Appendix C. Dissemination Efforts

PRISM RAINBOWS (SEPTEMBER 1994 AND FEBRUARY 1996)

JOURNAL OF VISUAL IMPAIRMENT & BLINDNESS RESEARCH REPORT

PROJECT PRISM: A National Collaborative Study on the Early Development of Children with Visual Impairments

Division of Special Education, University of Northern Colorado, Greeley, co 80639
303-351-2691 1-800-395-2693 FAX 303-351-1061

Anchor Center for Blind Children
3801 Martin Luther King Boulevard
Denver, CO 80205

Blind Childrens Center
4120 Marathon Street
P.O. Box 29159
Los Angeles, CA 90029

Dallas Services for Visually Impaired Children
4242 Office Parkway
Dallas, TX 75204-3629

The Foundation for Blind Children
1235 E. Harmont
Phoenix, AZ 85020

New Mexico School for the Visually Handicapped Preschool
230 Truman, N.E.
Albuquerque, NM 87108

Perkins School for the Blind
Preschool Services
175 North Beacon street
Watertown, MA 02172

Visually Impaired Preschool Services
1229 Garvin Place
Louisville, KY 40203

PRISM RAINBOW #1
September 1, 1994

This is the first rainbow — or update - on our PRISM data. We are writing this information for PRISM parents, but we are also sending it to everyone involved with the project, including project evaluators, site coordinators, and advisory board members.

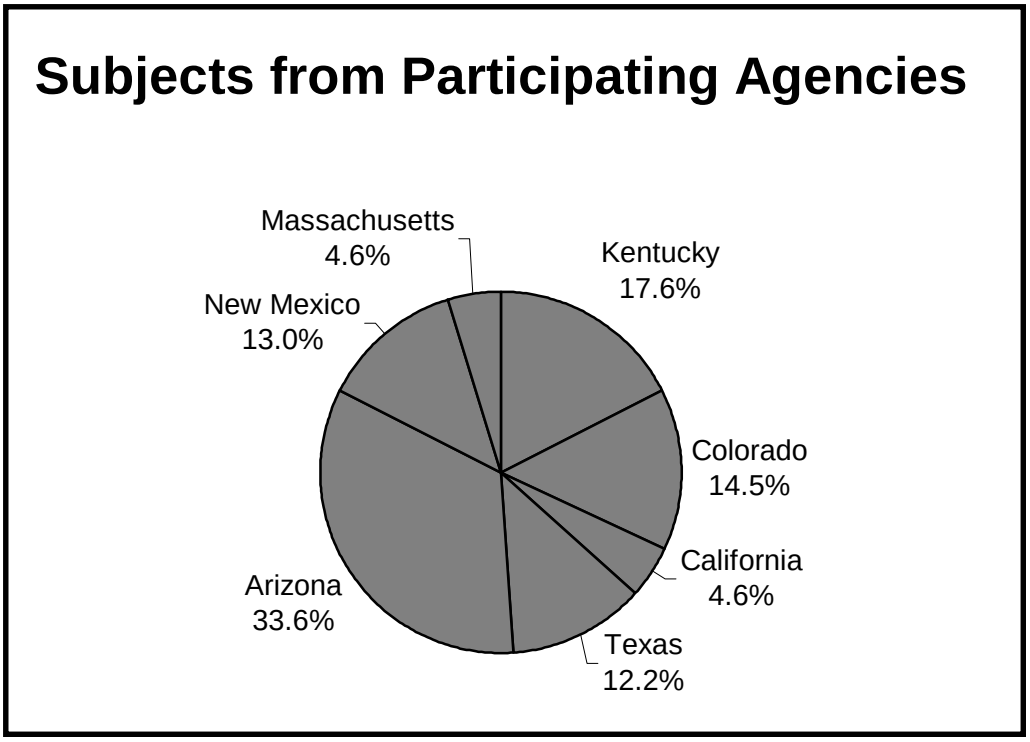
As of today, there are 139 children and families and 18 project evaluators. We seem to be adding families at the rate of about 10 per month. This is really great! Thank you all for your continuing cooperation and support!

PRISM staff seem to spend a lot of time eating together — so much so, that one of the project evaluators thought our project logo should be a knife, fork, and spoon! It seems like a good idea, then, to use “pie charts” to talk about the information we have so far. You’ll notice that we do not yet have all the information on all the children. So, remember as you read this that the information will probably change as we add more children.

WHERE YOU’RE FROM

The first pie chart shows where the first 131 children and families in the project live. About one-third of you live in Arizona, while a little over 1/6 of you live in Kentucky. After these two states, you live in Colorado, New Mexico, Texas, California, and

Massachusetts, in that order. California and Texas were the last two agencies to join the project, so we do not have too many families from these states right now.



INFORMATION ABOUT PRISM FAMILIES

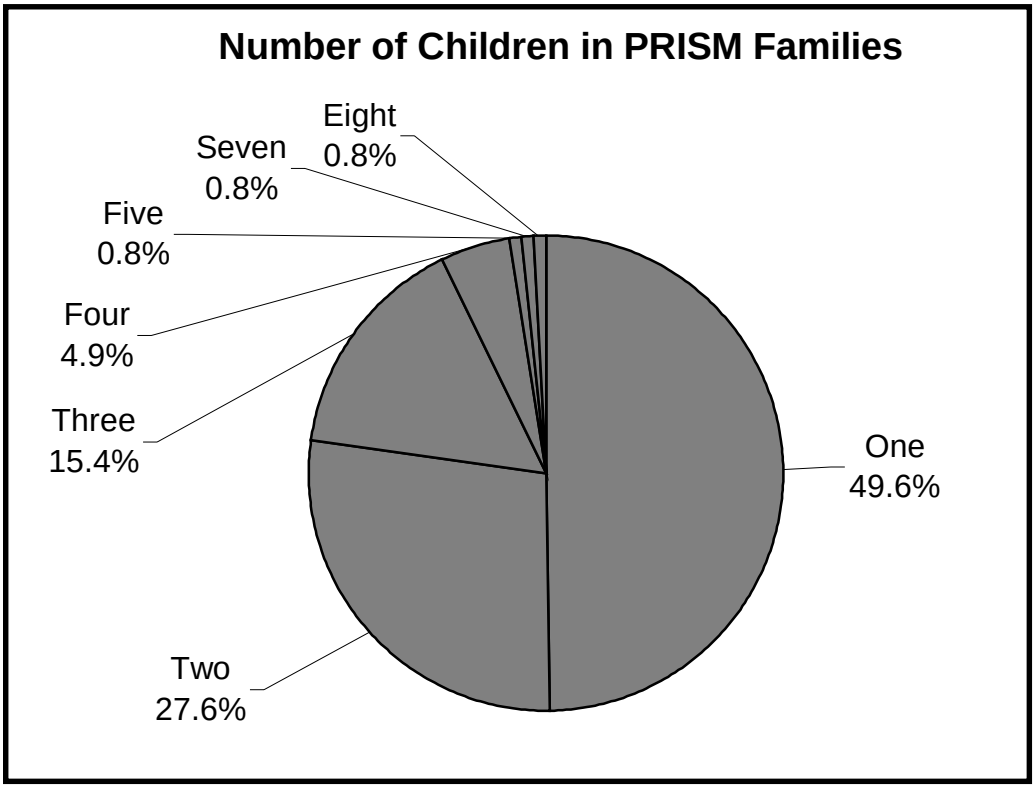
Based on the information we have right now, the average age of mothers at the birth of their PRISM baby was 26.6 years, while the fathers' average age was 29.1 years. Mothers on average have finished 13.0 years of school, while fathers have finished 13.3 years. Ninety-eight (98) children have both parents living at home, while 20 children have only one parent at home right now. Most families (about 94%) speak English, but 7 speak Spanish at home.

