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ABSTRACT

This report is the second in a series of publications developed to assist in the planning and development of a comprehensive, coordinated service delivery system for Arizona infants and toddlers who are developmentally delayed or at risk of developing handicapping conditions, and their families. It documents the number of children in Arizona currently being served, and the number in need of special services, based on the prevalence and incidence of certain characteristics in the population and an interpretation of the broad definition of who needs early intervention provided in Public Law 99-457. Three distinct groups are considered: (1) children who are experiencing developmental delays; (2) children who have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay; and (3) children who are at risk of having substantial developmental delays if early intervention services are not provided. The report provides numerical projections of the size of the target population through the year 2000, and examines the geographic, ethnic, and socioeconomic distribution of the target population across Arizona. Appendices contain statistical data and eligibility policy formation information. Includes 50 references. (JDD)

BIRTH TO 3

PLANNING FOR ARIZONA'S FUTURE

Assessing the needs of infants and toddlers who are developmentally delayed or at risk of developing handicapping conditions and their families

PART II

DISCOVERING WHO WILL BE SERVED

ARIZONA INTERAGENCY COORDINATING COUNCIL

DEPARTMENT OF ECONOMIC SECURITY
PHOENIX, AZ 85061

Early Childhood Planning Project

Assessing the needs of infants and toddlers who are developmentally delayed or at risk of developing handicapping conditions and their families

Part II

DISCOVERING WHO WILL BE SERVED

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INTERAGENCY COORDINATING COUNCIL FOR INFANTS & TODDLERS
Building a strong early intervention system in accordance with Public Law 99-457

Rose Mofford
Governor

William P. Allaire
Council Chair

Marlene J. Morgan
Executive Director

June 21, 1989

Dear Reader:

"Discovering Who Will be Served" is the second in a series of publications developed to assist the Interagency Coordinating Council for Infants and Toddlers in addressing the needs of very young children with, or at risk of, handicapping conditions and their families.

The process of planning and developing a comprehensive service system for infants and toddlers with handicapping conditions and their families requires the collection of information on the population currently being served as well as projections regarding the total size of the population in need of services. These figures can be compared to establish a more global picture of the gap between children served and projected estimates of the number of children in need of services...the unserved population.

This information will assist the Council in long-range budget planning, identifying the location of services, assuring an equitable distribution of resources and determining potential personnel needs, in accordance with Public Law 99-457, Education of the Handicapped Act Amendments of 1986.

Hopefully, the document also will serve as a resource to policymakers, planners, providers and advocates as well as the citizenry of the state of Arizona.

Sincerely,

Bill Allaire
Bill Allaire,
Chairperson

Marlene Morgan
Marlene Morgan, MSW
Executive Director

BA:MM:cc

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PREFACE

This report is Part II of a series of three publications prepared for the Arizona Interagency Coordinating Council to assist in the planning and development of a comprehensive, coordinated service delivery system for infants and toddlers who are developmentally delayed or at risk of developing handicapping conditions and their families.

The publication series consists of the following three reports: (1) **Understanding Arizona's Agencies**; (2) **Discovering Who Will Be Served**; and (3) **Arizona's Parents Speak Out**.

Understanding Arizona's Agencies, Part I, is a report identifying the key agencies in the State of Arizona who have been designated by the Arizona legislature and U.S. Congress to respond in a variety of ways to the special needs of young children and their families. The purpose of the report is to provide policy-makers, service providers, and parents with a summary description of the legislated programs in the State of Arizona that have been mandated by federal and state laws, and interpreted at the policy and implementation level within the respective agencies. A description of each agencies' mission, eligibility requirements, and services is provided.

Discovering Who Will Be Served, Part II, is a report on the number of children in the State of Arizona in need of special services, based on the prevalence and incidence of certain characteristics in the population and an interpretation of the broad definition of who needs early intervention provided in P.L. 99-457. Three distinct groups are considered: (1) children who are experiencing developmental delays; (2) children who have a diagnosed physical or mental condition which has a high probability of resulting in developmental delay; and (3) children who are at risk of having substantial developmental delays if early intervention services are not provided. The report provides numerical projections of the size of the target population through the year 2,000, and graphic displays of the geographic and ethnic distribution of the target population across Arizona.

Arizona's Parents Speak Out, Part III, reports on the needs of Arizona's families as identified by the parents and caregivers of young infants and toddlers who are developmentally delayed or at risk of developing handicapping conditions. A statewide, representative sample of 600 parents served by Arizona's key agencies were surveyed in face-to-face interviews with trained interviewers. Respondents were asked questions related to the nature and type of services they were receiving, their satisfaction with the services, their need for other services, financial needs, information needs, and emotional support needs. The report summarizes their responses, as well as identifies unique needs as represented by different ethnic groups and rural vs. urban residency.

ACKNOWLEDGEMENTS

The authors wish to express appreciation to the following persons for their assistance in completing this study:

To Marlene Morgan, who as the Executive Director of the Arizona Interagency Coordinating Council and our Contract Manager provided unwavering support, enthusiasm, and commitment to this analysis and its potential for influencing positive change for young children and their families.

To Mary Slaughter, Chairperson of the ICC Problem Identification and Definition Subcommittee monitoring the implementation and completion of this report, for her commitment to obtaining information on the families and children for whom this report is intended to help.

To all the members of the ICC, for their commitment to substantive and quality investigations that result in information for the future, as well as for immediate, short-term solutions.

To all the agency personnel who gave of their time to assist us in securing the necessary information for this analysis, especially Sundin Applegate, Joan Sandberg, Susan Burke, Linda Yee, Kate Zipsnis, Joanne Woodley, and Joan Kiser. There are many others, too numerous to mention, who shared information with us, and without their help, this report would be much less complete. It is only through this spirit of cooperativeness and involvement that the "comprehensive, coordinated" system articulated in P.L. 99-457, Part H, will begin to be realized.

To Bob Horn and Marci Gerlach for the creation and development of our cover page. To Cindy Trojaniak for her exceptional patience and skills in preparing this report for publication; to her we owe the inclusion of well-organized, easy-to-read graphics and narrative material.

INTRODUCTION

One of the biggest challenges facing the state of Arizona as it begins to implement Public Law 99-457 is discovering who will be served in the statewide, comprehensive early intervention system. Although the law provides broad policy guidelines, it yields to the states issues related to specifying the definition of developmental delay and the optional inclusion of at-risk populations, providing state-level flexibility and responsibility.

These decisions will affect the total size of the population that will be determined eligible for early intervention services. The purpose of this report is to provide an estimate of the size of the Arizona population of infants, toddlers and preschoolers in need of early intervention and preschool services. It is useful to review key elements of Public Law 99-457, Part H, as a guideline for developing the rationale related to an estimate of the size of the population to be served.

Public Law 99-457, Part H

Public Law 99-457, Part H (Sec. 671), establishes a Congressional finding and policy regarding "an urgent and substantial need--

"(I) to enhance the development of handicapped infants and toddlers and to minimize their potential for developmental delay,

"(2) to reduce the educational costs to our society, including our Nation's schools, by minimizing the need for special education and related services after handicapped infants and toddlers reach school age,

"(3) to minimize the likelihood of institutionalization of handicapped individuals and maximize the potential for their independent living in society, and

"(4) to enhance the capacity of families to meet the special needs of their infants and toddlers with handicaps.

"(b) Policy.--It is therefore the policy of the United States to provide financial assistance to States---

"(1) to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency program of early intervention services for handicapped infants and toddlers and their families, "(2) to facilitate the coordination of payment for early intervention services from Federal, State, local, and private sources (including public and private insurance coverage), and

"(3) to enhance its capacity to provide quality early intervention services and expand and improve existing early intervention services being provided to handicapped infants, toddlers and their families."
(100 Stat. 1146)

Within this broad mandate, the law provides general definitions of the target population in Sec. 672:

"(1) The term 'handicapped infants and toddlers' means individuals from birth to age 2, inclusive, who need early intervention services because they--

> *"(A) are experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures in one or more of the following areas: Cognitive development, physical development, language and speech development, psychosocial development, or self-help skills, or*
> *"(B) have a diagnosed physical or mental condition which has a high probability of resulting in developmental delay.*

Such terms may also include, at a State's discretion, individuals from birth to age 2, inclusive, who are at risk of having substantial developmental delays if early intervention services are not provided.
(100 Stat. 1146)

The challenge

The law requires states to make two major decisions regarding the definition of the population of children who will be served through the statewide early intervention system. A report by the Administration on Developmental Disabilities (ADD) describes and discusses the state challenge in regard to what children and families will be served (1).

Children to be served represent three distinct groups. The first two groups are mandatory. (1) children experiencing developmental delay, and (2) children with a diagnosed physical or mental condition which has a high probability of resulting in developmental delay (often referred to as "established risk").

The first major state decision is to determine a definition of developmental delay and established risk that will be used in determining eligibility for services (1).

The second major decision is determining whether or not to include the optional category of "at-risk" children in the definition and the subsequent eligibility criteria that will be used to identify this group for services. The third group consists of children "at risk" of having substantial developmental delays if early intervention services are not provided. Inclusion of this group of children, which may include biological and/or environmentally at-risk children, is not mandated by law.

Discovering who will be served

As the ADD report (1) suggests, the overall decision related to the definition of eligibility for early intervention service is one of "whether to cast a wide net or a narrow one." The purpose of this study is to estimate the number of children who are in need of early intervention services in the state of Arizona and project the size of this population to the year 2000. The most valid estimate would logically be based on the Arizona eligibility definition for early intervention services. However, a definition of eligibility for the state of Arizona has not yet been approved and adopted.

Therefore, this report will provide a projection of the size of the population to be served by first discussing the size of the mandatory population (developmentally delayed and established risk), and then estimating the size of the biologically at-risk population.

A prevalence rate of 3% of the total Arizona population of infants and toddlers (0-3 years of age) is used to estimate that there are 6,027 children who are developmentally delayed or at established risk who would be eligible for early intervention services in 1989.

A prevalence rate of 7% of the Arizona population of preschool children (3-5 years of age) is used to estimate that there are 14,028 children who are handicapped and in need of early intervention services in 1989.

As will be described in a subsequent section, the 3% prevalence rate was selected after a review of three major sources of information: (1) professional literature, (2) other state estimates, and (3) national special education data.

A prevalence rate of approximately 8% of the total Arizona population of infants and toddlers (0-3 years of age) is used to estimate that in 1989 there were 15,670 children who were biologically at risk for having substantial delays if early intervention services were not provided.

Limitations

Two existing conditions contribute to the limitations of this study. The exact number of children who are developmentally delayed or at risk of developing a handicapping condition is not known. Equally important is the fact that the total number of children currently being served by the various state agencies is not known.

Lack of precision in the numbers

Regarding the limitation in specifying the number of children in need of services, there does not currently exist one standard definition that is used by all of the state agencies providing services to this age group. Each state agency is governed by its own laws and statutory responsibilities, eligibility definitions, and requirements regarding the nature of the services it provides. Therefore, services are not currently being provided to one uniquely definable group of children.

Secondly, the screening and referral system for statewide, comprehensive identification of children in need of early intervention services has not yet been established. Unless the child has medical and physical complications, he/she might not enter a service system until the family notices that developmental milestones are not being met and seeks professional help, or until the child enters the school system. Therefore, many children remain unserved because their delays in development have not been brought to the attention of the service providing community.

Thirdly, even when some children are brought by their parents to the family physician, public health nurse or other entry level provider, their future problems in development may remain unidentified because the quality and sophistication of current screening and assessment instruments and procedures are insufficient for identifying subtle future developmental problems. Many professionals in a position to screen and identify children who may have developmental problems have been insufficiently trained to perform that role effectively. They may also be unaware of the programs available to assist children and families with a wide variety of needs and problems.

