
The National Deaf-Blind Child Count: 1998-2005 in Review

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*The National Technical Assistance Consortium
For Children and Young Adults who are Deaf-Blind*

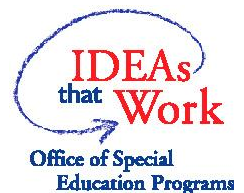
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INTRODUCTION

The National Consortium on Deaf-Blindness (NCDB), and its predecessors including the National Technical Assistance Consortium for Children and Youth who are Deaf-Blind (*NTAC*) and the Teaching Research Assistance to Children Experiencing Sensory Impairments (TRACES) projects, have been conducting an annual National Child Count of Children and Youth who are Deaf-Blind (Birth –21) since 1986. This national child count, commonly referred to as the “Census”, is conducted on December 1st of each year to supplement OSEP’s federal Child Count, which includes children as deaf-blind when deaf-blindness represents their only disability. Since the majority of children with deaf-blindness do have additional disabilities they are not included in the OSEP Child Count as deaf-blind (Mueller, 2006). In contrast to OSEP’s December 1 count, the Census data are collected for children with deaf-blindness in isolation, as well as those with additional disabilities. The Census represents the first, longest running, and most comprehensive registry of infants, young children, and students who are deaf-blind.

Rationale for an Annual Deaf-Child Child Count

Through the years, the collection of deaf-blind specific child count data and its ensuing analysis has provided valuable information. It has assisted state and national deaf-blind technical assistance projects in the design of their services, as well as in meeting the requirements of their various funding agencies. It has also been used to: 1) identify national and state technical assistance needs and activities for children and youth who are deaf-blind, their families, and the service providers and systems that serve them; 2) identify research needs; 3) develop personnel preparation programs; and, 4) target national and state product development and dissemination activities.

The Census has grown throughout the years and now represents a comprehensive data set including:

- The specific number and ages of the infants, young children, and students (birth through 21) who are deaf-blind throughout the country
- The primary etiology of their deaf-blindness
- Any additional disabilities they may have
- The type and degree of their hearing and vision loss
- Their ethnicity
- Their IDEA classification, special education status and placement
- Their living setting

In 1992, Baldwin suggested that before beginning a detailed discussion of the numbers and descriptors of those who are deaf-blind, it is important to ask:

“Why do we want to know this?”

The answer to this question remains as important today as it was when it was first asked. The continuance of the Census must not be thought of as simply the satiation of a grant or contract requirement, which once completed is shelved until the following year. In contrast, the foremost reason for continuation of the Census remains that posed by Baldwin in 1992:

“The real reason to gather all possible data on each and every person who is deaf-blind is to ensure that these people are getting the highest quality services that the professions have developed.”

With this as the purpose, the discussions around collecting, and using the information collected, becomes extremely important and focused. *NTAC*, (now NCDB, the National Consortium on Deaf-Blindness) proposes that the Census be used to assist in answering the following:

1. Who are the children and youth with deaf-blindness throughout the country, how many are there and what is the relationship of the Census to the IDEA Part B and Part C annual December 1 Child Counts?
2. What is the extent of the vision and hearing losses of those reported on the Census and what additional disabilities do they manifest?
3. Where are those reported receiving services and how does this impact technical assistance and training needs?
4. Where are they living and how does this impact technical assistance and training needs?

As an initial attempt to answer these questions, *NTAC* conducted a comprehensive review and synthesis of Census information across 8 years, from 1998-2005. The information presented represents an ongoing data collection partnership between the State/Multi-State Deaf-Blind Projects across the country and *NTAC*.

Considerations for the Reader

When reading the information that follows, the reader should note that:

- Each state deaf-blind project has the discretion of establishing the criteria for their own project services.
- The Census is a point-in-time snapshot and reflects those infants, young children, and students identified and eligible for services from State/Multi-State Deaf-Blind Projects on December 1 of each year. Thus, in many instances, projects serve more infants, young children and students over the course of the year than are reported on the December 1 child count date.
- The language and reporting elements used in the Census are consistent with those found in Section 618 of IDEA. As federal reporting categories have changed, *NTAC* has adopted these changes and followed the OSEP crosswalks for aggregating and comparing data elements. For example, the exiting requirement “returned to regular education” was changed to “no longer receives special education” and “graduated with certificate” was changed to “received a certificate.”

- The Census data presented are based on aggregate data reported by each State/Multi-State Deaf-Blind Project and the aggregated counts provide a national perspective. There is substantial variability in the individual state project data reports.
- The variability across projects serves as an important part of *NTAC*'s, as well as the projects, needs assessment information and often is used to target services and technical assistance activities.

The following pages present first, an Executive Summary of the review, followed by a more detailed discussion and presentation of selected Census data collection elements.

Executive Summary

In reviewing the Census data submitted since 1998, it becomes quickly apparent that there is no single portrait that can be painted to portray a typical student with deaf-blindness and those with deaf-blindness are as varied as the number reported.

Question 1: Who are the children and youth with deaf-blindness throughout the country, how many are there and what is the relationship of the Census to the IDEA Part B and Part C annual December 1 Child Counts?

Definition of Deaf-Blindness

Although each state deaf-blind project has the discretion of establishing the criteria for their project services, the IDEA 2004 definition of deaf-blindness must be used for defining students in early childhood special education (3-5) and school age special education (6-21) programs and for their inclusion on the Census (Killoran, 2007). The IDEA 2004 definition of deaf-blindness, as published in the final Part B regulations, states that:

“Deaf-blindness means concomitant hearing and vision impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness” (Section 300.8 (c) (2)).

For infants and toddlers receiving Part C early intervention services, deaf-blindness is defined as:

“Concomitant hearing and vision impairments or delays, the combination of which causes such severe communication and other developmental and intervention needs that specialized early intervention services are needed” (Killoran, 2007).

The Uniqueness of Deaf-Blindness

Deaf-blindness has a tremendous impact on a child’s ability to understand and interact with both their physical and social the environment. Lack of access to auditory and visual information for children with deaf-blindness impacts all areas of their development. Their abilities are also impacted by their age at the onset of their deaf-blindness, the type and degree of their sensory losses, their environment, and the presence of additional disabilities (Alsop, Blaha and Kloos, 2000). In addition to deaf-blindness, over 90% of children on the Census have one or more additional disabilities. Thus, the population of children and students with deaf-blindness is a diverse group with a broad continuum of needs and learning styles.

As such, the delivery of appropriate services and intervention requires not only a knowledge of the impact of deaf-blindness on the child’s development, unique needs and learning style, but also of effective instruction, accommodations, and assistive technology that incorporates strategies in recognition of the child’s deaf-blindness. Unfortunately, the lack of or misidentification of a child or youth’s deaf-blindness, and its resultant unique intervention

requirements, has been a consistent problem. One, which all too often, results in a lack of, or delay in, receiving the appropriate intervention and instruction critical to their early development (Muller, 2006).

The Numbers of Infants, Young Children and Students with Deaf-Blindness

Although varied across individual states, national data indicate that the State and Multi/State Projects have consistently reported approximately 10,000 children and students with deaf-blindness since 1995. The number of children annually reported has doubled since the inception of the Census in 1985. This number continuously rose from the originally identified 4,227 children and youth in 1985 until 1997, when the child count peaked at 11,053. In 1997 and 1998, several states began cleansing their data, which resulted in a decrease of over 1,100 reported on the 1998 count. The count then gradually began to again rise to over 10,000 until 2003, when what appears to be a decreasing trend began with 9,658 individuals being reported on the 2005 Census.

However, this apparent decrease is misleading. In 2003, OSEP's Part B exiting data elements were integrated into the Census and as such, the total counts since 2003 include only those in early intervention or special education on the day of the child count, December 1, of each year, rather than a cumulative count of those in early intervention throughout the year. As such, those who exit from early intervention or special education prior to the December 1 reporting date are no longer included in the total reported for the Census.

In order to reflect the entire number of children and students reported by the State/Multi-State Deaf-Blind Projects, NCDB will begin reporting two totals with the 12/1/2006 Census report. These two counts will reflect: 1) the total reported, and 2) the total reported minus those students who have exited from early intervention or special education prior to the December 1 count date.

It is interesting to note that when contrasted to OSEP's 2005 child count the percentage of infants and young children with deaf-blindness (as reported on the 2005 Census) served in Part C early intervention (EI) programs and in Section 619 early childhood special education (ECSE) programs is higher than that reported by OSEP for all children with disabilities in the corresponding age groups (birth through 2 and 3-5). This difference may in part be attributed to the fact that deaf-blindness, although a low-incidence disability, impacts a child's development more noticeably and at an earlier age than developmental delays and other more mild disabling conditions. Especially since speech and language delays make up the largest percentage as children reach the age of 3.

In contrast to the EI and ECSE percentages, the percentage of school-aged students reported by OSEP quickly overtakes the percentages reported on the Census. This is logical since the number of students with high-incidence disabilities (i.e. learning disabilities) included on OSEP's Part B counts has continuously increased.