Most families make $20,000 a year or less, but there are PRISM families from all income levels. Table 1 shows how many families we have at each income level:

Table 1: Family Annual Income Level
(Based on 47 families)

Less than $10, 000	16 Families
$10,000 - $20, 000	9 Families
$20,001 - $30,000	6 Families
$30,001 - $40,000	4 Families
$40,001 - $50,000	7 Families
More than $50,000	5 Families

Most of you have only one (49.6%) or two (27.6%) children in your family. But some of you have as many as eight! The pie chart below shows how many families have how many children.

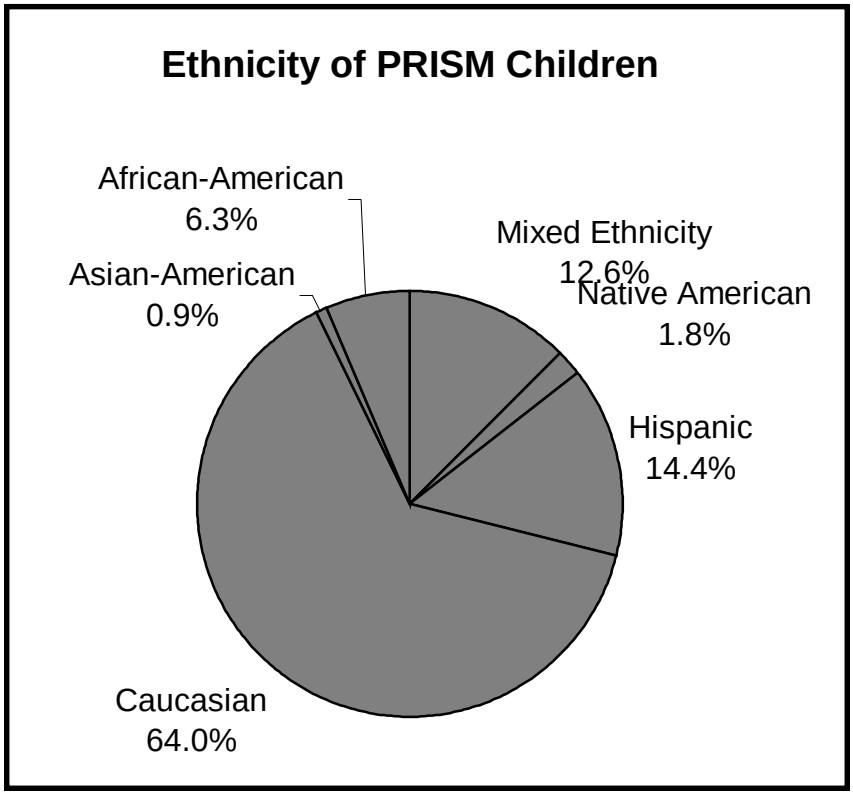


INFORMATION ABOUT THE PRISM CHILDREN

We are really pleased that so many families from a variety of different backgrounds are a part of PRISM. The next pie chart gives an idea of the number of different cultures that make up project PRISM.

Most of the children are Caucasian (white), but a large number are Hispanic and African-American. We also have children who are Native Americans, AsianAmericans, and about one-eighth who represent various combinations of ethnic backgrounds.

Most children seem to enter the project at about 9-1/2 months of age. So far, the youngest baby entering the project was 1 -month-old and the oldest child was 22months-old.



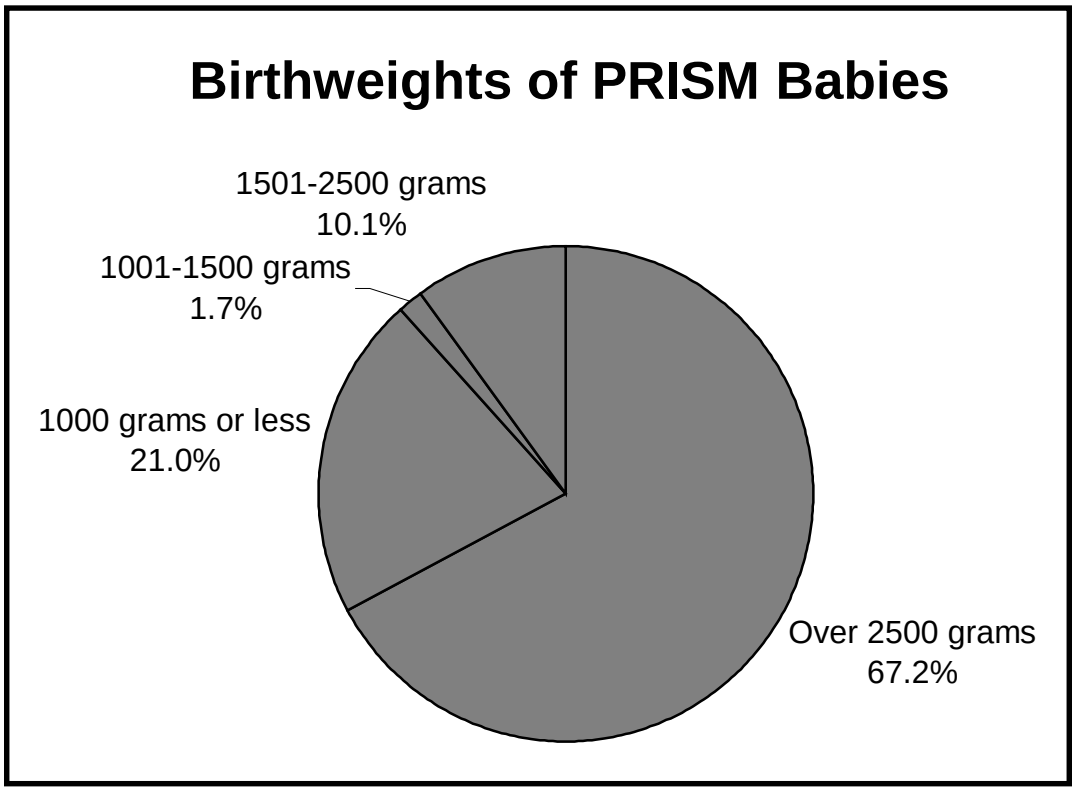
There are more boys (58.3%) than girls (41.7%) involved in the project right now, including five sets of twins. At the time they first enter the project, many children (52.2%) have already been diagnosed with an additional impairment - usually cerebral palsy or a developmental delay, but some children have more severe disabilities. We're keeping track of how these diagnoses of additional impairment change over time.