How many are currently served

Determining the number of children currently being served is important for identifying the gap between those eligible and served and those eligible and unserved. Knowledge of the gap in services can assist planners in establishing short-range and long-range goals toward full service to all eligible children and their families.

Several barriers become apparent when attempting to determine the number of children who are currently being served by Arizona's agencies. First of all, summary reports by different state and federal agencies use different age categories to aggregate the data for analysis and reporting. Infants and toddlers (birth through 2 years of age) are seldom reported on as a group. Rather, one agency may report information on the age category of birth to four years of age, while another agency may provide summary information on who is being served in the birth to three year old group.

Because many infants and toddlers are served by more than one agency, and because some are served by the same agency for more than one qualifying condition, child counts across agencies include an uncertain amount of double counting. Even within an agency unduplicated counts cannot always be obtained. A recent survey of over 550 parents in the state of Arizona by O'Connell et al. (2) suggests that approximately 28% of children currently served are served by more than one agency.

Until very recently, few states have had an inter-agency database for tracking children with special needs across agencies which can eliminate the problems of multiple counting. The state of Arizona is currently developing such a tracking mechanism.

Finally, it is worth noting that any attempt to estimate the number of children in need of services is likely to make at least one of two basic kinds of errors: (1) Type I error consists of including cases which should be excluded, and (2) Type II error consists of excluding cases which should be included. These cases are also sometimes referred to as false positives and false negatives.

In attempting to address the issue of how many children are currently being served, errors arise because the available categories of data which must be used to estimate the numbers are not defined in precisely the same way as the emerging definition for who will be served under the state's early intervention umbrella.

As a result, one is constantly faced with the choice of whether or not to include in the estimates the agency data that would result in identifying many eligible children, but which would also include some children who might not meet the definition for early intervention services under P.L. 99-457, Part H.

In attempting to determine the number of children eligible for early intervention services who are currently being served, a very rough estimate will be provided based on the suggestion of duplication found by O'Connell et al. (1989). This will necessarily produce both Type I and Type II errors.

Summary

This report is divided into 3 sections.

Section I provides an overview of 4 demographic characteristics of the state of Arizona as it relates to population and other socioeconomic trends influencing the size of the target population.

Section II presents the estimated number of infants and toddlers who are developmentally delayed or who have a diagnosed physical or mental condition which has a high probability of resulting in developmental delay (established risk).

Section III presents the estimated number of infants and toddlers who are "at risk" of having substantial developmental delays if early intervention services are not provided (biological risk).

Section IV presents information on how many children are currently served in the Arizona system.

SECTION I

Arizona's Children

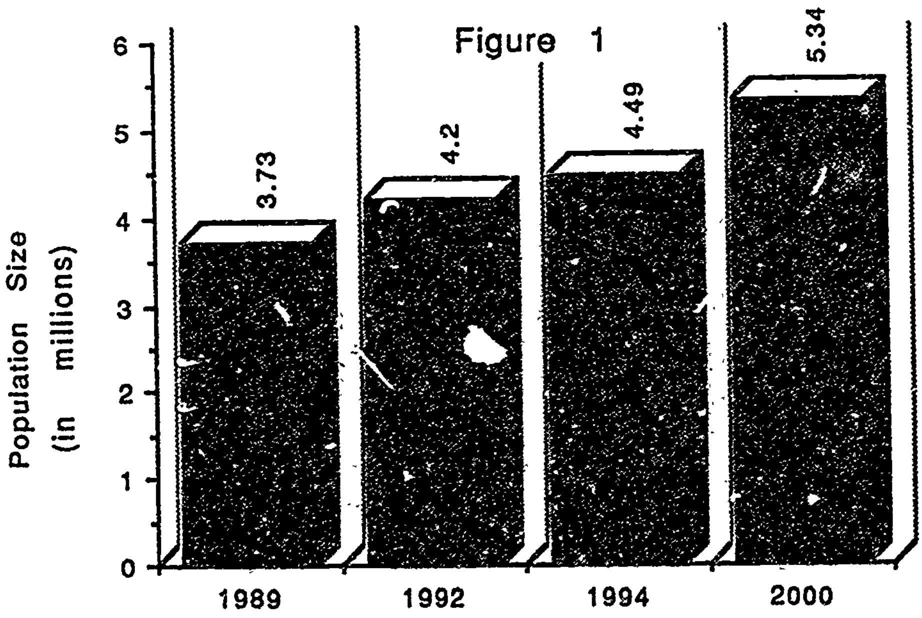
Four demographic characteristics of the state of Arizona are presented:

1. The size of the Arizona population in general and geographic distribution.
2. The projected size of the Arizona population between the ages of birth through five years of age to the year 2,000.
3. The ethnic distribution of the population across the state.
4. Socioeconomic characteristics of the state affecting future trends.

Arizona's general population

In 1988 there was a total of 3,548,400 people in the state of Arizona (3). Arizona has been and will continue to be one of the fastest growing states in the United States, at least into the first decade of the 21st century. It is expected to grow from 3.36 million in 1986 to 5.34 million by the year 2,000 (4). Arizona is the sixth largest state by area.

The following graph, Figure I, displays the anticipated growth for Arizona from 1986 to the year 2000 (4).



Arizona has become a predominantly urban state. Fifty-seven percent (57%) of the state's population resided in Maricopa county in 1988 (3), with the majority residing in Glendale, Mesa, Phoenix, Scottsdale, and Tempe. Another 19% of the population resided in Pima county, with over half living in Tucson. The remaining 24% of the population is distributed across 13 counties in rural settings, with population centers consisting of less than 55,000 people (3). Table 1 displays the size of Arizona's 2 largest counties and all other counties.

TABLE 1

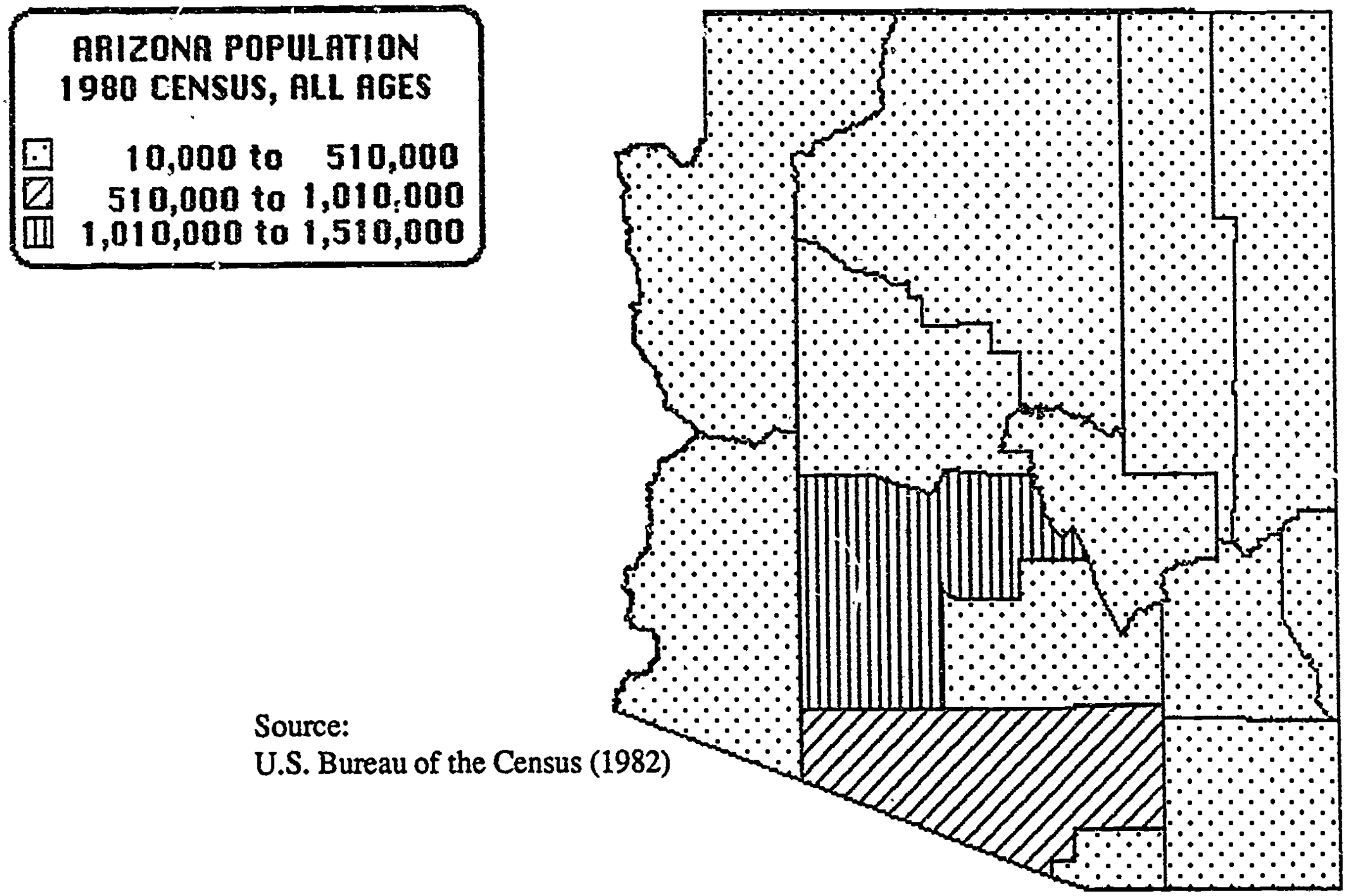
POPULATION ESTIMATES FOR ARIZONA COUNTIES, 1988

County	July 1988 Estimate
Maricopa	2,035,500
Pima	664,400
All Others	848,500
Total	3,548,400

Appendix A provides a complete table of population projections for each Arizona county for the years 1989-2000.

The map of Arizona on the following page, Figure 2, depicts the distribution of the Arizona population across the state of Arizona for 1980.

Figure 2



Source:
U.S. Bureau of the Census (1982)

The population size of Arizona's youngest children

Arizona's population of birth to four-year-olds is also one of the fastest growing groups in the country. Between 1980 and 1987, there was a 34% increase in the size of this population group (5). This is partly due to childbearing by the Baby Boom generation. In addition, Arizona was one of the few states to show growth in the 18-24 year old age cohort during this period, and was also one of the highest ranked states with respect to net migration.

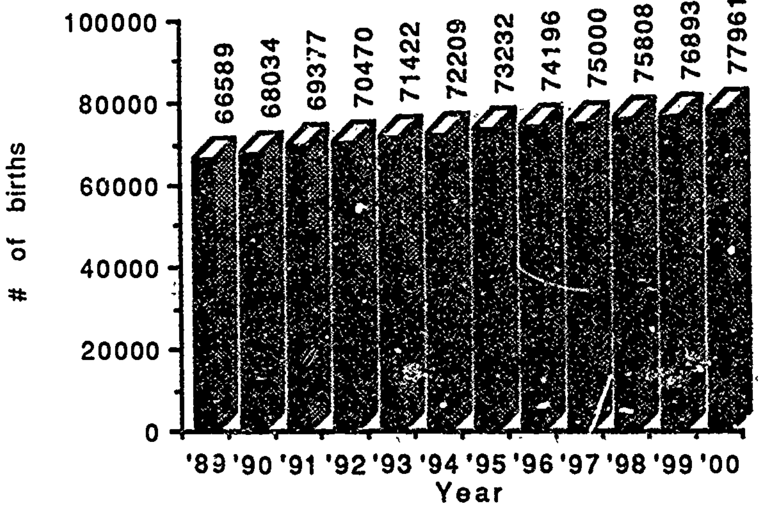
Population projections by Arizona's Department of Economic Security predict that the size of Arizona's infant and toddler population will continue to increase until sometime after the year 2,000 (6). Between 1989-2000 there will be a 17% increase in the size of this group. In 1989, children five years of age and under represented 11% of the total state population. By the year 2000, they will represent 9% of the total population.