Finally, the numbers of students reported by OSEP for the 18 and older age group drop dramatically and are well below those reported on the Census. Again, this is logical given the fact that the vast majority of special education students fall into high-incidence disability

categories and exit school by age 18. Students who are deaf-blind typically stay in school to through age 21, thereby making up a much larger percentage of the total 18-21 Part B population.

Race/Ethnicity

There has been little variation in the race or ethnicity of children and students reported by the State/Multi-State Deaf-Blind Projects since 1998. American Indian and Alaskan Natives make up the smallest group (2%) reported on the Census, followed by children and students of Asian and Pacific Island descent (3%), Hispanic and Latino, (12%) and Black (14%) children and students. White children and students represent the largest group (56%) of those reported.

Though small, there are several categories in which differences are seen between OSEP's Race/Ethnicity counts and the Census, with OSEP's reported percentages being 3% higher for students of Hispanic or Latino origin and 5% higher for students who are Black. The OSEP percentages include all students with disabilities reported by state education agencies, and as such, these differences may *possibly* be attributed to the over identification of minority students (i.e., learning disabilities and/or behavior disorders) in high-incidence disability categories. A smaller percentage of students of Asian origin are reported on the Census than on the OSEP Part B count.

Question 2: What is the extent of the vision and hearing losses of those reported on the Census and what additional disabilities do they manifest?

Deaf-blindness is defined, in part, as concomitant vision and hearing impairments that in combination result in severe communication and other developmental and educational needs. However, the type of loss (conductive/ sensorineural, auditory neuropathy) and the degree (mild, severe, profound) of hearing losses and the type and degree of vision losses (low vision/totally blind) varies greatly from student to student. Some children have legal blindness coupled with mild hearing losses, others may have more impact on their hearing than their vision, and fewer still are both totally blind and profoundly deaf. Regardless of these varying degrees, it is this combination of vision and hearing loss that results in an ongoing lack of clear and consistent access to the auditory and visual information presented day-to-day.

Projects are required to document the primary classification of visual impairment and hearing impairment for each child or student, and then report the classification that best describes the individual's documented degree of vision and hearing loss. They must select the one option that is most descriptive of the student's documented loss.

Vision

There has been little variation in the primary vision classifications of children and students reported by the State/Multi-State Deaf-Blind Projects since 1998. Across the years, legal blindness is clearly the most frequently reported classification, representing nearly one-fourth (24%) of those reported. An additional 8% are considered totally blind. When combined with low vision (21%) and light perception only, (9%) 62% of children and students reported on the

Census have been identified with significant visual impairments. Since 1998, the percentage of individuals reported with cortical vision impairments (CVI) has more than doubled, from 8% to 17% in 2005. This may be in part due to an increased awareness of CVI and its educational impact, as well as numerous national and state technical assistance activities geared towards appropriate assessment and intervention strategies.

Hearing

There has also been little variation in the primary hearing classifications of children and students reported and this lack of variation is consistent with that reported for vision classifications. Children and students with profound losses represent the largest percentage (15%) of individuals reported within a single classification and when combined with students with moderately severe (11%) and severe hearing losses (13%), the overall percentage of those reported with severe and/or profound hearing losses increases to nearly 40%. In contrast, only 14% of students are reported with mild losses and 13% with moderate losses. Children and students reported with diagnosed progressive hearing losses are reported as 3% of the population, whereas only 2% are reported with diagnosed progressive vision losses.

In contrast to the increase seen in the percentage of individuals reported with cortical vision impairments, the percentage of those reported with central auditory processing disorders (CAPD) has remained fairly consistent since 1998, ranging from a high of 10% to a low of 6%. Interestingly the reporting of CAPD peaked in 2001, which coincides with the delivery of several national and state technical assistance activities addressing CAPD and CVI. However, there was not a corresponding peak in the CVI data reported, nor was the increase in reporting CAPD sustained.

Additional Disabilities

Not surprisingly, over 90% of children and students reported on the Census are identified as having one or more additional disabilities. The types and combinations of these disabilities are consistent across all age groups and ethnicities, although they do appear to be reported more often in those reported with more severe vision and hearing losses.

Sixty-six percent of those reported as deaf-blind on the Census are also reported as having a cognitive impairment, followed by physical impairments (57%) and complex health care needs (38%). Somewhat surprisingly, based on the limited communication skills of the majority of those reported on Census, less than 9% are reported to have behavior challenges. Nearly 30% are reported to have an additional impairment under the “Other” category.

Etiologies

Projects are also required to identify and code the etiology of the individual’s deaf-blindness. Currently, there are over 100 potential etiologies to select from. However, in 2005, ten etiologies accounted for over 70% of the individuals reported.

The top ten etiologies include:

1. Heredity (2,107)
2. Prematurity (1,112)
3. Pre-natal complications (790)
4. Post-natal complications (715)
5. CHARGE syndrome (572)
6. Microcephaly (369)
7. Cytomegalovirus (CMV) (334)
8. Hydrocephaly (284)
9. Meningitis (279)
10. Usher syndrome (246)

Although the specific order of this top ten has changed from year-to-year since 1998, with CHARGE syndrome showing the greatest growth, these top ten rankings have been consistent across the years. CHARGE is now the leading single syndrome associated with deaf-blindness as reported on the Census.

Question 3: Where are those reported receiving services and how does this impact technical assistance and training needs?

In previous years, Part C Early Intervention Settings and Part B Educational Settings (3-5 and 6-21) were a single, combined Census reporting element. Prior to the December 1, 2006 count, the Census required that projects report the educational setting code from the appropriate age subcategories that best described the individual's early intervention or education setting. These settings, and their respective definitions, were based on previously used OSEP reporting requirements and definitions.

Early Intervention settings

Since 1998, and consistent with national Part C data, the vast majority of infants and toddlers with deaf-blindness have received early intervention services in their home, averaging over 70% across the years. The provision of home-based services peaked at 78% in 2000 and by 2005 has gradually decreased to an average of 70%. Twenty-seven percent (ranging from a high of 38% in 1998 to a low of 20% in 2000) of infants and toddlers have received early intervention in "Other" settings including programs designed only for young children with developmental disabilities, combination home and center-based programs, and residential, clinic and hospital facilities. Only 2% of those reported received services in community settings such as daycare, child care centers, preschools or other community settings and 1% of the children reported by the projects as deaf-blind were not receiving early intervention.

Early Childhood Special Education Settings

Unfortunately, the trend for serving young children in natural environments as evidenced in services to infants and young children in Part C disappears at age three and the vast majority of preschool-aged children (3-5) with deaf-blindness were served in separate settings. Since 1998, over 72% of preschoolers received their services in separate early childhood special education programs, separate schools and residential facilities. In contrast, less than 20 % were served in fully or partly integrated settings including regular early childhood programs, combined early childhood/early childhood special education programs or in reverse mainstreamed settings. Only five percent of the preschool-aged children reported received their early childhood special education program in their home.

School-aged Settings

The trend for placing students with deaf-blindness in separate settings beginning at age three also continues throughout the student's subsequent years in school age special education. As with ECSE, since 1998 the vast majority of school-aged students, nearly 80%, have received their services in separate classrooms, schools or residential facilities. On the average, 39% of students with deaf-blindness are served in separate classrooms, 24% are served in private or public separate schools and just over 10% are served in public or private residential facilities. Six percent of students are served in home and hospital programs and 1% has been served in a home school setting. (Note: A Home and hospital program refers to settings in which a child is placed by an IEP team. In contrast, home school is a setting in which a parent voluntarily enrolls their child). Less than 1% of school-aged students with deaf-blindness are reported to be served in post-secondary education or vocational settings and 1% of those reported are receiving no educational services at all.

Only 15% of those reported since 1998 have been served in regular education environments. On the average, only 8% of school-aged students with deaf-blindness have been served in regular classrooms and only 7% in resource settings. Interestingly there has been little variability in these settings throughout the years, despite the federal emphasis on the provision of services to students in least restrictive settings and the inclusion of students in the general education curriculum. These data indicate that more intensive and effective efforts to include children with deaf-blindness within the general education setting are very necessary.

Question 4: Where are they living and how does this impact technical assistance and training needs?

Nearly 90% of infants, children and students with deaf-blindness are living at home with their parents and extended family members. Unfortunately, this is as true for young adults as it is for infants and toddlers. Less than one percent of those reported on the Census live independently in apartment settings and only 2% are reported to live in group homes. These data continue to support the need for comprehensive technical assistance and family support activities, as well as technical assistance related to post-secondary transition and independent living.

THE CENSUS TOTALS

The number of children annually reported by the State/Multi-State Deaf-Blind Projects has doubled since the inception of the Census in 1985. This number continuously rose from the originally identified 4,227 children and youth in 1985 until 1997, when the child count peaked at 11,053. In 1997 and 1998, several states began cleansing their data, which resulted in a decrease of over 1,100 reported for the 1998 count. The count then gradually began to again rise to over 10,000 until 2003, when what appears to be a decreasing trend began.