On average, PRISM subjects are about one month premature. We also know, however, that many of the children are very premature. Table 2 indicates the percentage of children at various gestational ages:

Table 2: Gestational Age of PRISM Children
(Based on 117 Children)

25 weeks or less	12.8%
26-29 weeks	9.4%
30-34 weeks	8.6%
35-38 weeks	20.5%
39 weeks or more	48.7%

The average birthweight for PRISM children is 2509.6 grams, or 5.5 pounds. The greatest number of children do in fact weigh more than 2500 grams at birth. But about one-third of the PRISM babies are considered low birthweight — weighing less than 1500 grams. And 21% are considered very low birthweight — weighing less than 1000 grams at birth.



In terms of visual impairment, project evaluators have reported to us over 32 different combinations of eye conditions and diagnoses for 115 children. We have tried to

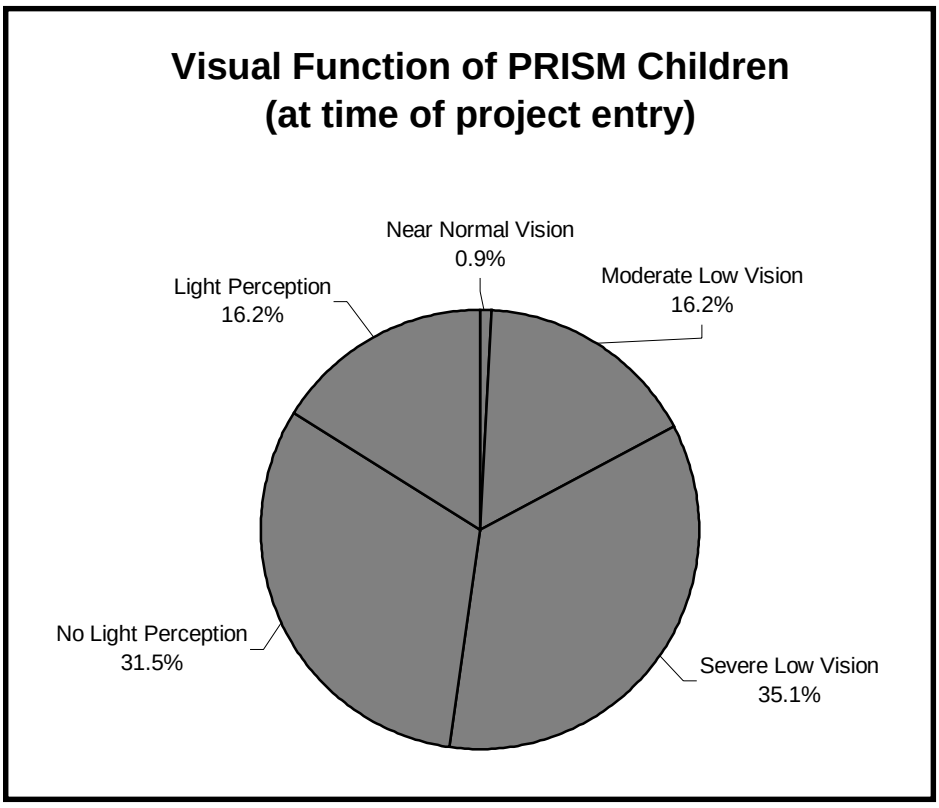
simplify these into 11 types of visual impairment, plus a catch-all group called “other.” The different types of eye conditions are listed in Table 3.

Table 3: Types of Visual Impairment of PRISM Children
(Based on 115 Children)

	Percent of Children
Optic nerve hypoplasia	22.6
Retinopathy of prematurity	19.1
Cortical visual impairment	17.4
Colobomas or structural problems	7.8
Albinism	7.0
Retinal disorders	6.1
Anophthalmia or Microphthalmia	4.6
Glaucoma	4.3
Leber’s congenital amaurosis	2.6
Cataracts	.9
Myopia	.9
Other	6.1

The average age of diagnosis of visual impairment was 3-1/2 months. Only one baby was diagnosed at birth, but almost one-third were diagnosed by the time they were one-month old. All diagnoses were made by the time the PRISM babies reached 13 months of age, but since we had asked that agencies include babies identified before 12 months of age, this doesn’t mean much. There are undoubtedly still some children whose visual impairment is not diagnosed until much later, but we can’t tell from this project. We’re pleased that the diagnoses are determined so early for the project ba-

bies.
In terms of visual function, or how the children are behaving visually, we again seem to have a good range of children involved in the project. The pie chart below shows that 31.5%, almost one-third, of the PRISM babies had no light perception at the time they entered the project, and thus they appeared to be totally blind. Another 16.2% had light perception, or some ability to respond to light. Both of these groups of children will most likely be tactual (touch) learners. About 35.1% of the children are classified as having severe low vision, meaning they respond visually to objects, but may also need touch to



learn. And 16.2% have moderate low vision and will probably be visual learners.

One thing we've noticed, though, is that visual function does not always stay the same. The functional vision of some children improves, while some do not do as well as they did before. We really will not know for a while whether this fluctuation in visual response is normal or even predictable - it could happen just because the children are having a bad day and/or are simply not interested in being tested!

WHAT'S NEXT FOR PROJECT PRISM

The project has been funded until September 1996, which means we have about two

more years to go. Your project evaluators will continue to visit about every 6-12 months, depending on your child's age. And we'll continue to code the information that you and the evaluators send to us and put it into the computer. We should have some good ideas by the end of the project of how children with visual impairments grow and develop, what the pitfalls are, and what seems to work best.