The faster rate of growth in five-year-olds (2.1% per year) may be due to greater immigration by families with five-year-olds than with younger children. The 0-5 year old age group is predicted to grow at an overall rate of about 1.6% per year from 1989 to 2000. The annual rate of natural increase from births has remained relatively stable at about 10.6 per thousand since 1982 (7). The annual crude birth rate has also remained relatively stable, fluctuating between 18.0 and 18.7 per thousand from 1980 to 1986 (8).

The following graph, Figure 3, depicts the estimated number of births each year from 1989 to the year 2000 (6). It shows a steady increase in the number of births throughout the next 11 years similar to the steady increase in the population as a whole.

Figure 3

Projected Number of Infants 1989-2000



This increase will affect each age group from birth through five years of age in a similar fashion.

As Table 2 shows, the trend of a steady increase in the size of this population over the next 11 years will have its greatest impact on the five year old age group, representing a 26% increase, while each of the other age cohorts represent a 17-19% increase.

TABLE 2

PERCENTAGE OF CHANGE BY COHORT, 1989-2000
(Each percent is based on total beginning population.)

Age of Cohort	1989	2000	Percent Change
0	66,589	77,961	17%
1	66,812	78,361	17%
2	67,492	79,023	17%
3	67,653	80,050	18%
4	67,699	80,874	19%
5	65,041	81,765	26%

Appendix B presents a complete table of the projected size of the Arizona population for ages 0-5 years from 1989-2000.

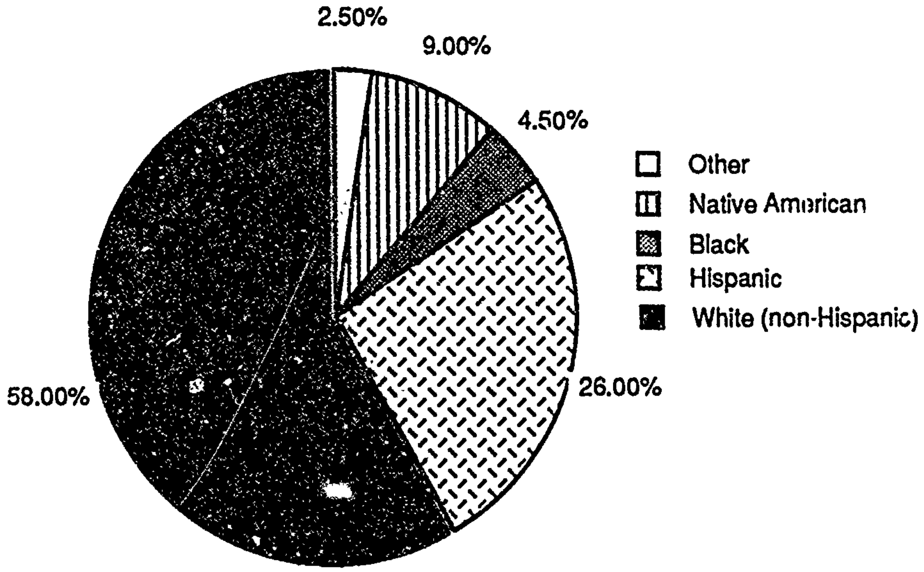
In the next 11 years, it is projected that the size of the 0-5 year old population will increase from 401,286 to 478,034 children (6).

Ethnic distribution

Arizona's population consists of richly diverse cultural subgroups. Almost half of the state population is represented by Hispanic (26%), Native American (9%), Black (4.5%), and other (2.5%) ethnic minority people. The following pie chart, Figure 4, illustrates this distribution.

Figure 4

Proportional Distribution of Ethnic Group for 1986 and 1987 in Arizona



Source: Arizona Health and Vital Statistics (1988)

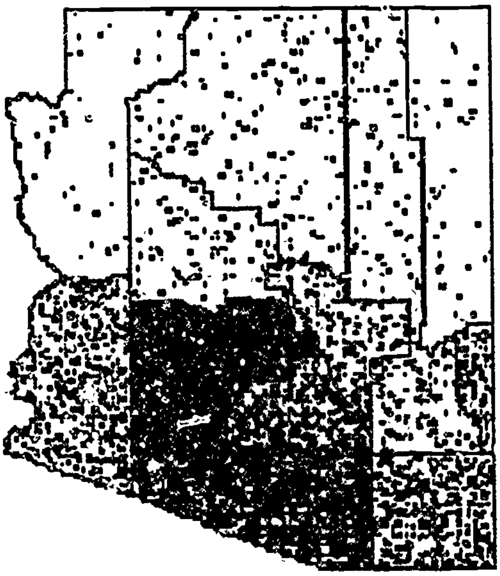
The Black population in Arizona is a much smaller percentage in Arizona than in the U.S., but the Indian and Hispanic populations represent much greater proportions. The rural percentage of Black, Indian, and Hispanic is higher than the overall urban percentage and the state as a whole (9).

Forty-two percent (42%) of the 1986 and 1987 births in Arizona were minority children (7, 10), while the 1980 census indicated that 25% of all ages in Arizona are Black, Indian, or Hispanic (11). Because the migration pattern of people to the state of Arizona indicates that more than 90% of new residents are

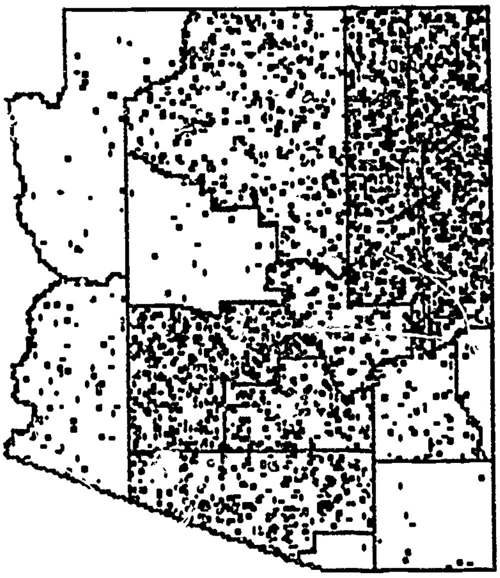
White (12), it is not known whether the proportion of minority to Anglo children will increase, remain the same, or decrease. It is known that the minority birthrate is higher than that of the White birthrate.

The following maps, Figure 5, represent the geographic distribution of Hispanics, American Indians, and Blacks in Arizona.

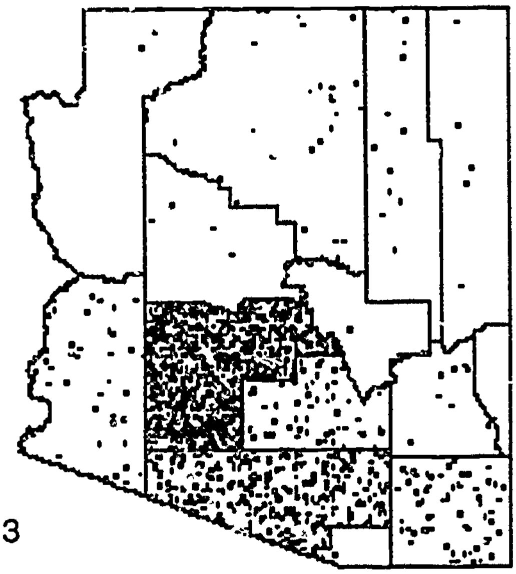
Figure 5


HISPANIC POPULATION (ALL RACES)
ALL AGES, 1980 CENSUS

Each Dot = 50 people


NATIVE AMERICAN POPULATION
ALL AGES, 1980 CENSUS

Each Dot = 50 people


BLACK POPULATION
ALL AGES, 1980 CENSUS

Each Dot = 50 people

Socioeconomic characteristics of the state affecting future trends

In addition to the increasing size of the population of young children in the state of Arizona, several socioeconomic characteristics of children and families in the state will affect the number of children in need of special services.

Poverty. In 1982 the basic needs of 15% of the children in Arizona were not being met; by 1985, that group of children had increased to 20% (13). Although one in every five children in the U.S. under the age of six live in poverty today, 26% of Arizona's children six and under live in poverty.

In a two year period of time (1983-1985), there was a 12% increase in the number of children living in poverty in the state. Over 170,000 children live in poverty in Arizona.

It is estimated that more than 60,000 children in Arizona are estimated to live on reservations. Although they represent 8% of the total child population in the state, they make up 23% of the children living in poverty (13).

Our state is experiencing an undeniable trend toward higher poverty rates among our young children. Poverty has been identified as a strong predictor of children's future developmental status. It is also known that very poor children are suffering from inadequate health care.

Family Structure. Over a ten year period of time (1975-1985), the family structure in Arizona changed dramatically (14). Single-parent families increased by 260%. The divorce rate in Arizona was 32% higher than the national average. An increasing number of women work outside the home. In 1985, 78% of women between the ages of 25 and 54 held full-time jobs.

More than 5,000 children have a parent who is in jail (14).

Over 8,700 babies in Arizona were born to teenage mothers (14). Teenage births account for 15% of all births in Arizona (14). In 1987, 12,342 of Arizona's teenagers got pregnant. Babies born to teen mothers with late or no prenatal care are 60% more likely to deliver a low birthweight baby than babies born to mothers between the ages of 20-34.

Child Abuse. Reports of child abuse in Arizona increased by 25% during 1983-84 (13). Brown and Cox (15) reported that child abuse cases increased by 13.5% from 1984-85 to 1985-86, and by a nominal .4% from 1985-86 to 1986-87. In 1986-87, more that 8,000 children under the age of 3 were reported victims of abuse (15).

Health care. In 1984, 1,116 babies were born to mothers in Arizona who had received no prenatal care (13). Mothers with inadequate prenatal care are 3 times more likely to deliver low birthweight babies, that is, babies weighing less than 5.5 pounds.

Despite an increase in the number of poor families in Arizona, there has been a decrease in the number of food stamp recipients (13). One out of every 10 children is eating a 54 cent meal three times a day in order to survive. Poor nutrition in childhood is known to increase the risk of lifelong health and developmental problems.

Children raised in environments characterised by the above factors are considered to be at "environmental risk" for developing delays in development. Specifically, environmental risk, as defined by Tjossem (16),

> "...applies to biologically sound infants for whom early life experiences including maternal and family care, opportunities for expression of adaptive behaviors, and patterns of physical and social stimulation are sufficiently limiting to the extent that, without corrective intervention, they impart high probability for delayed development." (page 5)

Summary. It is recommended that for planning purposes, a 3% prevalence rate be used to estimate the total number of infants and toddlers who are developmentally delayed or at established risk. It is also suggested that approximately 8% of the target population are at biological risk. The total number of target infants and toddlers, however, must take into consideration the overlap between these 3 groups. A study by Biro and Bell (48) in the state of Washington found approximately a 1% overlap between infants at established risk and infants at biological risk. The authors of this report could not identify any source reporting the overlap between infants and toddlers who are developmentally delayed and the other two target groups. Therefore, at this point in time it is not known what is the overlap between groups, and therefore, the total number of infants and toddlers in Arizona in need of early intervention.

The current proposed Arizona definition of eligibility does not explicitly include the category of environmental risk, although it does include several environmental risk factors under the heading "Targeted for Review" (Appendix C, page 3).

A recent survey of the states' progress toward developing a definition for developmentally delayed as requried by PL 99-457, Part H, has found that 16 states recognize one or more of 36 different criteria as placing infants and toddlers at risk due to environmental conditions (17). However, apart from some concensus on the importance of parental substance abuse and/or parental mental retardation or illness, there appears to be minimal agreement among states on which environmental risk factors to consider. Consequently, we will not attempt in this report to estimate the number of infants and toddlers at environmental risk or review the arguments regarding the importance of environmental risk any further.