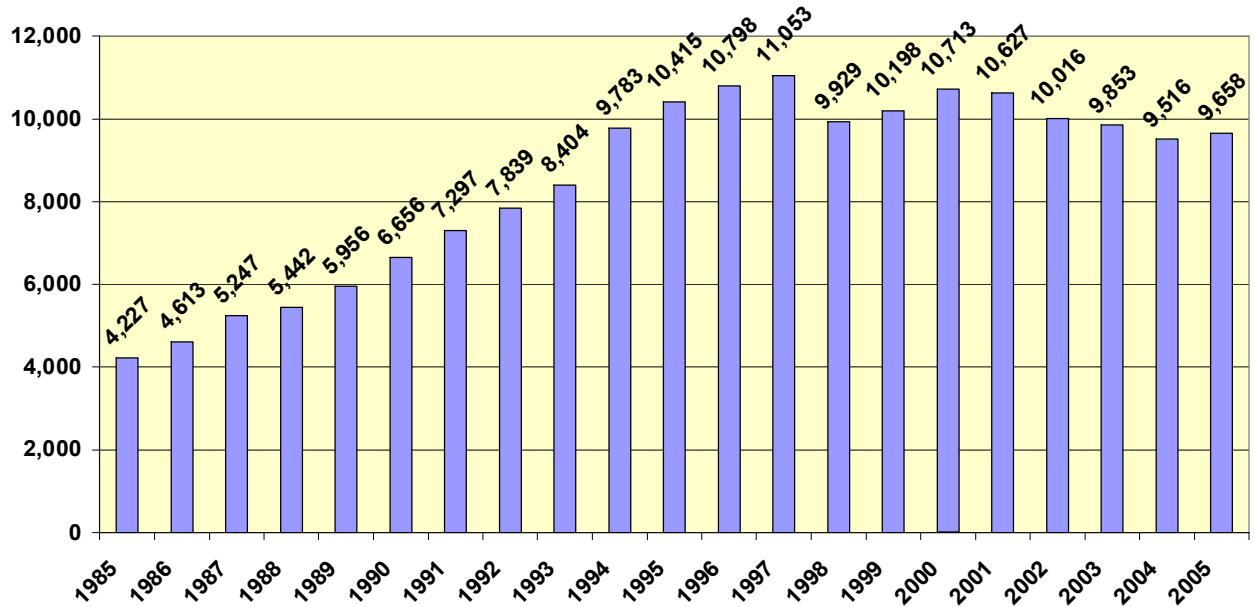


Figure 1: Number of children and youth (birth-21) reported by State/Multi-State Deaf-Blind Projects

However, this apparent decrease is misleading. In 2003, OSEP's Part B exiting data elements were integrated into the Census and as such, the total counts since 2003 include only those in early intervention or special education on the day of the child count, December 1, of each year. Those students who exit from early intervention or special education prior to the December 1 reporting date are no longer included in the total reported for the Census. OSEP's exiting categories include those students who have left special education and are who are known to have:

- Transferred to regular education
- Graduated with regular high school diploma
- Received a certificate
- Reached maximum age
- Died
- Moved
- Dropped out

In order to reflect the entire number of children and students reported by the projects, NCDB will begin reporting two totals with the 12/1/2006 child count report. These two counts will reflect: 1) the total reported by the State/Multi-State Deaf-Blind Projects and, 2) the total reported minus those students who have exited from early intervention or special education prior to the 12/1 count date. Figure 2 illustrates these totals, and their differences for the 2003-2005 reports.

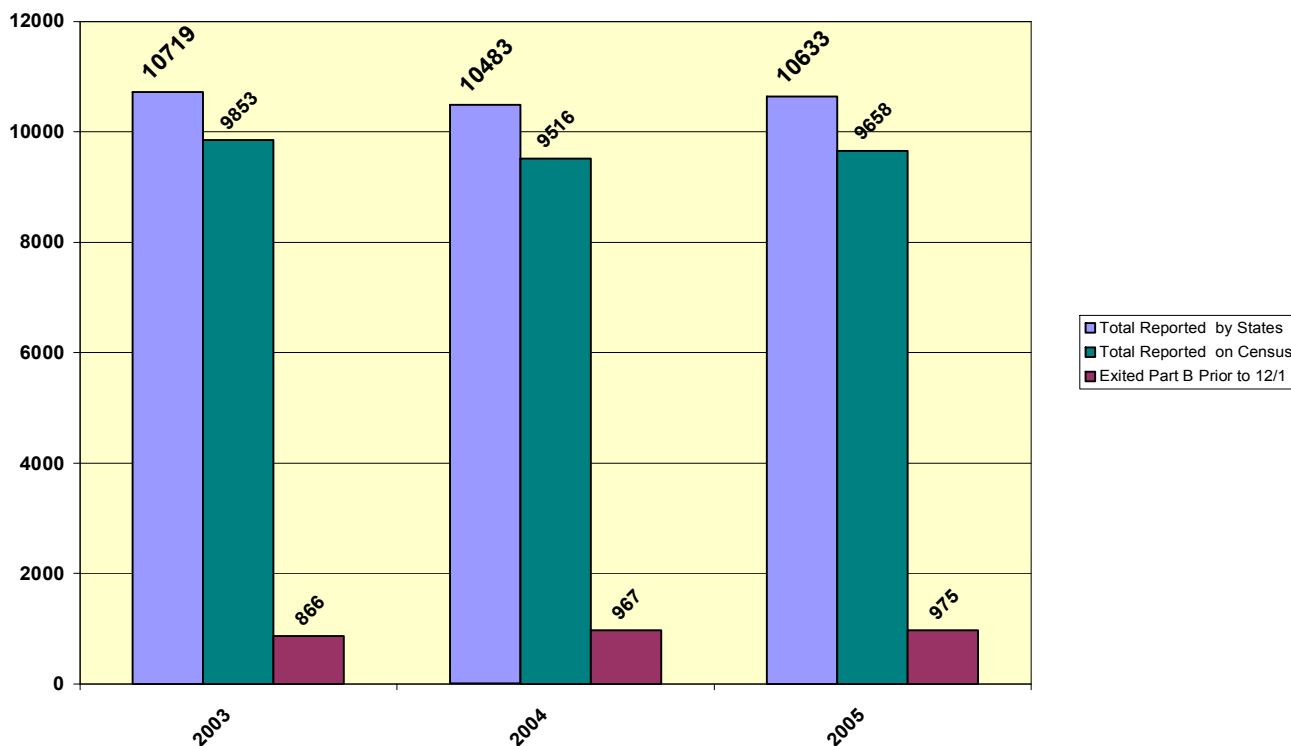


Figure 2: Total number of students reported and after exiting

When viewed from this perspective, it becomes apparent that the decreasing trend illustrated in Figure 1 resulted from a change in the reporting format in contrast to an actual decrease in the number of students reported and that the count has consistently been over 10,000 children and students since 1999.

In 2005, over 16% of exiting students received a diploma or received a certificate and only 16% exited due to reaching the maximum age for services.

The Child Count Age Groups

OSEP’s December 1 Part B and Part C Child Counts are reported by individual age, as well as aggregated age groups. For comparison purposes, the Deaf-Blind Census is also aggregated consistent with OSEP’s age groups. These groups include children and students aged:

- Birth – 2
- 3-5

- 6-11
- 13-17
- 18-21

Comparison by Individual Ages on 12/1/2005

Figure 3 presents the percentage of all children and students reported on OSEP’s 2005 child count within in a specific age group contrasted to the number of children reported for the 2005 Census within the respective age group. The percentage of children with deaf-blindness served in Part C early intervention (EI) programs (birth through 2) and in Section 619 (3-5), early childhood special education (ECSE) programs is higher than that reported by OSEP for all children with disabilities in the corresponding age groups (birth through 2 and 3-5).