Thanks to the parents on the Technical Advisory Committee and a couple of the Arizona parents who visited with the Committee last March, we learned that some of the questionnaires were just too hard to fill out over and over again they were not geared to blind children and they raised too many feelings. We heard you! Some forms we have eliminated completely, and some we've reduced to only once per year. We hope this makes it a bit easier. Please complete the forms you have for now; eventually, everyone will have the new packets with the correct forms in them.

We know that one of your frustrations is that there are no tests out there that address your child's visual impairment and his or her unique way of learning. It's one of our frustrations, too. We hope that Project PRISM will eventually lead to new tests. And if it does, it will happen because all of you — parents, project evaluators, site coordinators, and agencies — gave so much of your time and energy to make it happen. Thank you!

Kay Ferrell, *Principal Investigator*

Sally J. Deitz, *Project Director*

Kevin Stewart, *Graduate Research Assistant*

Lisa Baird Speaker, *Secretary*

One of the parents on the Technical Advisory Committee is interested in writing something to help parents of blind children. "I will always remember the fear of the future that we faced when Brooke was born, and I found very little comfort in the sparse written materials available," he wrote. He would be interested in talking with any parent who is willing to talk about his or her experiences — for example, how you have dealt with things in the context of your family, how you deal with the medical and educational bureaucracy, and how you have built relationships with your child who is visually impaired. You can enclose a sealed letter addressed to John in your PRISM envelope, and we'll be sure it gets to him, or you can reach John at:

John A. Jostad, 303-221-2248 (work), 303-221-4203 (home), 303-4844919 (fax at work)

PROJECT PRISM: A National Collaborative Study on the Early Development of Children with Visual Impairments

Division of Special Education, University of Northern Colorado, Greeley, co 80639
303-351-2691 1-800-395-2693 FAX 303-351-1061

Anchor Center for Blind Children 3801 Martin Luther King Boulevard Denver, CO 80205
Blind Childrens Center 4120 Marathon Street Los Angeles, CA 90029
Dallas Services for Visually Children 4242 Office Parkway Dallas, TX 75204-3629
The Foundation for Blind Preschool 1235 E. Harmont Phoenix, AZ 85020
New Mexico School for the Visually Handicapped Preschool 230 Truman,N.E. Albuquerque, NM87108
Perkins School for the Blind Preschool Services 175 North Beacon Street Watertown, MA 02172
Visually Impaired Preschool Services 1229 Garyin Place Louisville, KY 40203

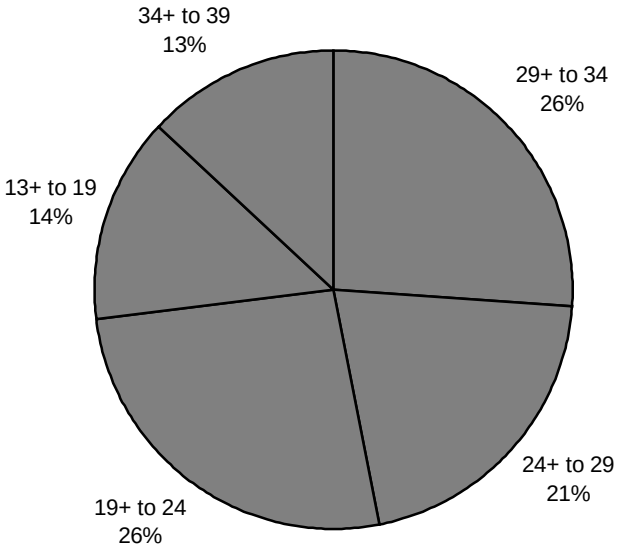
PRISM Rainbow #2
Spring, 1996

We now have 199 children enrolled in PRISM — only 1 more subject to reach our goal of 200. Since we do not receive all the information on a child and family at the same time, we can't tell you about all 199 children right now. But, we thought this would be a good time to report some of our data to PRISM parents, evaluators, administrators, and advisory board members.

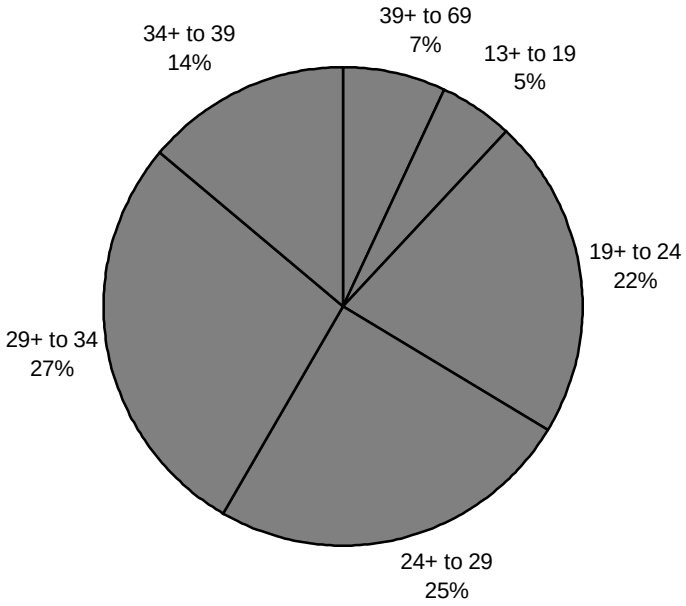
PRISM FAMILIES

When their babies were born, the ages of PRISM mothers ranged from 14 to 39 years and the ages of PRISM fathers ranged from 17 to 67 years. Age distributions for parents are summarized in the following pie charts.