SECTION II

Children with Developmental Delays or At Established Risk in Arizona

The introduction to this report summarizes the difficulties in estimating the size of the population of infants and toddlers who are developmentally delayed or who have a diagnosed physical or mental condition which has a high probability of resulting in developmental delay (referred to as established risk).

Since precise numbers of children are not currently available, a prevalence rate was selected based upon: (1) analysis of national special education data, (2) professional literature, and (3) other state estimates.

A recent report by the Administration on Developmental Disabilities (1) defines developmental delay in the following manner:

> "Children with developmental delay are children with or without an established diagnosis who by assessment measurements have fallen significantly behind developmental norms. It is the degree of delay required for service eligibility that must be decided." (pg. 9)

In considering a definition for children with a diagnosed physical or mental condition with a high probability of resulting in developmental delay, the following definition of established risk by Tjossem (16) is popularly accepted by professionals in the field of developmental disabilities as the following:

> "Established risk infants are those whose early appearing aberrant development is related to diagnosed medical disorders of known etiology bearing relatively well known expectancies for developmental outcome within specified ranges of developmental delay. The Down's syndrome infant is a classic example of established risk." (pg. 5)

The following estimates of the number of children in Arizona who represent children falling within these two mandatory categories for early intervention services are based on these broad definitions. Appendix C consists of the proposed definitions for child eligibility under P.L. 99-457, Part H, prepared by the Arizona Interagency Coordinating Council.

The numbers

The analysis leading to the selection of a prevalence rate for estimating the size of the target population indicated that it may be possible to increase the accuracy of the projected numbers by applying two separate prevalence rates to the group of children from birth through two years of age and the group of children between three and five years of age. A subsequent section describes the rationale behind the selection of prevalence rates.

A 3% prevalence rate is used to estimate the size of the population of children from birth through two years of age who are developmentally delayed or at established risk for becoming developmentally delayed.

A 7% prevalence rate is used to estimate the size of the population of children from three through five years of age who are developmentally delayed or at established risk for becoming developmentally delayed.

It is important to note that "prevalence" refers to the total size of the target population for the designated age categories. This differs from "incidence", which refers to the number of new cases each year. As a result, the prevalence estimates represent a cumulative assessment.

Source of Data. Data was obtained from the Arizona Department of Economic Security on the number of young children of various ages in the state, and the population projections for this age group from the present year until the year 2000. All state agencies are mandated to use these projection in their planning. The most recent Baseline Projections from the Department of Economic Security (9) were used and the prevalence rates were applied to each age category between birth and five years.

Results. Table 3 summarizes the estimated number of children with developmental delay or with a high probability of becoming developmentally delayed for two age categories (0-3 and 3-5 years) and for the total target population between birth to five years of age for the years 1989-2000.

TABLE 3

ESTIMATED NUMBER OF CHILDREN WITH DEVELOPMENTAL DELAY OR WITH A HIGH PROBABILITY OF BECOMING DEVELOPMENTALLY DELAYED

YEAR	3% of Ages 0-2	7% of Ages 3-5	Total for Ages 0-5
1989	6,027	14,028	20,055
1990	6,167	14,664	20,831
1991	6,301	15,070	21,371
1992	6,417	15,434	21,851
1993	6,511	15,728	22,239
1994	6,587	15,983	22,570
1995	6,675	16,230	22,905
1996	6,756	16,427	23,183
1997	6,820	16,545	23,365
1998	6,900	16,703	23,603
1999	6,981	16,848	23,829
2000	7,060	16,988	24,048

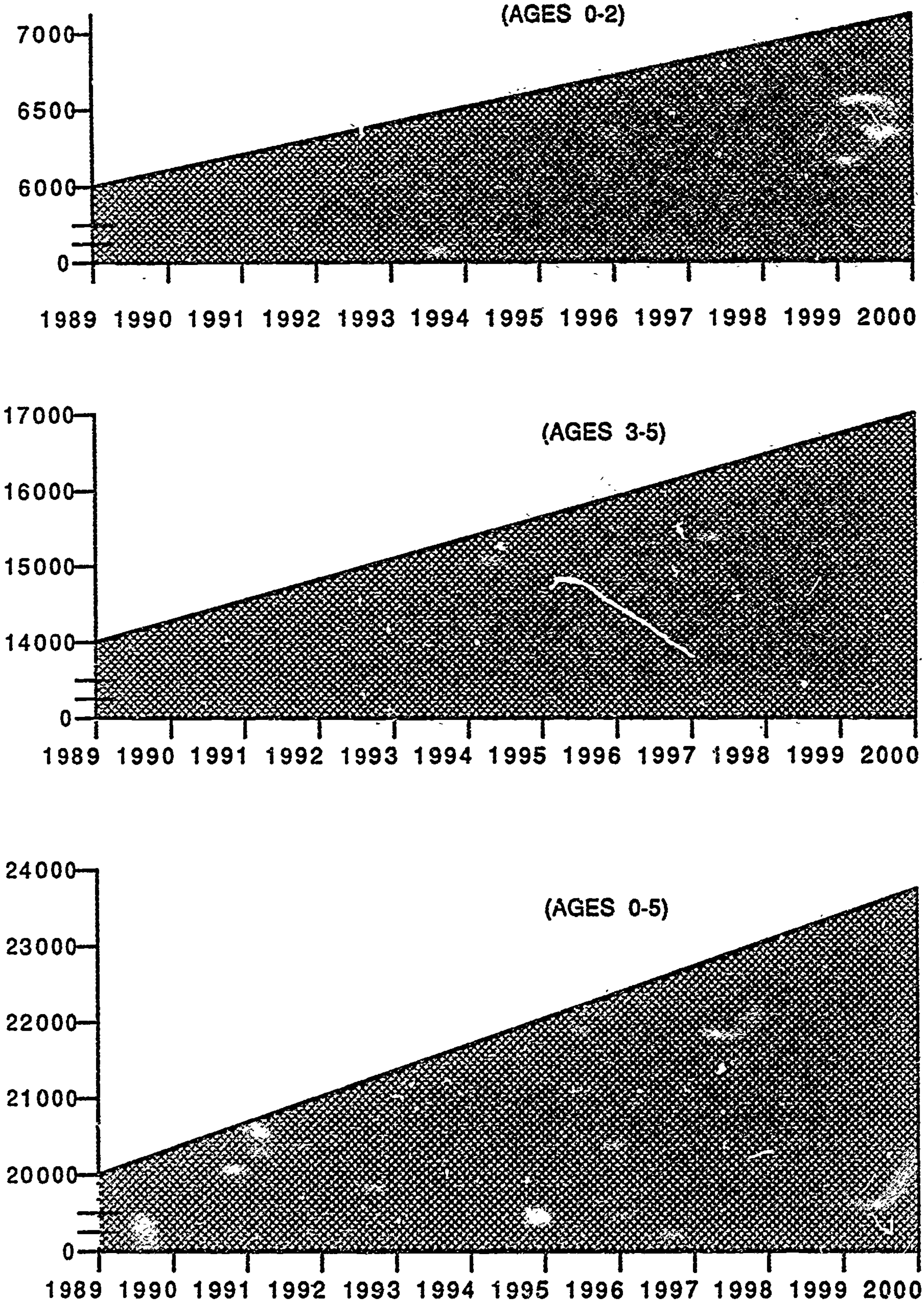
The estimated numbers in the above table indicate that the number of target infants and toddlers in Arizona who are going to need early intervention services is expected to rise from approximately 6,000 to 7,000 by the year 2000.

The estimated number of target preschool children who will need preschool handicapped services is expected to rise from approximately 6,000 to 7,000 by the year 2000.

Figure 6 graphically displays the increase in the size of these target populations between the years 1989-2000.

FIGURE 6

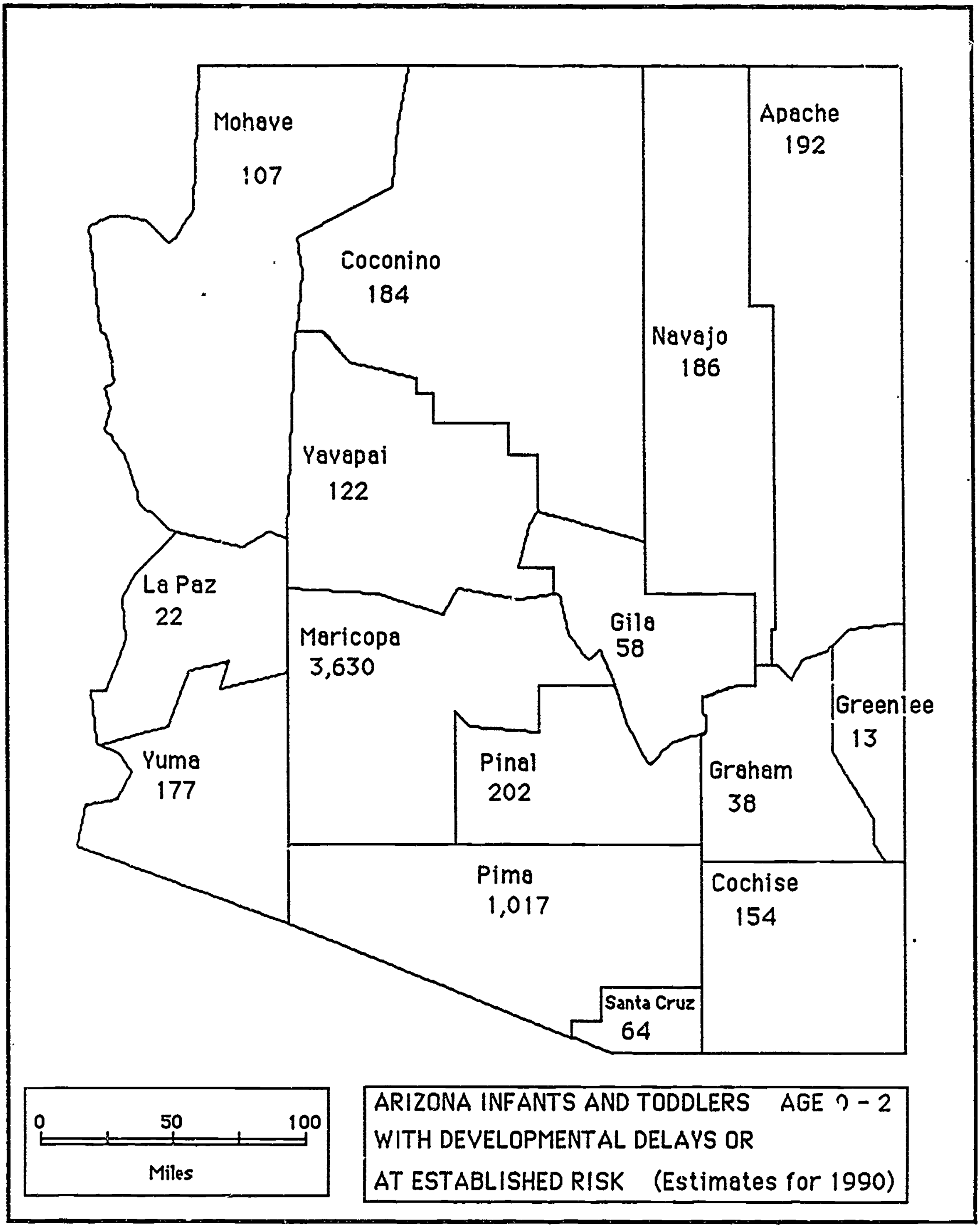
ESTIMATED NUMBER OF CHILDREN WITH DEVELOPMENTAL DELAY OR WITH A HIGH PROBABILITY OF BECOMING DEVELOPMENTALLY DELAYED



The following two maps, Figure 7 and Figure 8, illustrate the geographic distribution of target children for each age category, birth through two years of age and 3-5 year olds, by county in Arizona. These numbers should assist local and regional planners in establishing short-term objectives toward a full service goal.