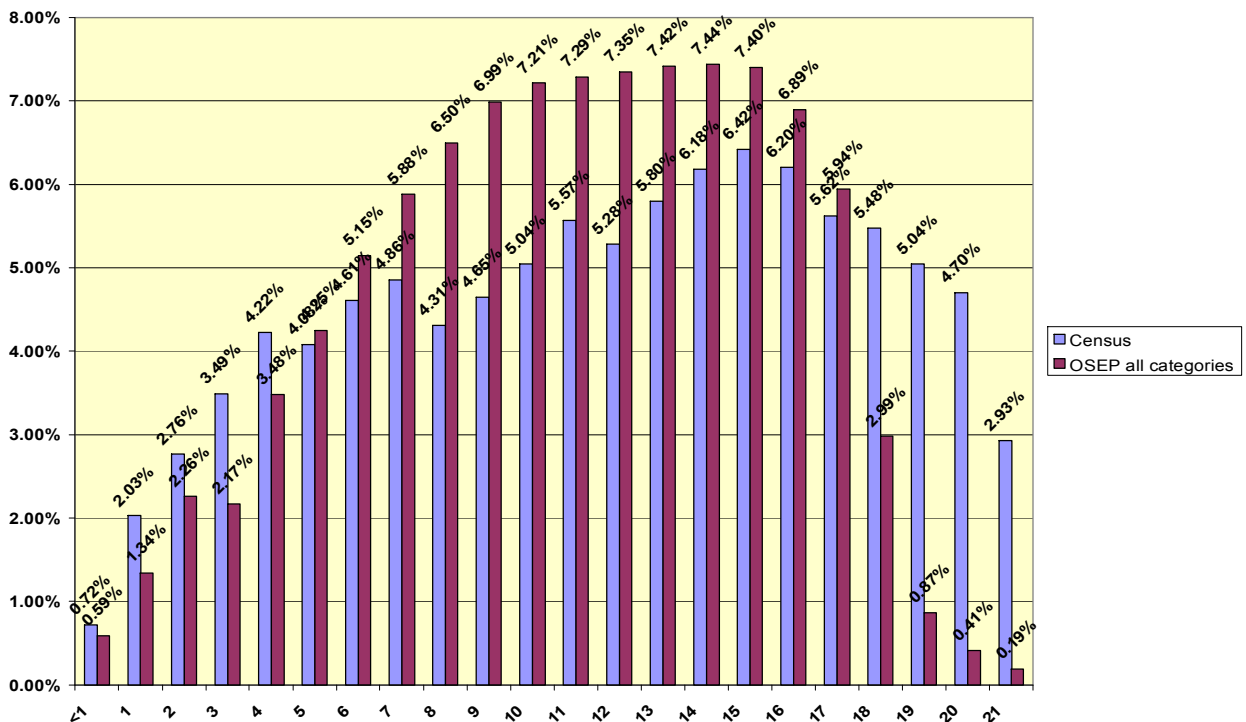


Figure 3: Comparison by individual age groups

This may be in part be due to the fact that deaf-blindness, although a low-incidence disability, impacts a child’s development more noticeably and at an earlier age than developmental delays and other more mild disabling conditions.

In contrast to the EI and ECSE percentages, the percentage of school-aged students with disabilities reported by OSEP quickly overtakes the percentages reported on the Census. This is logical since the number of students with high-incidence disabilities (i.e. learning disabilities) and included on OSEP’s Part B counts has continuously increased.

Finally, the numbers reported by OSEP for the 18 and older age group drop dramatically and are well below those reported on the Census. Again, this is logical given the fact that the vast

majority of special education students fall into high-incidence disability categories and exit school by age 18. Students who are deaf-blind typically stay in school through age 21, thereby making up a much larger percentage of the total 18-21 population of students with disabilities.

Comparison by Age Groups Since 1998

Figures 4 through 8 illustrate the percent of children and youth reported by the State/Multi-State Deaf-Blind Projects in each age group since 1998.