Age of Mothers at PRISM Child's Birth

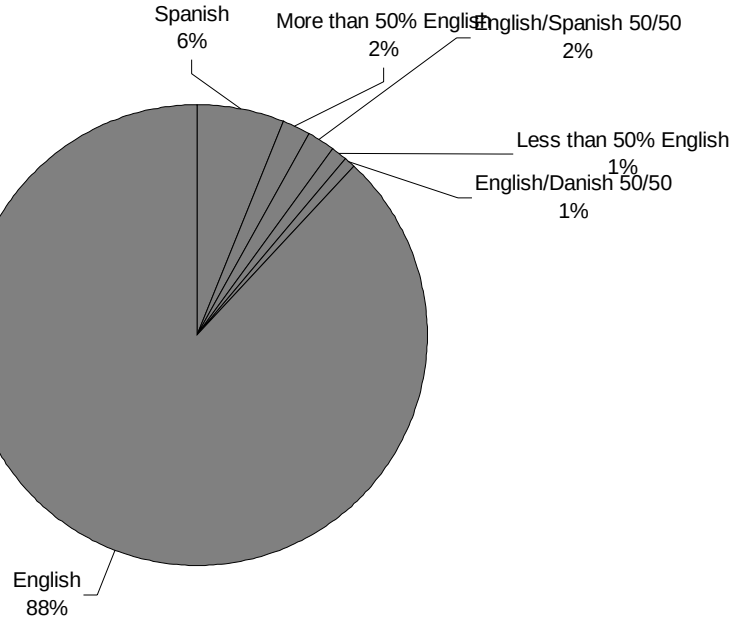


Age of Fathers at PRISM Child's Birth



Most of the PRISM families speak English at home (88.2%), and 5.9% use Spanish at home. The following chart illustrates the distribution of language as reported by 168 PRISM families.

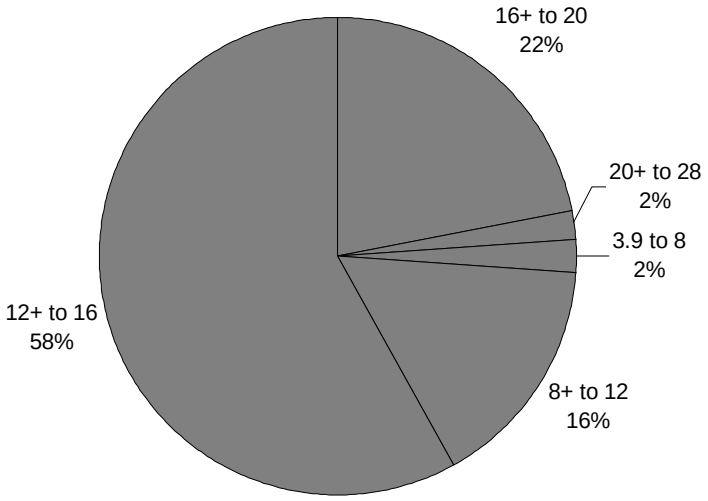
Primary Language as Reported by 168 PRISM Families



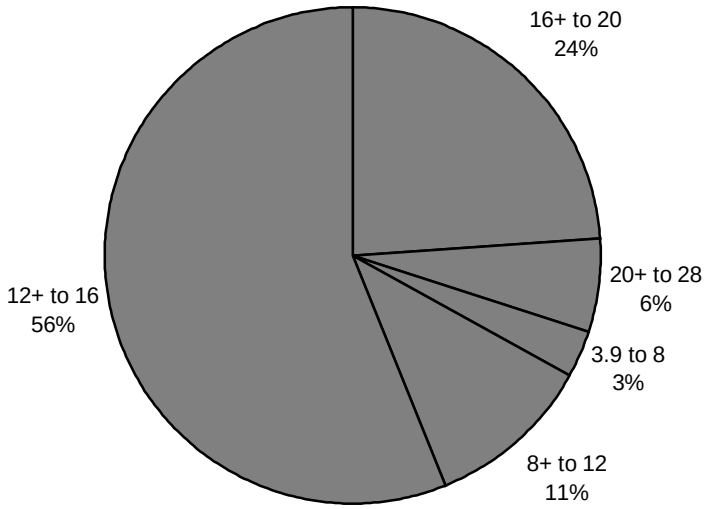
Reports from 157 families indicate that 100 families (63.7%) are Caucasian; 25 families (15.9%) are Hispanic; 19 (12.1%) families include one Caucasian parent; 7 (4.5%) families are African-American; 2 (1.3%) families are Native American; and 4 families (2.5%) are either Hispanic/Native American, Hispanic/Korean, or Hispanic/Filipino.

The number of years PRISM parents attended school are reported in the following diagrams. Most parents graduated from high school; some parents have been in school longer than project staff!

Years of Education of 165 PRISM Mothers



Years of Education of 151 PRISM Fathers

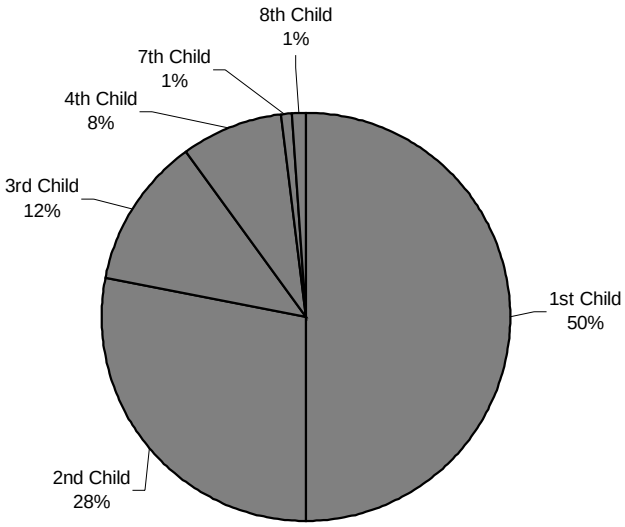


PRISM CHILDREN

Based on the information we have from 169 children, there are 70 girls (41.4%) and 99 boys (58.6%) in PRISM. The average entry age into PRISM is 8.7 months. Most babies entered PRISM when they were between 7 and 12 months old (70.1%). The average birthweight of PRISM babies was 5.65 lbs. (2568.9 grams).

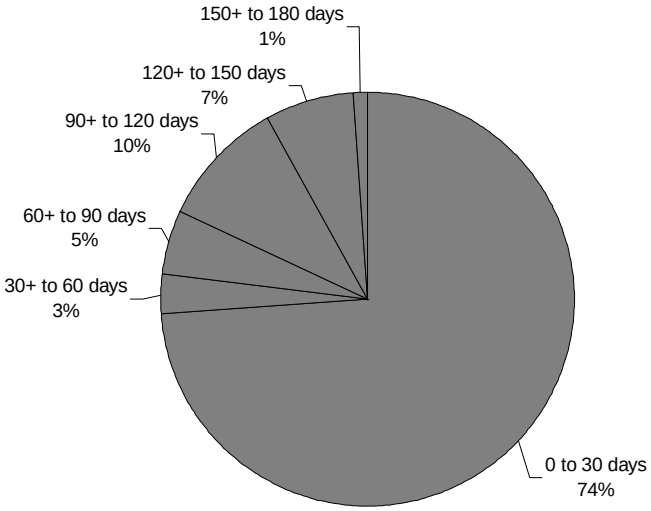
Ten PRISM children are twins (two are from two different sets of identical twins). Most PRISM children (92.2%) are single-birth children. Approximately one-half of PRISM children are the family's first born. The following chart summarizes the PRISM child's birth order in the family.