Arizona

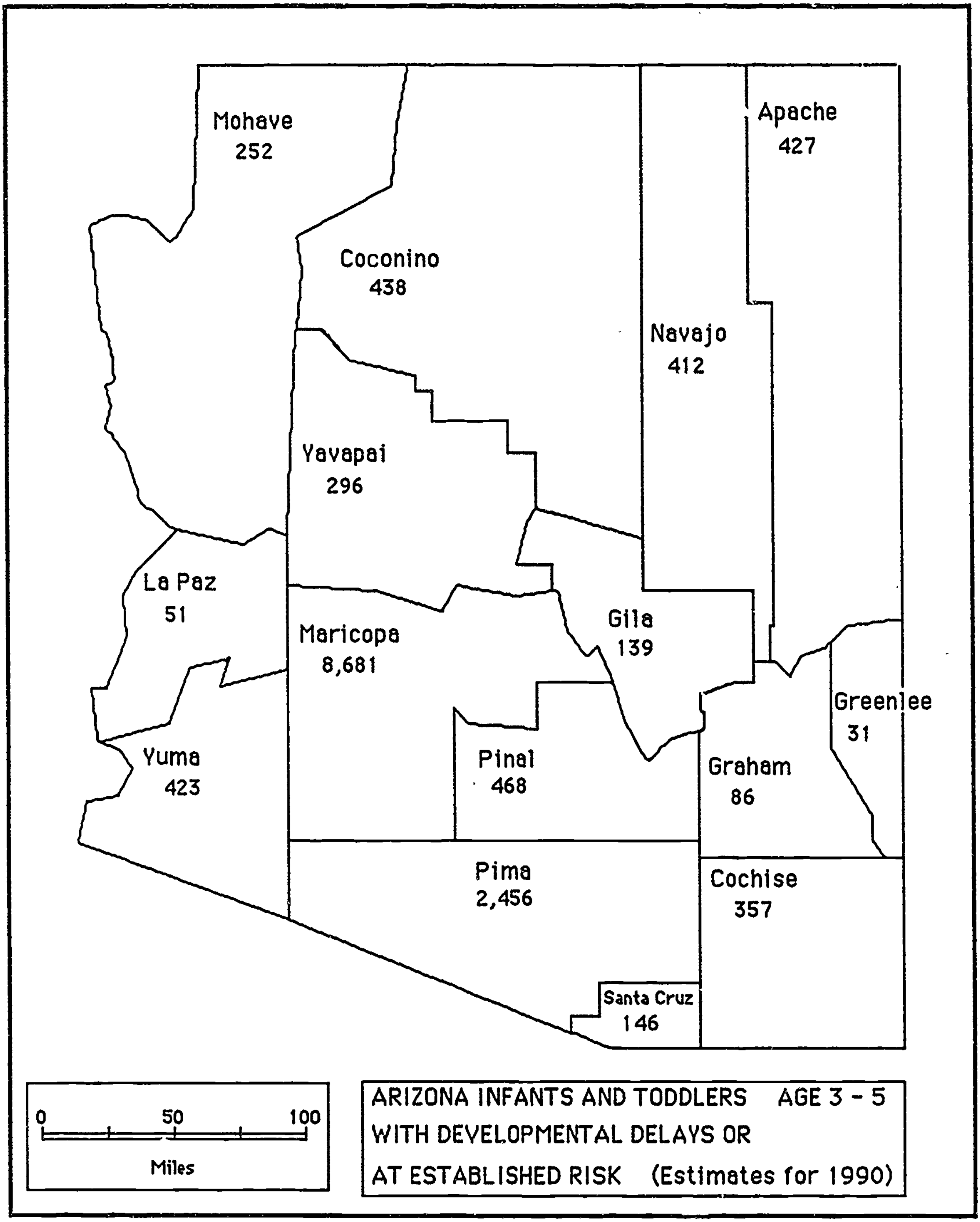
Figure 7



ARIZONA INFANTS AND TODDLERS AGE 0 - 2 WITH DEVELOPMENTAL DELAYS OR AT ESTABLISHED RISK (Estimates for 1990)

Arizona

Figure 8



ARIZONA INFANTS AND TODDLERS AGE 3 - 5
WITH DEVELOPMENTAL DELAYS OR
AT ESTABLISHED RISK (Estimates for 1990)

Discussion

The information in this section provides a rationale for the selection of the prevalence rates used in this report to estimate the total number of target children in need of early intervention and preschool services within the two mandatory categories.

Information from the following sources was reviewed: (1) national special education data, (2) professional literature, and (3) other state estimates.

National special education data. One strategy used to obtain an estimate of the prevalence rate of handicapping conditions within the population of young children from birth to five years of age was to review the rates and size of the school age special education population (18). The school system constitutes a fairly inclusive group of children who, under the increasing influence of P.L. 94-142, have experienced improved screening and identification outcomes over the last decade and a half.

By age 8 years, 11% of the school age population has been identified as in need of, and receiving, special education services under EHA-B during the 1985-86 school year (18). Table 4 displays the percentage of children served by handicapping condition as defined by special education legislation for the total special education population. It also displays the comparable percentage of 8 year old children served in special education relative to the total school age population.

TABLE 4

SPECIAL EDUCATION SERVICE RATES

Handicapping Condition	Percent of Special Education Population	% of Total 8 Year Old School Age Population
Learning Disabled	42.8%	4.7%
Speech/Language Impaired	25.8%	2.8%
Mentally Retarded	15.7%	1.7%
Emotionally Disturbed	8.6%	.95%
Visually Impaired, Hearing Impaired, or Deaf-Blind	2.3%	.26%
Multi-handicapped	2.1%	.23%
Orthopaedically Impaired	1.4%	.15%
Other Health-Impaired	1.3%	.14%
Total	100%	11.0%

Learning disabled children account for 42.8% of all children served under Chapter 1 of ECIA (SOP) and EHA-B. This is a diagnostic category that presents challenges to the diagnostician in terms of determining this type of disability in the birth to five year old group because it has traditionally been a school achievement based definition. There is currently a professional debate occurring regarding whether or not young children can be determined to have a learning disability. Arizona's state legislation does not recognize the use of this diagnostic label for children served under state preschool formula funding.

Similarly, another 25.8% of the national special education population are reported as speech and language-impaired. Although many children currently served in the Arizona preschool handicapped programs are diagnostically placed under this categorical definition, it represents another category in which difficulty exists in assessing and labeling very young children. Arizona statutes limit the number and type of children that can be placed into preschool handicapped programs under this diagnostic label. Certainly for children below the age of three years, delays in speech and language become even more difficult to diagnose.

Using a conservative approach, an estimate of the percentage of children between birth and three years of age who would be eligible for special education could be made by removing these two categories, learning disability and speech/language-impaired, from the overall percentage rate for school age children to arrive at an estimate of the percentage of children between 1-3 years of age who could be expected to be identified and served. These two categories account for 68.6% (42.8% + 25.8%) of the total special education population.

Using the 11% special education service rate for the 8 year old population as an indicator of the potential size of the target special needs population, and subtracting from it the 68.6% who have handicapping conditions which may not be diagnosable before the age of three leaves 3.45% (31.4% of 11%) of infants and toddlers identifiable for early intervention services.

This 3.45% may be identified as falling into the special education categories listed in Table 5.

TABLE 5

SPECIAL EDUCATION CATEGORICAL RATES FOR 0-3 YEAR OLDS

1.7 %	Mentally retarded
.96%	Emotionally disturbed
.26%	Visually impaired, Hearing impaired, or Deaf-blind
.23%	Multi-handicapped
.15%	Orthopedically impaired
.14%	Other health impaired
3.45%	Total

These are conditions which may be more readily identified in infants and toddlers using special education eligibility categories. However, current diagnostic instruments for infants and toddlers may not be precise enough to identify all children exhibiting these conditions, especially those with mild handicapping conditions at the younger ages.

Therefore, one could recommend the application of a conservative 3% prevalence rate to the Arizona population of 0-3 year old children in order to estimate and project the size of the target population.

Professional literature. A review of the professional literature revealed that various studies have arrived at the following conclusions:

1. At birth, 1-2 percent of all infants have discernible disabling conditions (19). This is supported by the Washington State High Priority Infant Tracking program, which determined that 1.8% of all newborns in the state of Washington had established risk factors identifiable at birth (20).

2. It is estimated that 2.5-3% of the general population is mentally retarded. Because of differing definitions and reporting methods, no firmer figure can be given (21).

3. "Harder" data indicates that 2.8% of children 0-4 years of age are mentally retarded (22).

4. Statistics compiled by the United States Public Health Service indicate that the incidence of severe mental retardation is 3-5 per 1000 (22). However, most studies report that children with severe mental retardation are only 3.5% of the total mentally retarded population. If so, the minimum incidence rate for the entire population would be 8.57%.

5. The U.S. Office of Education reported in 1976 that 6.018% of all children from birth to five years of age are handicapped (23).

6. It has been estimated that 1 million preschool-aged handicapped children need special education services, which is more than 4 times the number actually receiving services under P.L. 94-142 in 1983-84. Since the population under age 5 in 1984 was estimated to be 17,830,000, this implies that 5.6% of preschool-aged children need services (24, 25).

7. By age 5, estimates of children with disabling conditions range from 8.5% to 11-12%, using standards of P.L. 94-142 and P.L. 91-313 (19).

8. By age 8, 11% of all school age children were receiving services under EHA-B in 1985-86 (18).

Other state estimates. Other state estimates planning for the needs of children under P.L. 99-457 have tried to estimate the size of this population. However, apart from the broad guidelines for eligibility by the national legislation, there is much variability in how this population is defined. In what follows, the primary focus is on data which deals as much as possible with infants and toddlers who are developmentally delayed, or at established risk, and excludes (as much as possible) the factors of "biological risk" and "environmental risk".

1. The birth to three year old population: prevalence rates for infants and toddlers needing special services have been proposed in, or are being used by, seven states, as follows:

Idaho	6.5%
Massachusetts	4.9%
Illinois	3.0%
Texas	3.0%
California	2.9%
Iowa	1.0%

[6 state average = 3%]

Massachusetts originally reported that 10.6% of the birth to 3 year old population, who have established conditions or who are biologically or environmentally at risk, are served (26). Of these, 4.2% were considered at environmental risk, leaving 6.4% at established and biological risk. Their data on biological risk (27) indicates a prevalence rate for that factor of 1.6%, leaving 4.9% at "established risk". Recently, it has been suggested that the 10.6% estimate may be about 2% too high (Phone conversation with Karl Kastorf, 1/4/89).

The 1% figure for Iowa, a "mandate to birth" state, is based on Department of Education statistics for children age 0-2 years who are currently served and diagnosed. They use traditional special education categories for diagnosis, which appear to exclude children who are "at risk" (26). A committee is studying the establishment of eligibility criteria more consistent with P.L. 99-457.

2. Ages 3-5 years: Four states' minimum prevalence estimates are:

Texas	12.0%
Washington	6.8%
California	5.0%
Iowa	4.5%

[4 state average = 7%]

Texas is a state with a mandated early intervention program; studies there have estimated that 12% of the 3, 4, and 5 year old children meet the state's intervention eligibility standards (26).

3. Ages 0-5 years: Five states' minimum prevalence rates are:

Washington	4.9%
Illinois	8.0%
Florida	5.0%
Colorado	3.0%
Oklahoma	3.0%

[5 state average: 4.0%]

However, this excludes an additional 4% which Illinois estimates are at biological risk, and it also excludes an additional 8% which both Colorado and Oklahoma consider to be "at risk" of diabling conditions (66% of these actually use special education or related services) (26, 41).

Section III

Children at Biological Risk

P.L. 99-457, Part H, eligibility definition includes, at a State's discretion, individuals from birth through age 2, who are at risk of having substantial developmental delays if early intervention services are not provided (100 Stat. 1146).

