.2%) and retinopathy of prematurity (n = 11, 14.5%) were the most frequent visual disorders for participant children classified as having severe additional impairment.

J. The frequency of visual disorders differed according to ethnic subgroups. The most frequent visual disorder reported for African-American children was colobomas and other structural anomalies (n = 4, 44.4%); for Hispanic children, retinopathy of prematurity (n = 11, 39.3%); and for mixed ethnicity, optic nerve hypoplasia (n = 10, 32.3%). Visual disorders for caucasian participant children were similar to those reported for the total group.

K. At the conclusion of the study, 59.9% of PRISM subjects had been diagnosed with additional disabilities. Over one-third of the children with additional disabilities had conditions considered to be mild, while two-thirds were considered to be severe. There were no differences in the degree of additional disability among ethnic subgroups.

L. Over one-fifth of children in this study (n = 40, 20.8%) weighed less than 1000 grams at birth, although over two-thirds were born at 2500 grams or more (normal birth weight). Hispanic participant children reported significantly lower mean birth weights than other ethnic subgroups.

M. Similarly, one-fifth of children were born at 26 weeks or less gestation, while 61.6% were born at full term. Hispanic participant children reported significantly younger mean gestation than other ethnic subgroups.

N. The majority of children (n = 142, 75.9%) were hospitalized after birth for 30 days or less. The longest length of hospitalization was 180 days. Hispanic participant children were hospitalized after birth significantly longer than other ethnic subgroups.

O. Thirty-nine percent (39.0%) of children were from non-European American ethnic groups.

P. English was the primary language used in the homes of 87.5% of the participants.

Q. At the time the project ended, most children were living with two parents (n = 164, 85.5%).

R. The mean age at participant child's birth was 27.3 years for mothers (range = 14-44 years) and 29.7 years for fathers (range = 17-67 years). Mean years of education was 13.4 years for mothers and 13.6 years for fathers. All income levels are represented in the participants.

S. There is great variability in the range of developmental scores for each age group, regardless of the unit of comparison. Standard deviations of developmental scores appear to get larger as children get older.

T. In general, resolution acuity improved over the course of the project, for those children who responded to the Teller Acuity Card procedure. Children with visual disorders of cortical visual impairment, albinism, or structural anomalies tended to experience improved vision over the course of the study. Children with retinopathy of

prematurity, optic nerve hypoplasia, and anophthalmia or microphthalmia tended not to experience any change in visual impairment over time.

Research Question 1: Do children between birth and 59 months (5 years) of age who are visually impaired attain developmental milestones at chronological ages that differ from those of sighted children?

1.1 The age of acquisition for 12 milestones was delayed in comparison to typically developing children.

1.2 For 5 milestones, median age of acquisition was within the range of attainment for typical children. All 5 milestones that fell within the range for typically developing children were behaviors that required expressive and receptive communication.

1.3 Two milestones were acquired earlier by children in this study than by typical children (copying a circle; relating past experiences). Earlier acquisition is somewhat suspect, however, since data are available for less than 10% of the total sample.

Research Question 2: Do children between birth and five years of age who are visually impaired attain developmental skills in a sequence that differs from the sequence followed by sighted children:

2.1 Seven milestones were acquired in a different sequence for children in this study than for typically developing children.

2.2 Searching for a dropped object, feeding self bite-size pieces of food, and moving 3 or more feet by crawling were generally acquired in a later sequence by all children, with and without additional disabilities.

2.3 Walking without support, controlling bowel movements, and repeating 2-digit sequences were acquired in a later sequence for children with additional impairments.

2.4 Copying a circle occurred earlier in the sequence for children with additional impairments, but later in the sequence for children without additional impairments, though this, too, is suspect because of low numbers of children who had actually acquired the skill.

Research Question 3: Are there differences in the rate and sequence of development among sub-groups of children with varying etiologies of visual impairment?