Birth Order of 169 PRISM Children



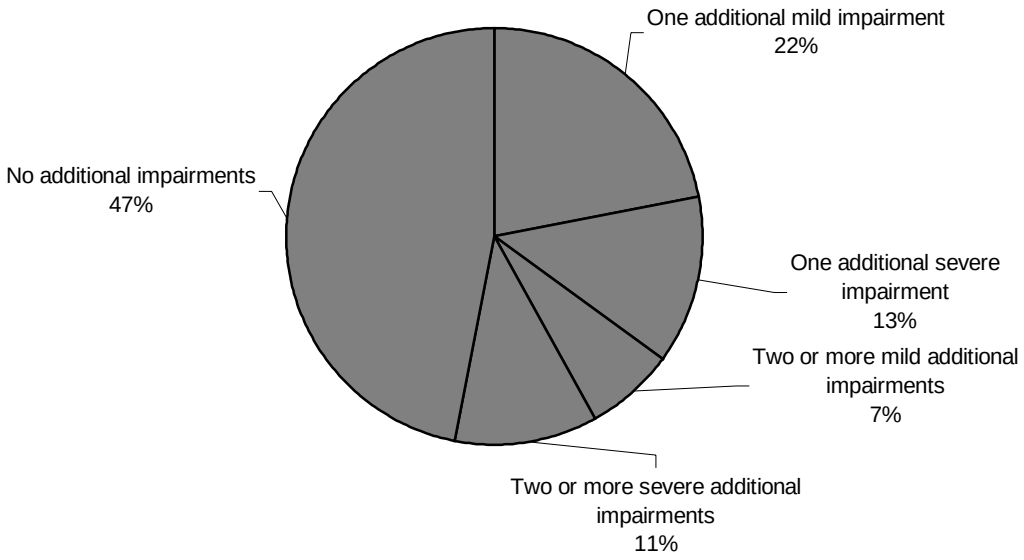
Based on data from 165 PRISM babies, the average hospital stay right after birth was 30 days, but 91 (55.2%) of these babies stayed in the hospital for 1 week or less. The minimum stay was I day and the maximum stay was 180 days. The chart below presents a breakdown of hospital stay in 30-day intervals.

Hospital Stay Right After Birth for 165 PRISM Babies



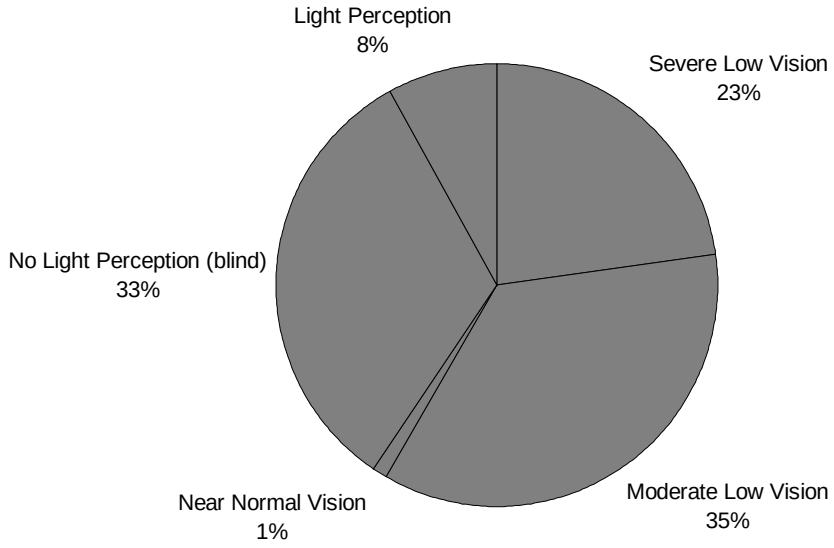
Over half of the PRISM babies have been diagnosed with an additional medical condition or disability. Only 47.3% are considered “visually impaired only.” This item has been one of the most difficult for us to figure out, because PRISM babies seem to have such a wide variety of complications. For now, we’ve grouped conditions together according to how severe the problem seems to be, but we’re working with a pediatrician to come up with a better way of looking at it.

Percent of 169 PRISM Children with Additional Impairments



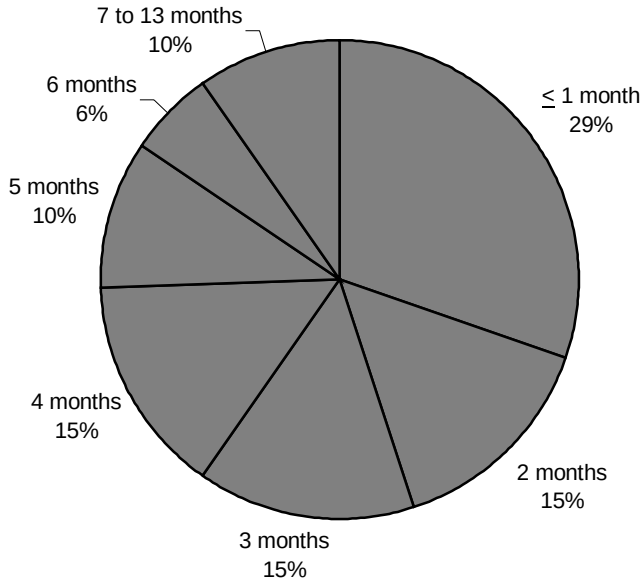
The classification of visual functioning at entry into PRISM was determined by the child’s best consistent response with both eyes to the Teller Acuity Cards. The classifications are reported in 5 categories of Visual Functioning in the chart below.

Visual Functioning of 164 PRISM Children at Project Entry (Using Teller Acuity Cards)



The age of the PRISM children at the time of diagnosis of visual impairment varies from less than one month of age to 13 months.