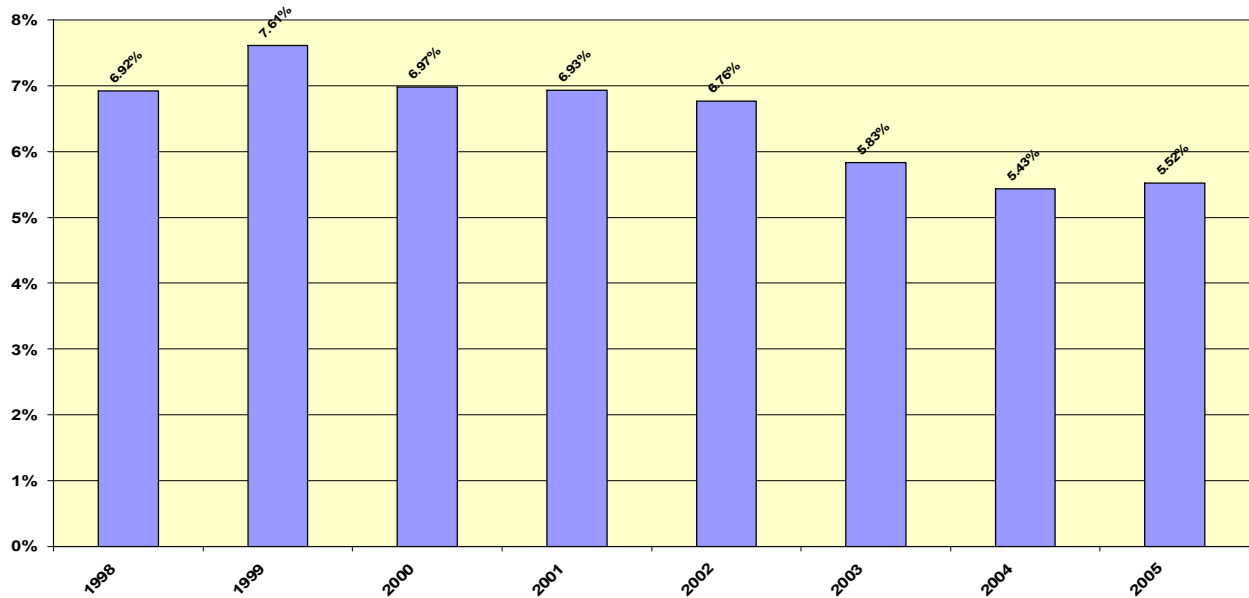


Figure 4: Percent of Census - Birth through 2

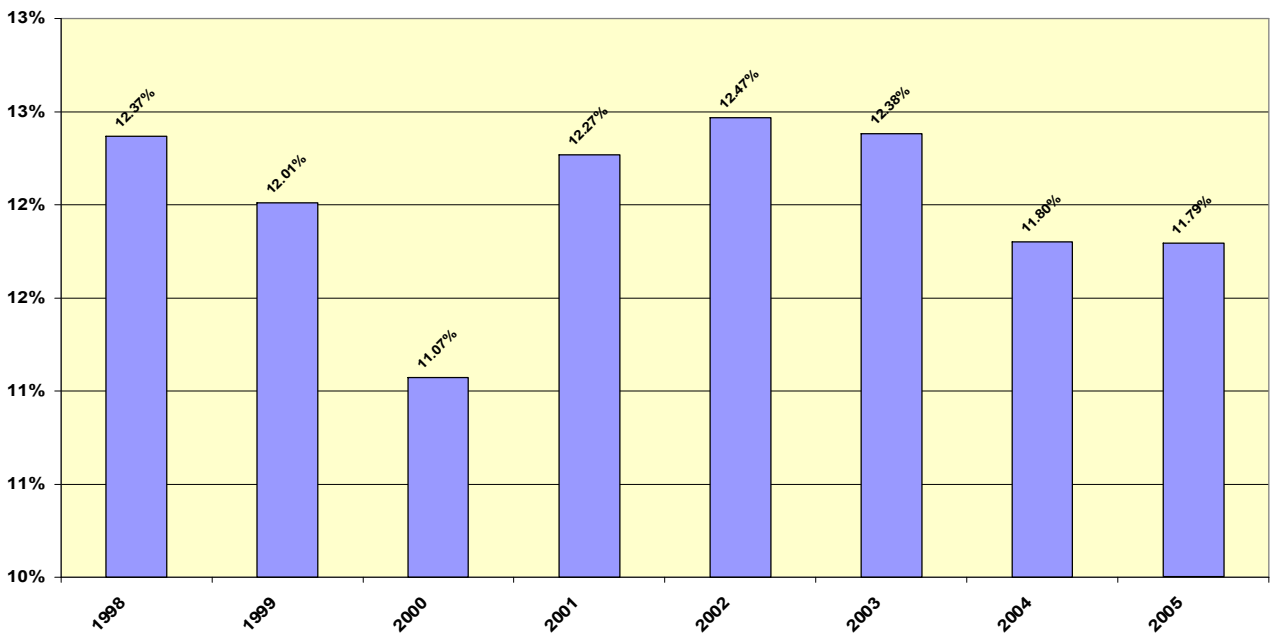


Figure 5: Percent of Census - 3 through 5

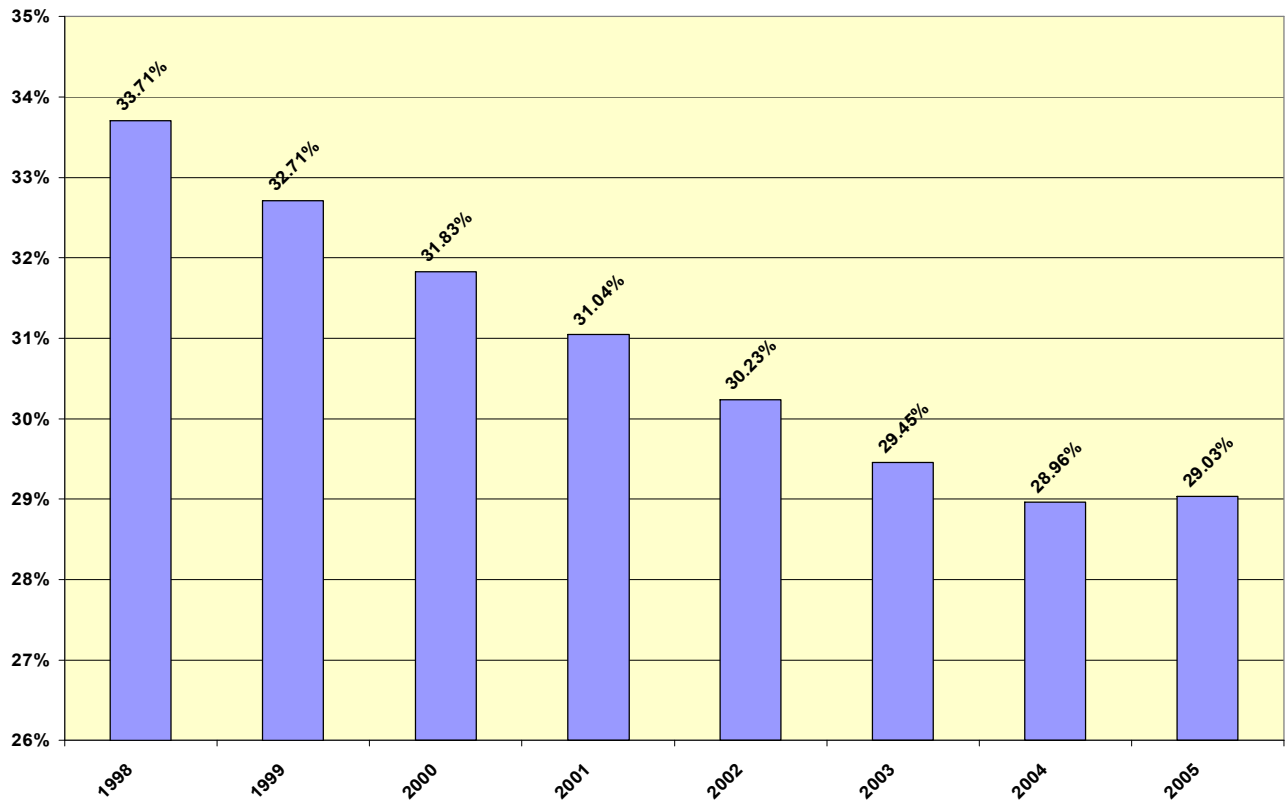


Figure 6: Percent of Census - 6 through 11

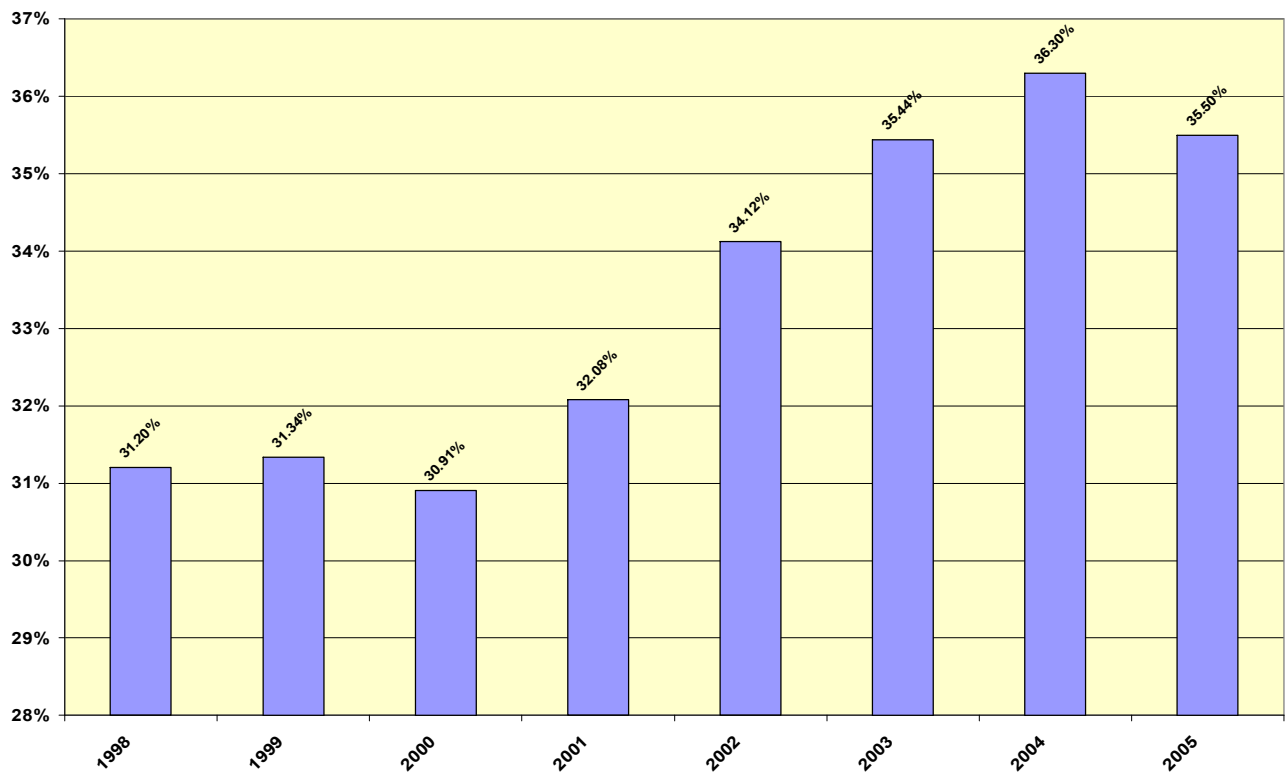


Figure 7: Percent of Census - 12 through 17

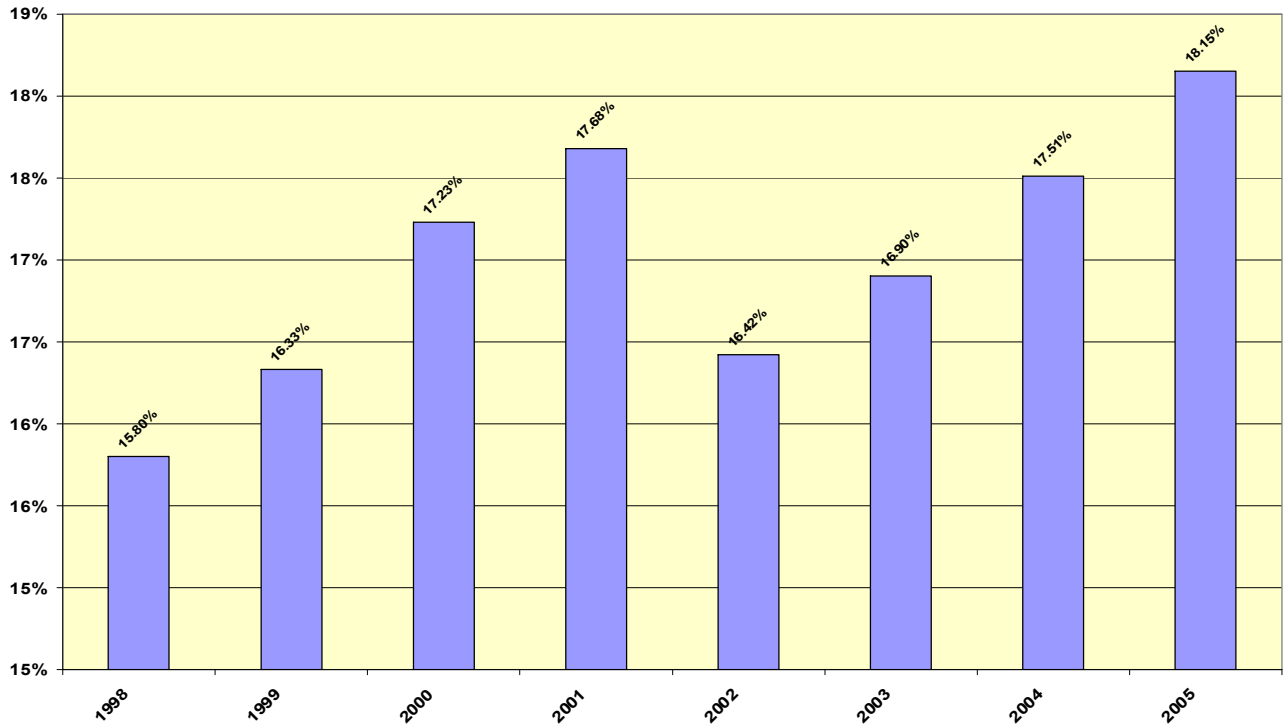


Figure 8: Percent of Census – 18 through 21

Figure 9 illustrates the percentage of all age groups reported since 1998. Three of the OSEP age groups (B-2, 3-5 and 18-21) are comprised of three years each, and two groups (6-11 and 12-17) are comprised of 6 years each. It is interesting to note that while there has been a small percentage decrease in the numbers of children reported in the Birth-2 category, the percentage of preschool aged children has remained fairly constant. Also, although there is a decreasing trend in the 6-11 age group, it is countered by an increasing trend in the 12-17 age group across the corresponding years, and the percentage of students in the 18-21 year age group has increased through the years.