The current proposed Arizona definition of eligibility includes the category of biological risk (see Appendix C for a description of the proposed eligibility criteria). Although this category of children is even more difficult to estimate than the previously discussed group, an effort was made to estimate the number of children who could be considered eligible under the biological risk category.

Since the additional category of environmental risk has not currently been included in the state's definition, it will not be discussed in this report.

Developing the rationale

A growing body of evidence is suggesting that biological risk at birth may be related to later disabilities. According to Tjossem (16),

> Biological risk specifies infants presenting a history of prenatal, neonatal, and early development events suggestive of biological insult(s) to the developing central nervous system and which, either singly or collectively, increase the probability of later appearing aberrant development. Early diagnosis of enduring developmental fault is often difficult and inconclusive in these biologically vulnerable infants who, most often, require close surveillance and modified care during the early developmental years. (pg. 5)

Harbin, Terry, and Daguio (17) recently completed a survey of states' Part H definitions. Seventeen states now include biological risk factors in their P.L. 99-457 eligibility criteria. A broad definition like Tjossem's is commonly used. A survey of these states revealed the following specific factors as most commonly employed:

1. Prematurity (9 states), variously defined as less than 32 weeks (5 states), with complications (2 states), or without qualifiers (2 states);
2. Low birthweight (8 states), variously defined as less than 1000 grams (3 states), less than 1500 grams (3 states), less than 2500 grams, or unspecified;

3. Factors sometimes considered as established risk, such as chromosomal abnormalities (4 states), unspecified established risk factors (3 states), sensory impairments (4 states), metabolic disorders (3 states), congenital anomalies/syndromes (3 states), or intraventricular hemorrhage, grade III/IV.

4. Various perinatal conditions, such as birth trauma/infection/disease (4 states); neonatal seizures (3 states), small for gestational age (3 states); complications at birth (3 states); mother exposed to medications known to cause brain damage (3 states); chemically dependent mother (2 states); abnormalities in tone (2 states); asphyxia with neurological complications (2 states); congenital infections/neonatal meningitis (2 states); prenatal infections such as CMV, rubella, AIDS (2 states), apgar <6 at 5 minutes, neonatal intensive care for more than 7 days, neonatal intensive care for more than 30 days, ventilator support for more than 48 hours, ventilator dependent, respiratory distress syndrome with prolonged mechanical ventilation, pregnancy complications.

5. Various post-natal conditions, including lead poisoning (3 states); serious accident/near drowning (2 states); growth deficiency/nutritional problems (2 states); failure to thrive, feeding dysfunction; significant medical problems (2 states); chronic otitis media (2 states); a traumatic illness/event; atypical development; delay, abnormal motor patterns.

The authors note that there is confusion and lack of agreement concerning what is considered to be <u>established risk</u> and what is considered a <u>biological risk</u> (17). Also, many state definitions which include a list of eligibility criteria include the phrase "but is not limited to the following".

The proposed Arizona definition (Appendix C) includes biological risk within it's "at risk" category, which also includes established risk. The biological risk eligibility criteria refers to:

> A child (birth through 18 months) who has [a] ... biological risk of becoming developmentally delayed. Specifically, those infants whose... [h]istory includes prenatal, perinatal, neonatal or early developmental events suggestive of biological insults to the developing central nervous system which, either singly or collectively, increase the probability of later developmental delay.

Except for the age restriction, this clearly corresponds to Tjossem's definition of biological risk.

Review of the literature

Although the above described biological risk conditions commonly appear, no consensus exists regarding an inclusive group of conditions which are known to expose a fetus or newborn infant to biological risk resulting in delayed developmental outcomes. For example, the Arizona proposed definition does not explicitly include meningitis, which ranks among the highest of the biological risk conditions (28, 29). It also does not explicitly include encephalitis, or "Failure to Thrive" (FTT) (19). Studies on the cognitive development of FTT infants show that, whether the cause is organic or inorganic, these children are at risk (30).

Most investigators focus their attention on low birthweight and related conditions. Rossetti (31) argues that a more accurate means of determining an infant's (biological) risk status includes birthweight and gestational age, considered simultaneously. Similarly, Bowden (20), argues that "The most common factor that placed a child in the biological risk category... is prematurity and/or low birthweight (less than 2,500 grams)." Other suggested biological risk factors include infections (especially maternal and/or congenital), seizures, respiratory distress, and maternal factors such as length of labor, method of delivery, neurological status during the first year of life, and various specific medical conditions (20, 29, 31, 32, 33).

Today, care of the newborn biologically at-risk infant is usually provided by neonatalogists, whenever possible, who are trained specifically to care for distressed newborns, working in neonatal intensive care units (NICUs) (32). However, not all babies at biological risk receive care in NICUs. Parents may refuse consent, or fragile infants may be born in hospitals without NICUs and die before they can be transported to an NICU. Other infants, even though at risk for <u>later</u> developmental delays due to prematurity, low birthweight, or other conditions, may not need intensive care immediately after birth.

Limited longitudinal research is available to assist in selecting those conditions most likely to produce future problems. Some follow-up studies suggest that the influence of low birthweight continues at five years of age. The lower the birthweight, the more likely that a deficit will appear in verbal, perceptuo-motor, and pre-academic performance (29). Because of the risk for later developmental delays, it is usually recommended that infants at biological risk be periodically evaluated or screened for some time after birth in order to facilitate the early diagnosis and treatment of developmental delays before they become disabling. As a result, follow-up care may become fragmented among different agencies, depending on the needs of the infant (34).

National estimates

A review of the professional literature yielded the following information:

1. Approximately 5 to 15 percent of all live-born infants can be classified as at (biological) risk. The number of these infants who will ultimately display some form of developmental deviance, cognitive deficit, school difficulty, or behavioral differences ranging from mild to severe falls in the 30 to 50% and above range ...

   The incidence of low birthweight (LBW) is about 8% ... Approximately 1.5% of LBW infants weigh less than 1,500 grams at birth. About 25% of these infants will die and 50% will display some form of neurodevelopmental delay ranging from mild to severe (31).

2. For infants who do not die in the first year of life, low birthweight may be associated with developmental disabilities, cerebral palsy, and other handicaps; 6.8% of all babies were LBW (<2,500 grams); 1.18% were very low birthweight (VLBW) (<1,500 grams). VLBW infants are at serious risk of disabilities: 42% will have some neurological handicap or congenital anomaly, with 14% severely affected, as compared with 19% and 2% of normal infants. On average, VLBW babies spend 57 days in neonatal intensive care (35).

3. 7-10% of all live births in the U.S. were delivered at or before 37 weeks' gestation (36).

4. Usher (37) provides evidence that moderately premature infants (gestational age 31-36 weeks) constitute 6-7% of the total live newborn group, but that about half of these weigh more than 2,500 grams at birth. Borderline premature infants (gestational age 37-38 weeks) account for 16 percent of the total live newborn group. In a more recent study, Usher (38), provides evidence that extremely premature infants (gestational age less than 31 weeks) account for .87% of all live newborns, and that very low birthweight infants (<1,500 grams) account for .85% of live newborns. In a six year study, 282 newborns were born extremely premature and had very low birthweights; 127 had very low birthweights but had a gestational age > 30 weeks, and 41 were extremely premature but had a birthweight of 1,500 to 2,500 grams.

5. Approximately one-third of low birthweight infants are not truly premature but are small-for-gestational-age (SGA). The incidence per population group will vary between 1.5% to 2% of all births. The overall neonatal mortality rate for this group is 3.4% (39).

6. In later childhood, 36-50% of SGA babies are failing in school; minimal brain dysfunction occurs in 25%. EEG abnormalities (without seizures) occur in 59-69 percent; and speech deficits occur in 26-33% (39).

7. Thirty percent (30%) of the infants identified as biologically at risk will require some form of intervention by age six (32).

8. A study that investigated the IQ of SGA infants 8-10 years after birth showed that very low birthweight infants born after at least 30 weeks of gestation had an average IQ of 83-84; infants born at 1,500 to 2,000 grams after at least 36 weeks of gestation had an average IQ of 85 (40). However, a number of other studies have shown that the IQ for <u>moderately</u> SGA infants <u>with no other anomalies</u> does not differ significantly from that of an appropriately grown term infant (39).

9. A study of the incidence of long-term central nervous system handicap by birthweight and gestational age showed that 50% of pre-term VLBW babies had long-term CNS handicaps, as did 31% of moderately premature LBW babies, and 24% of full-term but LBW babies, as compared with 14% for near-term but normal weight babies, and 10% of normal weight full term babies (41).

10. A two year follow-up of 151 VLBW infants in Canada showed that 91% were normal, 8% had mild to moderately disabling conditions, and 1% was severely disabled (38).

11. In one study, 49% of preterm SGA babies born in 1974 and 1975 presented with major neurologic and/or cognitive handicaps at 2 years of age (28).

12. Failure-to-Thrive syndrome affects roughly <u>3%</u> of the under six years of age group. It is more common among children with developmental disabilities than among non-disabled children (20, 35).

What other states are reporting

A review of other state estimates reveal the following:

1. <u>Washington state:</u> 9% of all Washington infants were born at biological risk due to low birthweight, low APGAR scores and other perinatal risk factors; 5.2% of all Washington infants were born weighing <2,500 grams (20).

2. <u>Iowa</u>: The incidence of disabling conditions in very low birthweight infants (<1,500 grams) is 35-40% (20).

3. <u>Massachusetts</u>: The number of surviving VLBW babies is 1.6% of all liveborn infants. These were considered to be at biological risk (27).

4. <u>Oklahoma</u>: In addition to the estimated 3% of all infants and toddlers at established risk, another 8% are "at risk" for other reasons (determined by DDST screening) (42).

5. <u>Illinois</u>: Approximately 4% of preschool children 0-5 years of age are at biological risk (42).

Summary

By definition, biological risk refers to infants who, as a result of a current or recent medical or biological condition, are expected to experience later delays in development. Many children who are biologically at risk develop normally. However, because of the risk factor, infants at biological risk have a higher likelihood than normal children of having special needs. This suggests that various components of the biological risk population need to be treated differently.

One strategy for subdividing this population into several groups, differentiated by severity of risk, is recommended by Ensher and Clark (34). They classify risks by the level of severity, and frequency and mode of screening:

1. I Mild, with screening by mail every 12 months;
2. II Moderate, with screening every 6 months; and
3. III Severe, with direct screening every three months.

This once again highlights the fact that many infants and toddlers at biological risk may not need intervention beyond the neonatal period, but may benefit from periodic screening for at least 18 months because of their much higher risk of experiencing later developmental delays.

Table 6 summarizes information about infants at biological risk, subdivided according to risk level. The conditions listed in the table are framed in terms of birthweight and gestational age because these conditions figure prominantly in the literature, and because data was available permitting the estimation of incidence rates which could be used to produce an unduplicated total. Many other relevant conditions were not included only because to do so would result in an uncertain amount of double counting.

In Table 6 the percentage of infants with an unfavorable outcome refers to the likelihood that in later childhood the infant will be failing in school, experience minimal brain dysfunction, have EEG abnormalities (with or without seizures), have speech deficits, or experience major neurologic and/or cognitive sequelae or other kinds of developmental delays (28, 31, 39, 41). The percentages are supported by the professional literature (28, 31, 41). Finally, the conditions in the table were classified into the risk levels according to their percent unfavorable outcomes.

The total incidence rate of 7.78% for biological risk in Table 6 applies to infants, i.e., children in their first year of life.