Age of Diagnosis of Visual Impairment for 157 PRISM Children



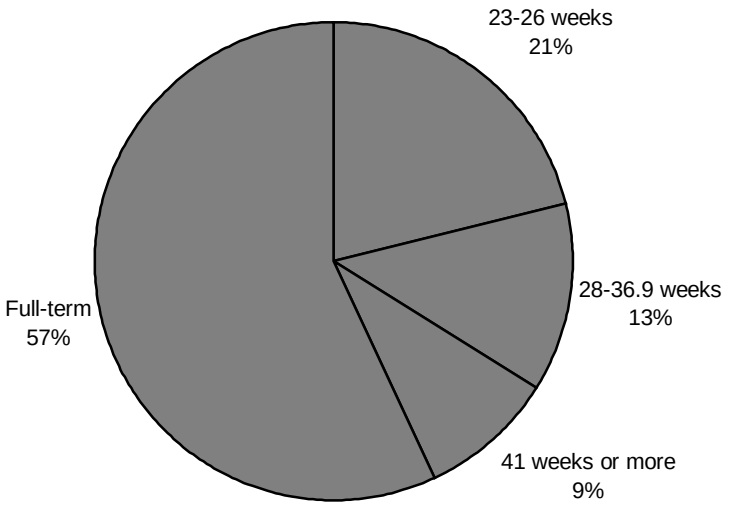
There are 49 classifications of types of visual impairment. The most frequent visual impairments are listed in the following table.

Most Frequent Visual Impairments of 165 PRISM Children

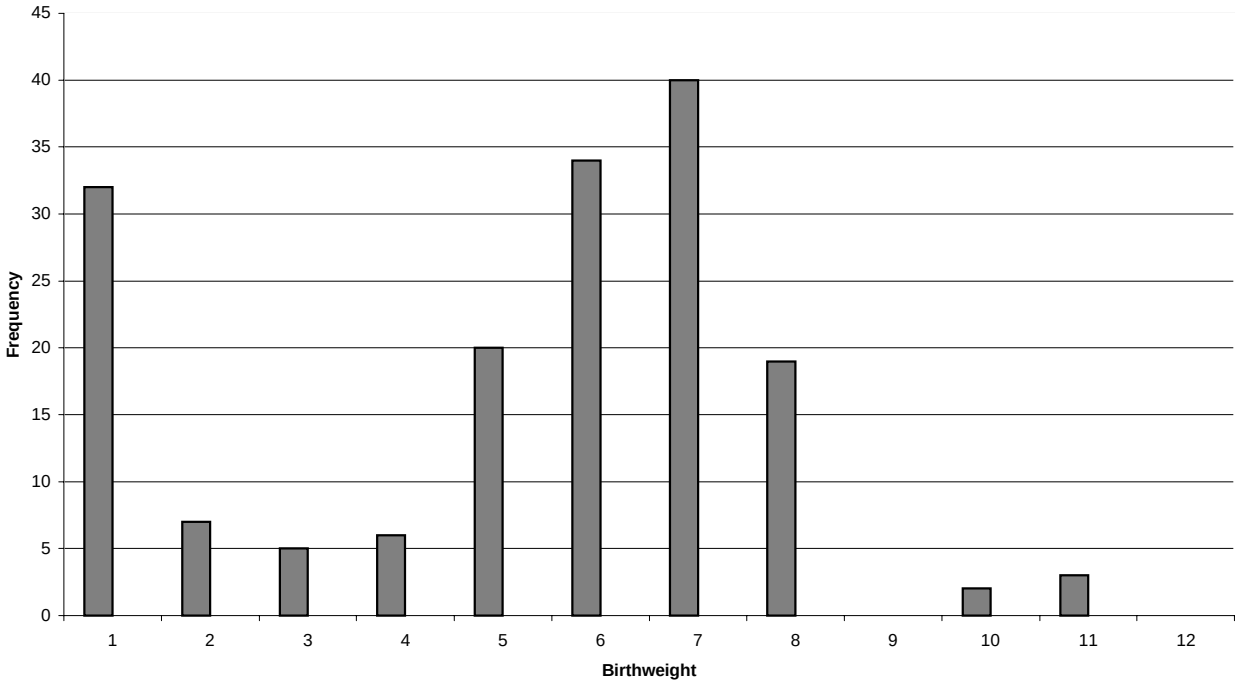
Category/Type	Number (Percent)
Retinopathy of prematurity	33(20.0%)
Optic nerve hypoplasia	27(16.4%)
Cortical visual impairment	22(13.3%)
Albinism	14(8.5%)
Coloboma	6(3.6%)
Glaucoma	5(3.0%)
Microphthalmos	5(3.0%)
Aniridia	4(2.4%)
Leber's congenital amaurosis	3(1.8%)
Cataracts	3(1.8%)
Anophthalmos	2(1.2%)
Bilateral detached retinas, glaucoma	2(1.2%)
Cytomegalo virus (CMV)	2(1.2%)
Septic optic hypodysplasia (hypoplasia)	2(1.2%)
Optic atrophy	2(1.2%)
Others	33(20.0%)

Data for 166 babies indicate that 35 babies (21.1%) were less than 26 weeks' gestation at birth. There were 57 (34.3%) pre-term babies (less than 37 weeks' gestation) at birth. The next chart shows gestation in weeks for PRISM babies.

Gestation for 166 PRISM Babies

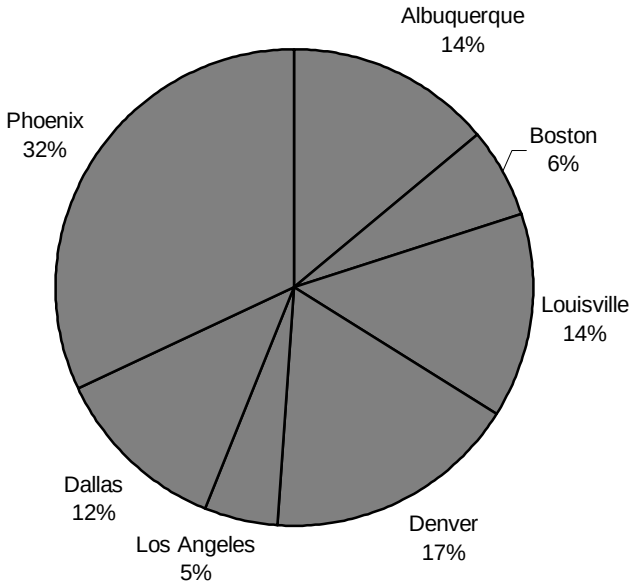


Data for 168 babies indicate that 57 (33.9%) babies had birthweights less than, 5.5 lbs. A histogram illustrating the birthweights in pounds follows.



The 7 agencies and the percent of 191 children they enrolled in the project are:

PRISM Agencies



The ethnicity of the PRISM children in the seven agencies is illustrated in the next table.

Numbers and Percentage of 157 PRISM Children by Agency and Ethnicity.