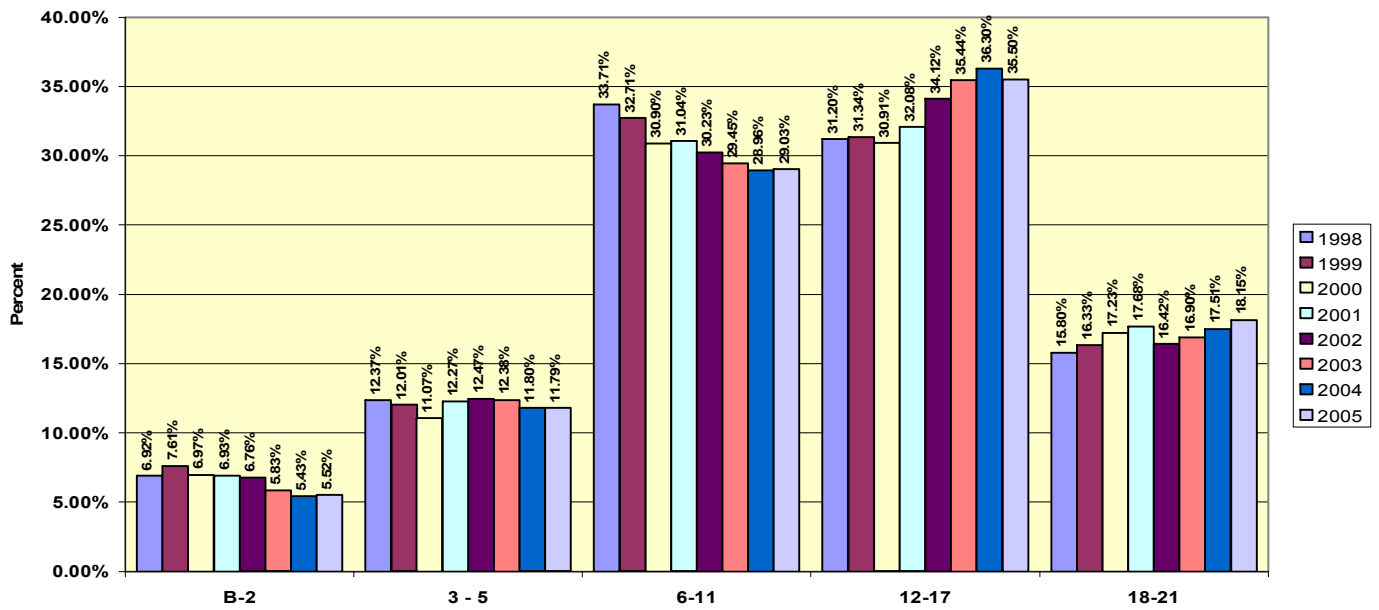


Figure 9: Percent by age groups across years

It must be noted that the total counts illustrated are based on aggregated data reported by each state/multi-state deaf-blind project and that these total counts provide a national perspective.

RACE/ETHNICITY

OSEP, as well as NCDB, requests that State/Multi-State Deaf-Blind Projects identify the Race/Ethnicity of each individual reported on their respective child counts. This information is used to assist in identifying unserved and underserved individuals and their families, as well as to identify any issues or trends related to over identification.

The Census Race/Ethnicity categories, and their corresponding definitions, are current with OSEP's categories and definitions. Children and students must be reported in one of the following five categories.

1. American Indian or Alaska Native: A person having origins in any of the original peoples of North and South America (including Central America) and who maintains tribal affiliation or community recognition.
2. Asian or Pacific Islander: A person having origins in any of the original peoples of the Far East, Southeast Asia, the Indian subcontinent, or the Pacific Islands. This includes, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, Viet Nam, Hawaii, Guam, and Samoa.
3. Black (not Hispanic): A person having origins in any of the Black racial groups of Africa.
4. Hispanic: A student of Cuban, Mexican, Puerto Rican, South American or Central or other Spanish culture or origin, regardless of race.
5. White (not Hispanic): A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

Race/Ethnicity across Years

There has been little variation in the race or ethnicity of children and students reported by the State/Multi-State Deaf-Blind Projects since 1998. However, the percentage of "Not Reported and Missing" race and ethnicity information has decreased from a high of 25% in 1998 to a low of 6% in the most recent reporting period. As the percent of race and ethnicity information reported has increased through the years, increases in the percents reported within a specific individual category have also increased. These increases should be viewed as a result of the increased accuracy of reporting by the projects however, rather than as an actual increase in the percentage or numbers of children and students reported within the category.

American Indian and Alaskan Natives make up the smallest group (2%) reported on the Census, followed by children and students of Asian and Pacific Island descent (3%), Hispanic and Latino, (12%) and Black (14%) children and students. White children and students represent the largest group (56%) of those reported. It is important to note that OSEP, and as a result *NTAC*, does not allow reporting in more than one Race/Ethnicity category and as a result, many multi-ethnic children are forced fit into a single category.

Figure 10 illustrates the percentage of children and youth reported by the State/Multi-State Deaf-Blind Projects within a specific Race/Ethnicity category since 1998.

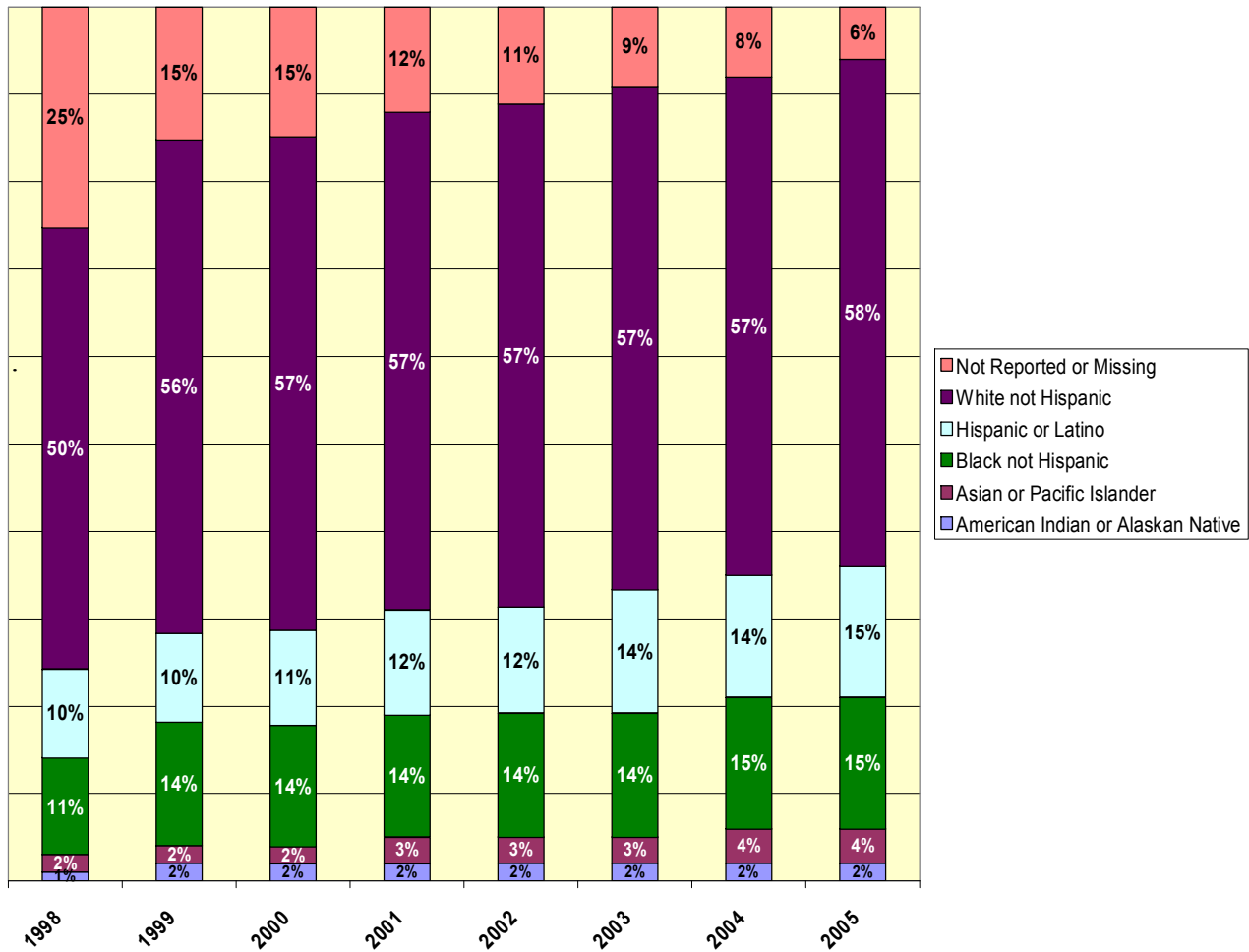


Figure 10: Percent Race/Ethnicity by category

Race/Ethnicity Comparison with OSEP 12/1/2005 Count

Figure 11 presents the percentage, by Race/Ethnicity categories, of all children and students reported on OSEP’s Part B 12/1/2005 child count contrasted to children and students reported on the 2005 Census. Though small, there are several categories in which differences are seen between the counts, with OSEP’s reported percentages being 3% higher for students of Hispanic or Latino origin and 5% higher for students who are Black.