Because of the focus on the neonatal period, the size of the biologically at risk target population is usually discussed in terms of <u>incidence</u> rates (e.g., the number of cases per 1000 live newborns), rather than in terms of <u>prevalence</u> rates, as was the case with infants and toddlers who are developmentally delayed or at established risk. To obtain <u>prevalence</u> rates for infants and toddlers age 0-2 years who are at biological risk, it will be necessary to add together the following:

1. The number of cases in the newborn cohort, based on the incidence rate; <u>plus</u>

2. The number of <u>surviving</u> cases in the previous year's newborn cohort, who now constitute the 1 year old cohort; <u>plus</u>

3. The number of <u>surviving</u> cases in the previous year's 1 year old cohort who are now two years old; <u>plus</u>

4. The number of additional infants and toddlers who are biologically at risk due to <u>post</u>-natal factors such as malnutrition, trauma, disease, etc.

In other words, the prevalence rates for infants and toddlers age 0-2 years of age will be the same as this incidence rate if losses due to mortality in this group are offset by additional children due to post-natal disease or trauma resulting in biological risk. Lacking evidence to the contrary, we shall assume for present purposes that the <u>incidence</u> rate for <u>infants</u> is the same as the <u>prevalence</u> rate for infants <u>and toddlers</u>. This means that about 8% of infants and toddlers are at biological risk.

In 1989, this would mean that 15,670 infants and toddlers are at biological risk. It must be considered, however, that many of these may not need intensive early interventions services; most (approximately 70%) will need only periodic screening and follow-up services to make sure they are developing normally.

The Arizona Newborn Intensive Care follow-up program in 1988 was tracking 1600 - 2400 biologically at-risk infants, out of about 3000 who had been in the NICP. Some of the other biologically at-risk infants may be enrolled in the EPSDT program (funded in Arizona by AHCCCS), for which approximately 80,000 preschool children in 1988 were eligible (47). Some of the AHCCCS-eligible children may be at-risk, but many are not. At this time, it is not possible to estimate what percentage of biologically at-risk preschoolers are being served by EPSDT and/or the NICP, but the numbers may be substantial.

TABLE 6

INFANTS AT BIOLOGICAL RISK DUE TO LOW BIRTHWEIGHT AND/OR SMALL-FOR-GESTATIONAL-AGE [a]

Risk Level	Conditions	Incidence Rates Number	Incidence Rates Percent	Percent Unfavorable Outcome
SEVERE	VLBW (<1500 G) or Pre-term (<37w) SGA	708	1.12%	42-50%
	Meningitis	79	0.12%	30-50%
MODERATE	LBW (1500-2500G) and Moderately Premature (G.A. = 31-36w)	2,500	3.95%	31%
	LBW (1500-2000G) and Full-term (>38w)	55	0.09%	32%
MILD	LBW (2000-2500) and Full-term	551	0.87%	21%
	Normal BW but require NICU	1,035	1.63%	?
TOTAL	BIOLOGICAL RISK	4,928	7.78%	30%

[a] Arizona, 1987

Sources: Fitzhardinge (28); Bricker (32); Szanton (35); Lubchenco and Koops (41); Zipsnis (44); Yee (45); Rose (46);

SECTION IV

CHILDREN CURRENTLY BEING SERVED

In Arizona, just as in the rest of the United States, services for infants and toddlers who are developmentally delayed or who are at risk for becoming developmentally delayed are provided by a number of different agencies, each with their own legislative mandates and eligibility criteria, as well as unique services.

A simple grand total of the number of children served across the agencies who provide services in Arizona would be misleading for reasons mentioned earlier in this report; that is, many children are served by more than one agency, resulting in duplicative counts, and each agency has its own reporting requirements resulting in age groupings that can not be readily compared across agencies.

In addition, it must be remembered that the services provided to the children who are counted by the respective agencies vary greatly, depending upon the statutory requirements, including eligibility criteria and service options, that govern each of the agencies. For a more complete discussion of each agency's eligibility requirements and a description of the services they provide, see *Birth to 3: Planning for Arizona's Future (Part I)*, by O'Connell and Leftwich (49).

Data on the number of children currently being served was obtained from 7 Arizona state agencies. In this section, tables will be presented that illustrate how many children each agency is serving during the designated reporting period by age category (as identified by the agency).

In an attempt to estimate the total number of infants and toddlers in Arizona who are receiving *some type and level of service*, data from a survey of 531 parents (2) will be presented that suggests that there is 25% duplication rate of children served by Arizona agencies. This duplication rate is then applied to the total number of children served across Arizona agencies to estimate the number of children currently served.

There are an estimated 4,576 infants and toddlers in the state of Arizona who are receiving some type and level of early intervention services (including screening, evaluation, rehabilitation, educational and medical interventions).

This represents 23.5% of the total estimated number of infants and toddlers in Arizona in need of early intervention services.

Division of Developmental Disabilities

Table 7 provides a summary of the number of children between the ages of birth to five years of age who were served by the Division of Developmental Disabilities (DDD) and the categorical conditions under which they were determined eligible for the year 1993.

The numbers in the table corresponding to the categorical characteristics are a duplicated count, that is, a child might be designated in the data base as exhibiting more than one developmental disability. Therefore, the numbers in each column yield a duplicated total. However, the second total at the bottom of the table is an unduplicated count for the corresponding age category, and indicates the total number of children by age who received services from DDD for that particular year. It is not possible to provide an unduplicated count for the categorical characteristics at this time.

The Division of Developmental Disabilities is statutorily required to provide early intervention services, including in-home educational and rehabilitative interventions, family assistance, and support services. It is not, however, an entitlement program. Unfortunately, not all of the children served by DDD are receiving the full range and frequency of services they have been identified as needing.

TABLE 7

DIVISION OF DEVELOPMENTAL DISABILITIES
SERVICE NUMBERS BY CATEGORY

CATEGORY	AGE IN YEARS					
	0-1	1-2	2-3	3-4	4-5	TOTAL
Autism		1		2	5	8
Cerebral Palsy	3	18	27	44	[illegible]	141
Epilepsy/seizures	6	21	40	48	33	148
Mental Retardation	2	16	17	31	33	99
At Risk/Developmental Delay	32	221	315	333	334	1235
Hearing Impairment	2	8	16	20	21	67
Vision Impairment	3	20	30	47	61	161
Communication Disorder		7	21	53	94	175
Behavior Problems		1	1	14	18	34
Medically At Risk		3	3	3	3	[illegible]
Intense	1	14	32	16	14	77
Moderate	4	47	35	36	21	143
Minimum	4	20	32	32	22	110
Non-ambulatory	1	8	21	38	31	99
Non-mobile		2	3	6	6	17
Dyslexia						0
Muscular Dystrophy		1		1	2	4
Spina bifida	4	4	4	7	7	26
Trouble with the Law	1					1
Mental Health	1					1
Other	3	23	22	30	33	111
TOTAL (DUPLICATED)	64	432	617	757	757	2627
TOTAL (UNDUPLICATED)	36	247	337	381	391	1392
DUPLICATION (UNDUP/DUP)	56%	57%	55%	50%	52%	53%

Source: Division of Developmental Disabilities, CIS data base, SPSS run dated October 27, 1988.

Table 8 illustrates the number of children receiving four levels of service: (1) fully served, (2) partly served, (3) underserved, and (4) waiting list. As the table indicates, for children from birth to one year of age, only 7.5% are fully served; 82.5% are partly served. For each age category except five year olds, less than half of the total number of children are fully served. For the five year old category, 51% are fully served. Twenty three percent (23%) of the children between the ages of birth through two years of age who have been identified by DDD as in need of early intervention services are on a waiting list. Likewise, thirty percent (30%) of the three and four year olds are on a waiting list.

TABLE 6

CHILDREN SERVED BY DES/DDD

	AGE					
	0-1	1-2	2-3	3-4	4-5	Total
Fully Served	3	03	205	249	289	849
Partly Served	33	141	113	100	57	444
Underserved		3	19	32	45	99
Waiting List	4	62	121	162	175	524
Total	40	309	458	543	566	1916
Fully Served	7.50%	33.33%	44.76%	45.86%	51.06%	44.31%
Partly Served	82.50%	45.63%	24.67%	18.42%	10.07%	23.17%
Underserved	0.00%	0.97%	4.15%	5.89%	7.95%	5.17%
Waiting List	10.00%	20.06%	26.42%	29.83%	30.92%	27.35%
Total	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%

AGE:	0-2	3-4	0-5
Fully Served	38.54%	48.51%	44.31%
Partly Served	35.56%	14.16%	23.17%
Underserved	2.73%	6.94%	5.17%
Waiting List	23.17%	30.39%	27.35%
Total	100.00%	100.00%	100.00%

SOURCE: Division of Developmental Disabilities, CIS Database, SPSS run dated October 27, 1988.

Department of Education

Two programs within the Special Education Section of the Department of Education provide services to children between the ages of birth to five years: (1) Child Evaluation Centers, and (2) Preschool Handicapped Program.

Table 9 provides a summary of the number of preschool handicapped children at each of 3 age levels by handicapping condition who were served through the preschool formula grant program under Section 619 of Part B of the Education of All Handicapped Children's Act for the 1987-88 school year census count. A total of 2740 children between the ages of 3-5 years were served (this is an unduplicated count).

The 3 Child Evaluation Centers in the state of Arizona reported in 1987-88 providing screening and evaluation services to 805 children between the ages of three through five years of age, with 101 children falling within the birth through 2 year age range. Table 11 includes a breakdown of the number of children by age category.

TABLE 9

SPECIAL EDUCATION P.L. 94-142 CENSUS COUNT (12/1/87)

HANDICAPPING CONDITION	AGE 3	4	5	TOTAL 3-5
Mentally retarded	35	46	133	234
Hard of hearing	9	21	27	57
Speech or language impaired	225	453	1270	1948
Visually handicapped	8	27	17	52
Seriously emotionally disturbed	13	34	19	66
Orthopedically impaired	14	44	35	93
Other health impaired (homebound)	0	0	2	2
Specific learning disabled	4	11	168	183
Multi-handicapped	18	27	60	105
TOTAL	326	683	1731	2740

Source: Arizona Department of Education - Special Education Section, 94-142 Special Education Census Count, 12/1/87.

Children's Rehabilitative Services

Children's Rehabilitative Services (CRS), in the Department of Health Services, provides health care to chronically ill and physically disabled children from 0-21 years of age. Children must be determined eligible by meeting certain medical conditions which are deemed to have a potential for cure or significant improvement through medical care, surgery, or therapy.

For the reporting period of 1987-88, CRS (50) reported serving 5061 children from 0-5 years of age; 2586 children were between the ages of 0-3 years (this represents an unduplicated count). Table 11 includes a breakdown of the number of children by age category. Children served by CRS are assigned diagnostic codes based on the ICD9CM consisting of hundreds of categories. This data provides a duplicated count, since children can be diagnosed with more than one condition, as is the case with the data in Table 7. The CRS data includes conditions which do not fit CRS eligibility requirements as well as those which do. Therefore, it is not possible at this time to provide a table of children served by CRS by age and CRS-eligible handicapping condition.

Newborn Intensive Care Program

The Newborn Intensive Care Program (NICP), in the Department of Health Services, provides consultation, transportation, hospital services, and newborn follow-up services to critically ill newborns in need of medical intervention beyond what is normally needed.

In 1987 the NICP reported serving 2715 infants (45). This compares to a total of 60,320 births in Arizona for that year.

Since birthweight is a key characteristic for the identification of biologically at-risk infants (although it has been recommended that it not be used in isolation of other variables), Table 10 compares the number of infants born at 4 birthweight levels who were enrolled and served by the NICP with the number of infants born at each birthweight level but not enrolled in the NICP. Seventy-four percent (74%) of very low birthweight babies (less than 1500 grams) were served by the NICP. Only 29% of babies born at a birthweight between 1500-2500 were served by the NICP.