Agency	African American	Caucasian	Hispanic	Native American	Caucasian Mixed	Other	Total (%)
Denver, CO	0	18	4	0	4	1	27 (17.2%)
Los Angeles, CA	1	4	1	0	0	1	7 (4.5%)
Dallas, TX	2	12	2	0	2	1	19 (12.2%)
Phoenix, AZ	0	33	12	1	10	1	57 (36.3%)
Albuquerque, NM	0	10	5	1	2	0	18 (11.5%)
Boston, MA	0	9	1	0	0	0	10 (6.4%)
Louisville, KY	4	14	0	0	1	0	19 (12.1%)

The Research Questions

Data entry is at the stage where the milestone data will be entered soon. Since sequence and rate of development are part of our research questions, we are looking forward to being able to have more information on the milestones. We are also working on a classification system for the infant temperament styles based on the Carey Temperament Scale. It is exciting to be very close to reaching our goal of 200 children.

Next Steps

The project officially ends on September 30th, so many of you have already participated in your last assessment. Others will have one last assessment sometime in the next six months. We expect that is good news for BE of you -children, families, and teachers alike!

We still have until December 31, 1996, to finish analyzing the data and to write the final report for the U.S. Department of Education. In January, 1997, we will send a report to you, too. Thank you for helping us find out more about the development of young children with visual impairments — we know this has been a lot of work, and we really appreciate your confidence in us and your cooperation with the study. You made it happen!

Research Notes

Project PRISM: A National Collaborative Study on the Early Development of Children with Visual Impairments

S.J. Deitz, K.A. Ferrell

The University of Northern Colorado is conducting a federally funded five-year longitudinal study examining the rate and sequence of development of children ages birth to five years who are blind or visually impaired. The study is funded by the U.S. Department of Education, Research in Education of Individuals with Disabilities Program. Conducted in seven sites throughout the country and currently including over 100 children, the study explores interactions among child, family, and service variables. This research will yield data regarding not only the development of children with visual impairments, but also the child, family, and service variables which predict these outcomes. Upon completion of Project PRISM in 1996, it is estimated that over 200 children and families will have participated.

Project PRISM is unique as a model of large-scale multi-site research with a lowincidence population. It is a collaborative effort of teacher educators who designed and now direct the project, program administrators who cooperate at each of the, seven sites by giving program staff time and expertise, early intervention practitioners who are trained to conduct the assessment battery at eight data points in each infant's life, and families who agree to be followed over a five-year span to contribute to the research project goals.

Previous studies of the development of children with visual impairments have been limited by small, homogeneous samples and inadequate instrument selection and administration. These limitations have hindered the conclusions to be drawn about the population as a whole and have not provided solid normative data on development of this low-incidence group.

Prior to undertaking this study the investigators, in collaboration with other colleagues, conducted a four-year pilot study—VIIRC (Visually Impaired Infants Research Consortium)—which explored the acquisition of developmental milestones of young children with visual impairments. A summary of VIIRC's first-year results appears in the October 1990 Journal of Visual Impairment & Blindness (pp. 404-410).

The VIIRC data collection was initially conducted by interviewing primary caregivers of 82 subjects in four New York City programs serving this low-incidence population. However, after the first year, colleagues from throughout the country contributed data using the scripted interview and instrument, so that 314 children were included by the end of the four-year pilot study.

Findings of the VIIRC pilot study indicate that the median age for acquisition of these milestones by children with visual impairments was at or near the age for typical children. For children diagnosed as having one or more secondary handicapping conditions, however, the probability of developmental delay was higher and there was decreased overlap with typical norms.

The VIIRC pilot study contained several limitations that make it difficult to apply the findings to the larger population of children with visual impairments. These limitations included possible inaccuracy of parent/caregiver recall of milestone acquisition, possible bias in the scripted interview, lack of uniform data on visual functioning, possible sample bias because each subject was receiving early intervention services, and possible underdiagnosis of secondary disabilities due to the young age of many subjects. In an effort to correct for some of these limitations, investigators set out to design the current study, Project PRISM, in which selected individuals were trained to high reliability to conduct standardized assessments over time.

University of Northern Colorado, H023C10188

To collect data, a battery of standardized and project-designed assessments are conducted at eight specific ages during each subject's involvement with the project. The assessments include tests administered to each child, parent self-reports, reports by case managers, and interviews of caregivers.

The child measures include assessments of visual acuity, development across domains (language, social, fine and gross motor, socialization, and self-help), and adaptive behavior. The family measures include a stress index, demographics, and assessments of each child's home environment. The service measures are questionnaires of model, intensity, and perceptions of services. These forms are completed by the site evaluators, the parents, and the primary interventionist/case manager.

Seven agencies throughout the country that provide early intervention for children who are visually impaired are participating in Project PRISM. Agencies were selected to provide a balance of rural/urban, public/private, and center-based/home-based services. These seven agencies are: 1) Foundation for Blind Children in Phoenix, Arizona; 2) New Mexico School for the Visually Handicapped Preschool in Albuquerque, New Mexico; 3) Anchor Center for Blind Children in Denver, Colorado; 4) Visually Impaired Preschool Services in Louisville and Lexington, Kentucky; 5) Dallas Services for Visually Impaired Children in Dallas and Fort Worth, Texas; 6) Blind Children's Center in Los Angeles, California; and 7) Perkins School for the Blind in Watertown, Massachusetts. The last two sites are included due to supplemental funding provided by the Hilton/Perkins Project based at Perkins School for the Blind in Watertown, Massachusetts.

Each ;ear, from two to four teachers from each of the seven sites are brought together for a week of training on each of the selected instruments. Training, using both demonstration and videotape, is conducted by project staff to assure outcome interrater reliabilities over 90. These assessments are then imbedded into the services already being provided for the children and their families at each site. Participating families receive stipends for completing each assessment battery at the eight data collection times, and each of the seven sites receives an annual stipend for its efforts.

Between annual training sessions project staff conduct site visits to each site evaluator to confirm maintenance of the interrater reliability achieved during training. These site visits also allow opportunities to address concerns of the site evaluators and to coach them if necessary in assessment protocols.

Upon its completion in 1996, Project PRISM will provide original empirical data on the developmental patterns of young children who are blind or visually impaired and will identify predictors of developmental outcomes. This information will assist both families and service providers in defining best practice and in ensuring optimum development of children in the future.

Sally J. Deltz, Ph.D., (project director, Project PRISM) assistant professor, Marymount Manhattan College, 221 East 71st Street, New York, NY 10021;
Kay Alicyn Ferrell, Ph.D., (principal investigator, Project PRISM) professor of special education, Division of Special Education, University of Northern Colorado, Greeley, CO 80639.