The OSEP percentages include all students with disabilities reported by state Part C lead agencies and state education agencies, and as such, these differences may *possibly* be attributed to the over identification of minority students in high-incidence disability categories (i.e., learning disabilities and/or behavior disorders) and the inclusion of infants and toddlers (Part C) who are at-risk of developmental delays, rather than actually classified as developmentally delayed.

A smaller percentage of students of Asian origin are reported on the Census than on the OSEP

Part B count.

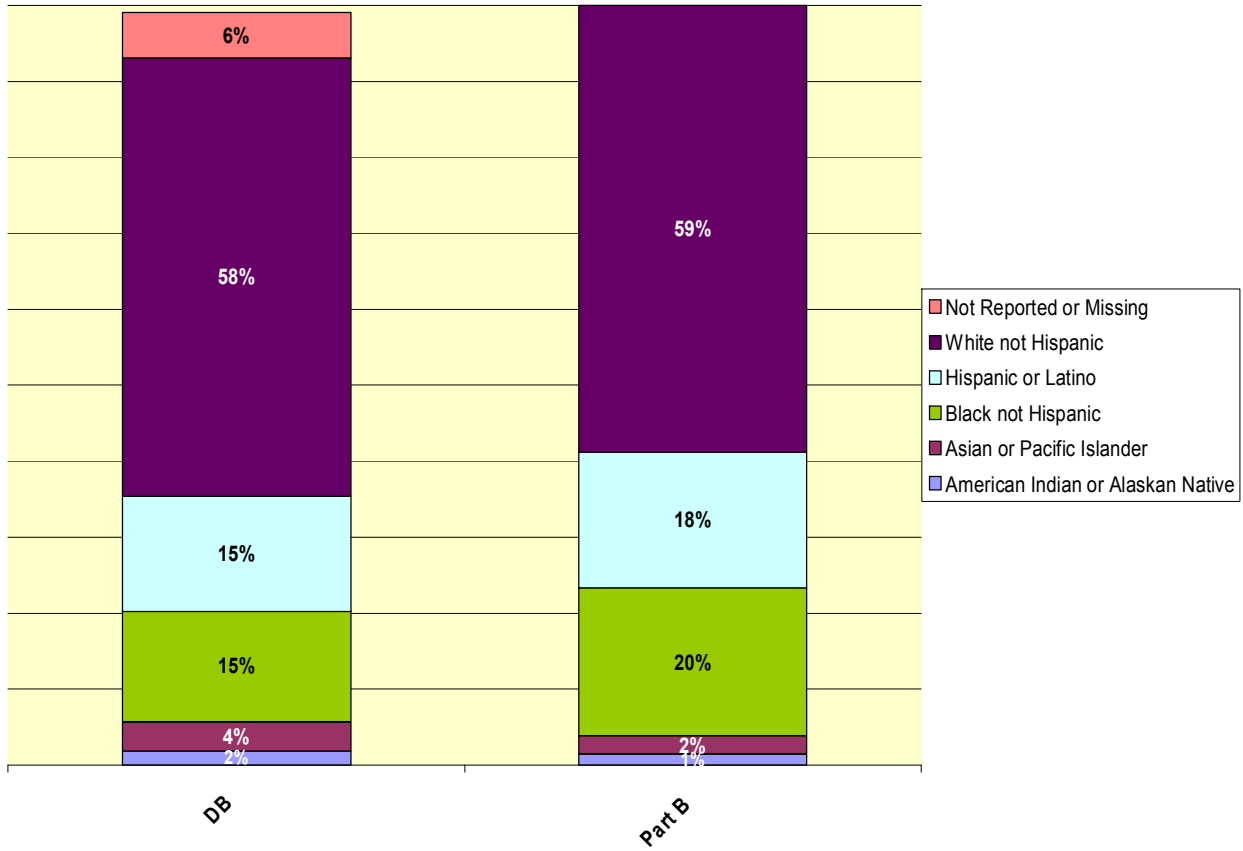


Figure 11: Comparison of Part B and Census Race/Ethnicity counts for 12/1/2005

PRIMARY CLASSIFICATIONS OF VISUAL AND HEARING IMPAIRMENTS

Projects are required to document the primary classification of visual impairment and hearing impairment for each child or student and then report the classification that best describes the individual’s documented degree of vision and hearing loss. They also must select the one option that is most descriptive of the student’s documented loss.

Primary Classifications of Visual Impairments

Possible selections for a child or student’s primary classification of visual impairment include:

1. Low Vision (visual acuity of 20/70 to 20/200>)
2. Legally Blind (visual acuity of 20/200 or less or a field restriction of 20 degrees)
3. Light Perception Only
4. Totally Blind
5. Diagnosed Progressive Loss

In addition, projects may report that the loss is due to a Cortical Vision Impairment, as well as when testing is non-conclusive and further testing is needed to more accurately determine the individual’s degree of visual impairment. Figure 12 illustrates the percent of primary vision classifications reported by the state multi-state projects across years.

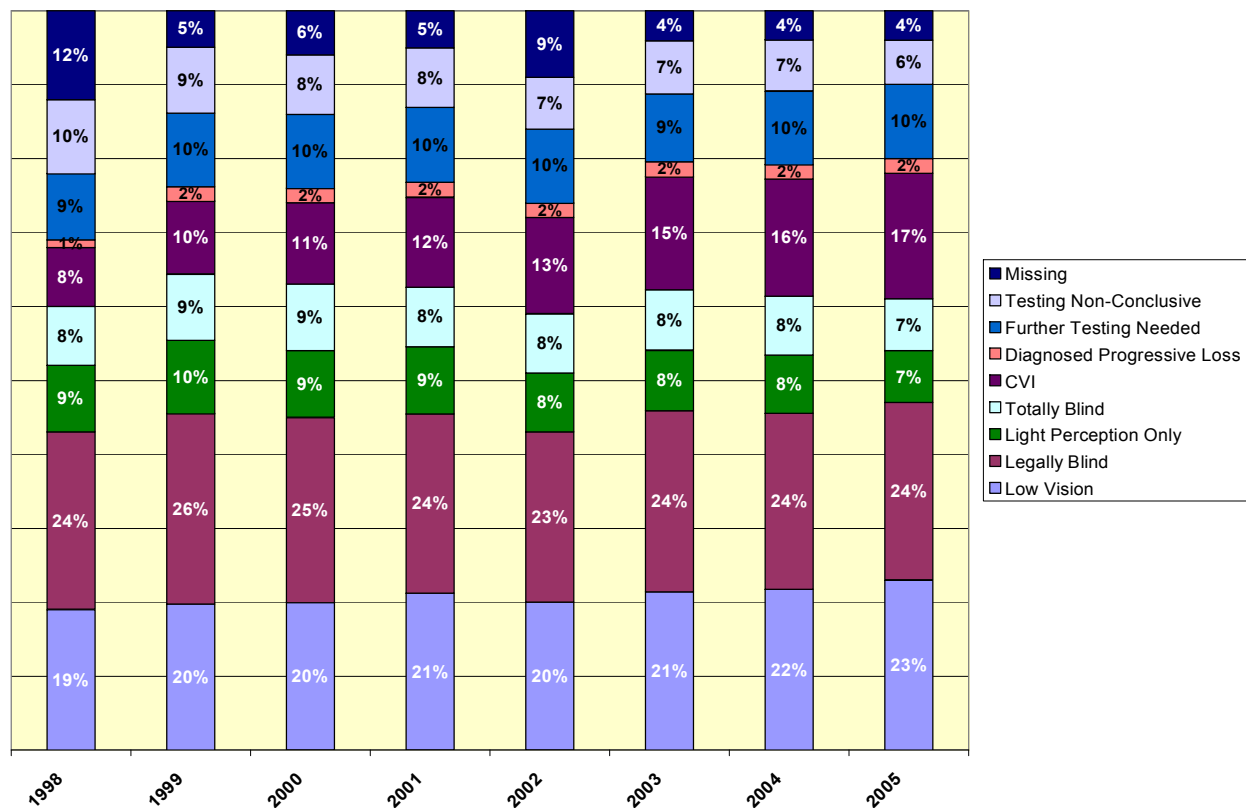


Figure 12: Percent of primary vision classifications reported across years

As seen in Figure 12, there has been little variation in the primary vision classifications of children and students reported since 1998. Across the years, legal blindness is clearly the most frequently reported classification, representing nearly one-fourth (24%) of those reported. An additional 8% are considered totally blind. When combined with low vision (21%) and light perception only, (9%) 62% of children and students reported on the Census have been identified with significant visual impairments.

It is interesting to note that as the accuracy of reporting has increased since 1998, and the percent of missing data has decreased from a high of 12% to the current 4% in 2005, there is no evidence of a corresponding increase in any of the five classifications of impairment. However, the percentage of individuals reported with cortical vision impairments (see Figure 13) has doubled, from 8% in 1998 to 17% in 2005. This may be in part due to an increased awareness of CVI, its educational impact and national and state technical assistance activities geared towards appropriate assessment and intervention strategies.