3.1 For 10 developmental milestones, children with retinopathy of prematurity acquired skills at a significantly later median age than children with the three other most frequent visual diagnoses.

3.2 Children with albinism scored significantly higher than children with cortical visual impairment at ages 6-11, 12-17, and 18-23 months, on both the Vineland and the Battelle Developmental Inventory (BDI).

3.3 At age 24-35 months, no differences were apparent on the Vineland, but children with albinism scored significantly higher than children with cortical visual

impairment, retinopathy of prematurity, and all other diagnoses on the BDI.

3.4 There were no significant differences in Vineland or BDI scores at ages 36-47 and 48-59 months.

Research Question 4: Are there differences in the rate and sequence of development among sub-groups of children with varying levels of visual function?

4.1 The sequence of developmental milestone acquisition did not differ for milestones 2-10 for the four visual functioning groups.

4.2 There was a significant difference in age of acquisition for milestone 10 (plays interactively with adults) between no light perception and severe low vision groups. Children with no light perception acquired this skill at an older median age than children with severe low vision. Milestone 10 was the first behavior acquired by children with severe low vision, while children with no light perception acquired four other skills before they attained Milestone 10.

4.3 Differences among children with varying levels of visual function were not apparent for any other milestone. While the sequence of median milestone acquisition occurs in a different order for each of the 4 levels of visual function (see Table 00), these differences were not statistically significant. No pattern to the differing orders is apparent.

4.4 There were no significant differences in Vineland and BDI scores for the 0-5, 12-17, or 36-47 month age groups based on visual functioning level.

4.5 At 6-11 and 18-23 months, children with moderate low vision scored significantly higher than children with no light perception on both the Vineland and the BDI.

4.6 At 24-35 and 48-59 months, children with moderate low vision scored significantly higher than children with no light perception on the BDI, but there was no significant difference in Vineland scores.

Research Question 5: Are there differences in the rate and sequence of development between groups of children who are visually impaired only and those who have one or more additional impairments?

5.1 Children with additional impairments generally acquired milestones later than children without additional impairments.

5.2 The age of acquisition was significantly later for children with additional impairments for 12 of 19 milestones.

5.3 For one milestone (copies circle), children with additional impairments acquired the skill at an earlier age, but this finding is suspect because of the small numbers of children (n=11) who had actually acquired the milestone by the end of the study.

5.4 Children without additional impairments acquired more milestones sooner (for 6 milestones) or within the range (for 4 milestones) of typically developing children.

5.5 There was a significant difference in rate of development as measured by the Vineland and the BDI for all age groups except 0-5 months when analyzed by degree of additional impairment. Scores were higher for the group with no additional impairment for all age groups.

5.6 Children without additional impairments scored significantly lower than the norming population on the BDI for all age groups except 0-5 months.

5.7 Children with no additional impairments, who had normal intellectual function and no light perception, attained BDI scores below the mean of the norming population for all age groups.

5.8 At age groups 36-47 and 48-59 months, children with mild additional impairments were more like those with no additional impairment, suggesting that the effects of mild additional impairment may dissipate with age, while the effects of severe disability are sustained longer.

Research Question 6: Are there differences in the rate and sequence of development among children who differ along various social, cultural, or other variables?

6.1 There were no differences in development based on income, ethnicity, parent age, parent education, or other socio-cultural variables.

6.2 The age of acquisition for 13 milestones was significantly different for children whose gestation was full-term or better. Children with full-term gestations acquired these milestones earlier than did children whose gestation was less than full-term.

Research Question 7: What difference in rate and sequence of development are associated with infant temperament styles?

7.1 Parenting Stress Index (PSI) total scores indicate a higher percentage of high scores (i.e., high stress) than was found in the norming sample.

7.2 There is a greater percentage of higher child subscale scores than in the norming sample, except at age 0-5 months.

7.3 At 6-11 months, there was a significant difference in Vineland and BDI total scores for children whose parents reported high stress on the child subscale.