TABLE 10

NUMBER OF ARIZONA INFANTS BY BIRTHWEIGHT AND NEWBORN INTENSIVE CARE, 1987

BIRTHWEIGHT (GRAMS)	TOTAL	IN NICP	NOT IN NICP
VLBW (<1,500 G)	734	541 (74%)	193
1,500-2,500	3,373	974 (29%)	2,399
ALL LBW (<2,500 G)	4,107	1,515 (37%)	2,592
NORMAL BW 2,500-4,000	53,171	1,035 (2%)	52,136
LARGE BW (>4,000 G)	6,042	139 (2%)	5,903
TOTAL	63,320	2,689 (4%)	60,631

Sources: Yee (45); Gersten & Mrela (10)

Head Start

Head Start is a national program under the Head Start Act. At least 10% of the slots in each Head Start program must be made available for children with special needs. Head Start programs in Arizona do not currently serve children between the ages of birth through two years. As Table 11 illustrates, 426 children with special needs were served by the Head Start Programs.

Total number of children served

Table 11 summarizes data supplied by state agencies serving children birth through 5 years of age who have special needs. Unfortunately, it was not possible to obtain equivalent data for the same year from each agency; the result is data ranging from 1985-1988.

Child counts supplied in the table are unduplicated within each agency, but since a child can be served by several different programs for different needs, the numbers in the table produce a duplicated count for each age group, intended to represent a "typical" year between 1985 and 1988. Another problem is that the total number of 3-5 year olds served by DES\DDD could not be determined because available data included 5 year olds in a larger grouping spanning ages 5-9, totaling 6,600 children served.

DDD served 36 infants, 247 one-year-olds, 337 two-year-olds, 381 three-year olds, and 391 four-year-olds that year. Extrapolating this trend, it seems likely that the number of five-year-olds was greater than 400. The number is likely to have been much larger, however, since 6,600 children age 5-9 were served, averaging 1,650 children per one-year age cohort. One can only guess that the actual number of 5-year-olds was between 400 and 1,600, but this is too wide a range to be meaningfully interpreted.

Some estimate of the extent of double counting in Table 11 can be made using results from a survey of parents of infants and toddlers with special needs who received services in recent years (2). Each of the agencies in Table 11 (except Head Start and Special Education Preschool Programs) were asked to send out a form letter to each family on their mailing list who had children born after January 1, 1985, who received services from that agency, inviting the parents to participate in a survey. Almost 10,000 letters were sent out; about 750 parents mailed in response forms indicating their willingness to participate in the survey. Of these, the parents of more than 600 children were interviewed; some parents had more than one disabled child. A total of 531 parents or other caretakers were interviewed.

One of the questions on the survey asked: "How many letters did you receive?" Twenty-eight percent (28%) said they had received more than one letter requesting their participation in the survey; several reported receiving six or more letters inviting their participation in the survey! In all, this is equivalent to a 28% duplication rate of families who receive services from more than one agency. Other questions during the interviews asked if the family had ever received services from the agencies such as those listed in Table 11, or if they currently get services paid for by those agencies. Again, the responses implied an overlap in service provision across agencies of 28% (for more precise details, see O'Connell, et al. in press). This means that an estimated unduplicated total of the number of children served by Arizona agencies can be obtained from the duplicated total in Table 11 by multiplying by .72, which produces the results printed on the line "EST. UNDUPLICATED TOTAL".

This approach implies that 2.3% to 2.4% of infants and toddlers received services from the agencies listed in Table 11 in a typical year from 1985 - 1988. Since we estimate that 10% of infants and toddlers are developmentally delayed or at established or biological risk of becoming developmentally delayed, this means that only about 23.5% of infants and toddlers in need of special services are currently being served.

TABLE 11

Children with Developmental Delays at Established, or at Biological Risk of Becoming Developmentally Delayed Served by Primary State Agencies in Arizona

AGENCY	YEAR	AGE 0-2	AGE 3-5
DHS/CRS	1987/8	2,983	2,476
DHS/MCH/NICU	1987	2,315	0
DES/DDD	1988	620	>712
ASDB	1987/8	334	205
ADE/CEC	1987/8	101	505
Head Start	1985/6	0	428
ADE/Preschool Programs	1987	0	2,740
TOTAL (DUPLICATED COUNT)		6,353	>6,923
EST. UNDUPLICATED TOTAL		4,576	>4,985 [= .72 x dup]
TOTAL POPULATION	1987	193,446	182,841
	1988	197,302	191,130
EST. PERCENT SERVED	1987	2.37%	>2.73%
	1988	2.32%	>2.61%

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APPENDIX A

APPENDIX A

ARIZONA POPULATION PROJECTIONS-COUNTIES
1989-2000

ARIZONA

Counties	1989	1990	1991	1992	1993	1994	1995	2000
Apache	66,400	68,500	70,100	71,800	73,500	75,200	77,000	84,200
Cochise	104,600	106,900	109,500	111,900	114,300	116,700	118,900	129,000
Coconino	97,700	100,700	103,700	106,800	109,700	112,500	115,400	129,100
Gila	41,000	41,500	42,000	42,400	42,800	43,300	43,700	45,800
Graham	25,100	25,200	25,400	25,500	25,700	25,800	25,900	26,300
Greenlee	9,500	9,500	9,500	9,400	9,400	9,400	9,300	9,100
La Paz	14,500	14,600	14,800	14,900	15,100	15,200	15,400	16,100
Maricopa	2,152,000	2,262,100	2,371,800	2,483,200	2,587,600	2,686,800	2,791,500	3,252,400
Mohave	83,600	85,800	88,100	90,200	92,400	94,700	97,000	108,400
Navajo	91,100	93,200	95,400	97,600	99,900	102,200	104,500	113,100
Pima	711,000	734,800	759,900	781,400	805,100	828,600	853,000	973,700
Pinal	113,100	116,300	119,500	122,800	126,200	129,600	132,900	149,100
Santa Cruz	30,900	31,700	32,600	33,400	34,200	35,000	35,800	39,800
Yavapai	101,000	104,200	107,300	110,600	113,900	117,100	120,600	140,200
Yuma	93,300	95,400	97,400	99,800	102,200	104,600	107,000	118,800

APPENDIX B

APPENDIX B

SUMMARY OF PROJECTED ARIZONA POPULATION

YEAR	AGE 0	AGE 1	AGE 2	AGE 3	AGE 4	AGE 5	TOTAL
1989	66,589	66,812	67,492	67,653	67,699	65,041	401,286
1990	68,034	68,480	69,061	69,740	69,875	69,871	415,061
1991	69,377	69,938	70,720	71,298	71.949	72,032	425,314
1992	70,470	71,274	72,149	72,927	73,477	74,075	434,372
1993	71,422	72,265	73,361	74,230	74,979	75,476	441,733
1994	72,209	73,116	74,229	75,318	76,158	76,856	447,886
1995	73,232	74,053	75,212	76,317	77,374	78,159	454,347
1996	74,196	74,970	76,024	77,174	78,246	79,249	459,859
1997	75,000	75,670	76,657	77,700	78,820	79,844	463,691
1998	75,808	76,663	77,533	78,509	79,518	80,583	468,614
1999	76,893	77,384	78,424	79,282	80,224	81,180	473,387
2000	77,961	78,361	79,023	80,050	80,874	81,765	478,034

Source: Baseline Prrojections, Table 6: School Age Population by Age
Department of Economic Security, Population statistics Unit, 12/86

APPENDIX C

INTERAGENCY COORDINATING COUNCIL FOR INFANTS & TODDLERS

Building a strong early intervention system in accordance with Public Law 99-457

Rose Mofford
Governor

William P. Allaire
Council Chair

Marlene J. Morgan
Executive Director

May 18, 1989

Dear Interested Person:

In accordance with the Education of the Handicapped Act Amendments of 1986, Public Law 99-457, each state shall establish a State Interagency Coordinating Council (ICC) which shall ensure the development of a statewide, comprehensive, coordinated, multidisciplinary interagency program of early intervention services for handicapped infants and toddlers and their families.

Enclosed is a copy of the definition of developmentally delayed approved by the ICC. It is the ICC intent to use the definition as it pertains to Public Law 99-457, Part H.

We would appreciate your review of this definition and your impressions about the impact of adopting this definition for Arizona. The deadline date for submission of comments is June 2, 1989.

Thank you for your input.

Sincerely,

Bill Allaire

Bill Allaire, Chair
Interagency Coordinating
Council

BA:lmb

Enclosure

Arizona Department of Economic Security • Site Code 791A • P.O. Box 6123 • Phoenix, Arizona 85005 • (602) 258-0419

ELIGIBILITY FOR SERVICES
UNDER
PUBLIC LAW 99-457, PART H

Children ages birth to three (3) years of age who are residents of Arizona and are developmentally delayed and/or at risk.*

I. <u>Developmentally Delayed:</u>

A child (birth through 2 years) who has not reached 75% of developmental milestones expected at his/her chronolgocial age in one or more of the following domains:

physical/fine and/or gross motor/sensory
congitive/adaptive
language/communications
social/emotional/personal
self-help

This will be based on professional assessment and will include parental input.

II. <u>At-Risk:</u>

A child (birth through 18 months) who has an established or biological risk of becoming developmentally delayed. Specifically, those infants whose:

> Early development is influenced by diagnosed medical disorders of known etiology bearing relatively well known expectancies for developmental delay, and/or
>
> History includes prenatal, perinatal, neonatal or earlly developmental events suggestive of biological insults to the developing central nervous system which, either singly or collectively, increase the probability of later developmental delay.
>
> For infants under one year this determination may be figured in weeks or months.

Also, for those children born after less than 36 weeks gestation, a "corrected" age is used to consider this prematurity in evaluating developmental achievement. This corrected age is not used after chronological age two (2) years.

Example:40 weeks gestational age
\- # of weeks of gestation

\# of weeks difference

The number of weeks difference is rounded to the nearest month, then subtracted from the birth age in months.

BIOLOGICAL CONDITIONS

Biological conditions include, but are not limited to:

- prematurity compounded by psychosocial and/or other health problems
- respiratory distress syndrome
- abnormalities in tone such as:
    - hypertonicity
    - hypotonicity
- neurological abnormalities
- in newborn intensive care for more than 48 hours
- prenatal (e.g. fetal exposure to alcohol, drugs, teratogens, congenital infections)
- low birth weight (less than 2,000 grams)
- significant nutritional deficiencies

ESTABLISHED RISK FACTORS

- chromosomal abnormalities
- metabolic disorders
- neural tube defects (e.g. spina bifida)
- periventricular leukomalicia
- congenital anomalies
- auditory impairment
- genetic syndrome
- hydrocephalus
- intraventricular hemorrhage
- cerebral palsy
- visually impaired
- children of developmentally disabled parents

<u>Targeted for Review:</u>

- victim of child abuse
- children of teenage mothers fifteen (15) years of age or younger

The Eligibility Determination:

Significant delays can be expressed in many ways, the following matrix lists ages and the corresponding delays in standard deviations, months and percentages to help clarify the term "75% of developmental milestones" used in the definition of developmental delay.

Age	Delay In Standard Deviations	Delay In Months	Delay In Percentage
1 year	-1.5	3 months +	25% +
1.5 years	-1.5	4.5 months +	25% +
2 years	-1.5	6 months +	25% +
3 years	-1.5	9 months +	25% +

- * In very young infants, it is more difficult to use a 25% delay cut off point. For infants under 18 months who are not determined to have an established or biological risk (at-risk), some professional judgment, with parent input, must be used to interpret and document evidence of delay significant enough for eligibility.

- * Careful assessment is necessary to determine developmental delay and must be performed by a competent professional with appropriate training in the area of developmental delays. Standardized tests, rating scales, developmental profiles and other instruments and procedures that meet acceptable professional standards must be used to document the nature and severity of problems necessitating intervention.

  Please note: Professional standards for this program must include a respect for parent input and observations about their child's development above and beyond what is routinely included in the administration of the above mentioned tests.

Appendix 16

END

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Date Filmed

March 29, 1991