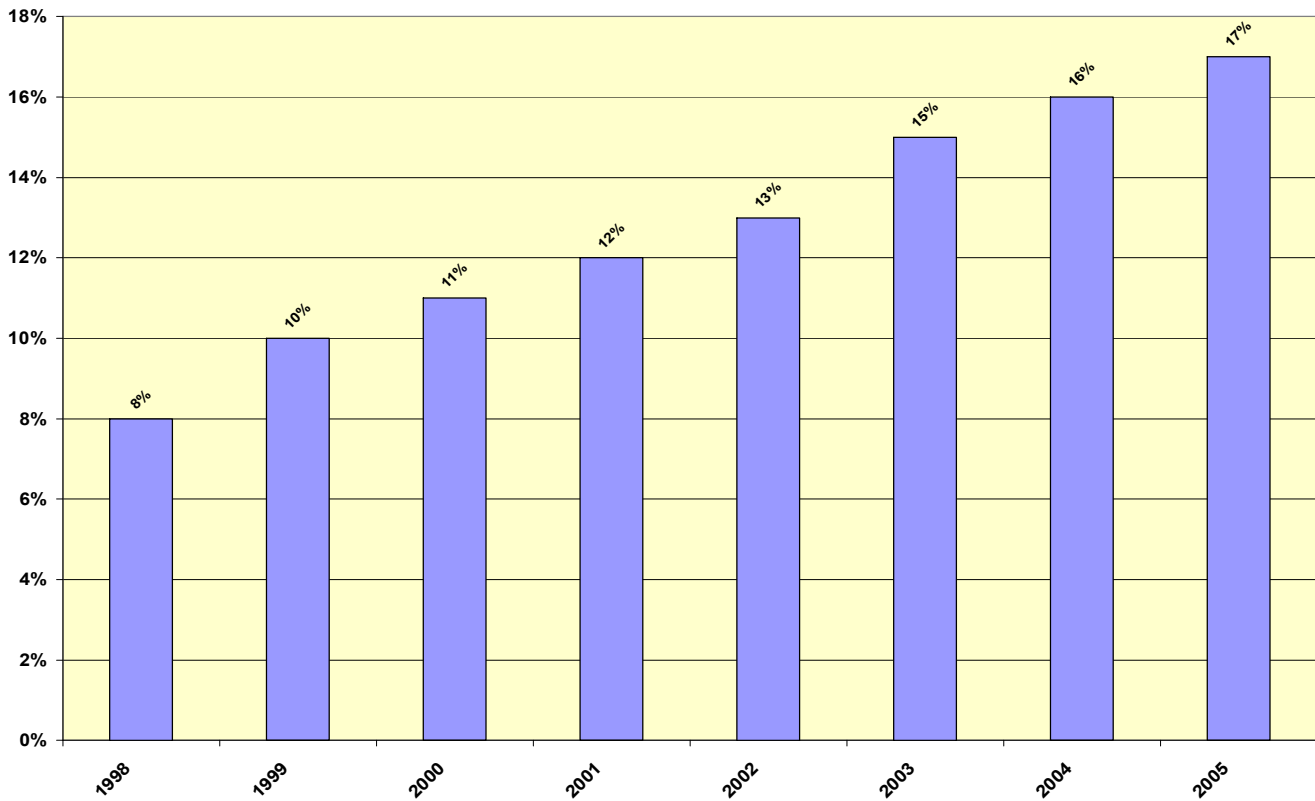


Figure 13: Percent of students reported with Cortical Vision Impairments across years

Beginning with the 12/1/2007 Census, the *Primary Classification of Vision Impairment* data element will be replaced with *Degree of Documented Vision Loss*. As part of this change, CVI has been taken out as a specific degree of loss, since it is actually a condition, or etiology, which results in a degree of loss, rather than a specific degree of loss itself. Information on CVI will continue to be collected as a separate data element.

Primary Classifications of Hearing Impairments

As with vision impairment, projects must also document the primary classification of the hearing impairment for each child or student and then report the classification that best describes the individual’s documented degree of loss. The possible selections for an individual’s primary classification of hearing impairment include losses that are:

1. Mild (26-40 dB loss)
2. Moderate (41-55 dB loss)
3. Moderately Severe (56-70 dB loss)
4. Severe (71-90 dB loss)
5. Profound (91+ dB loss)
6. Diagnosed Progressive Loss

Projects may again report that testing is non-conclusive and further testing is needed to more accurately determine the individual’s degree of hearing impairment.

As seen in Figure 14, there has been little variation in the primary hearing classifications of children and students reported since 1998. This is consistent with the lack of variation that is also reported for vision classifications.

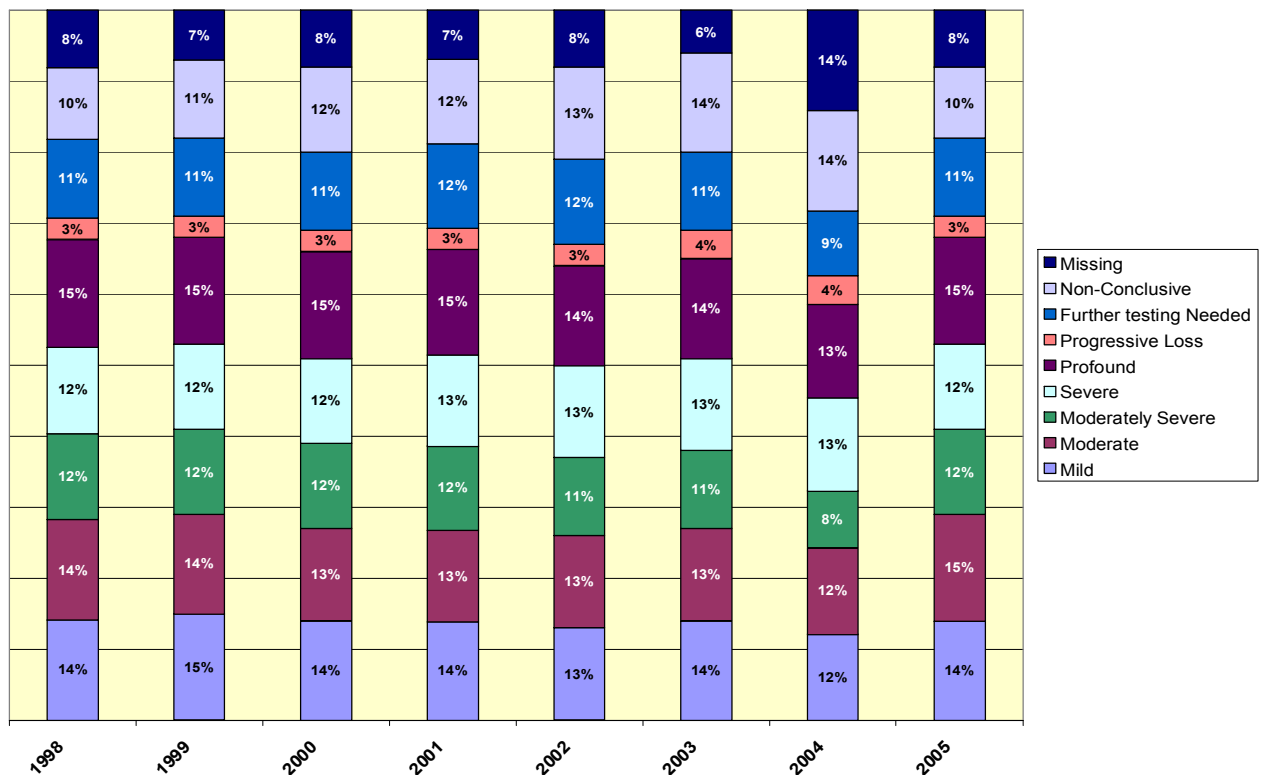


Figure 14: Percent of primary hearing classifications reported across years

Those with profound losses represent the largest percentage (15%) of individuals reported within a single classification and when combined with students with moderately severe and severe hearing losses, the percentage of those reported with severe and profound hearing losses increases to nearly 40%. In contrast, only 14% of students are reported with mild losses and 13% with moderate losses. Children and students reported with diagnosed progressive hearing losses are reported as 3% of the population, whereas only 2% are reported with diagnosed progressive vision losses.

It is also interesting to note that the percentage of students whose hearing assessments are non-conclusive and who require further testing to determine the degree of loss is higher than that reported for determining the degree of vision losses and the percentage of missing and non-reported data is also higher for hearing classification than that reported for vision. This is surprising since auditory assessment strategies and technology are well established.

In contrast to the increase seen in the percentage of individuals reported with cortical vision impairments, the percentage of those reported with central auditory processing disorders (CAPD) has remained fairly consistent since 1998, ranging from a high of 10% to a low of 6%.

Interestingly, the reporting of CAPD peaked in 2001, which coincides with the delivery of several national and state technical assistance addressing CAPD and CVI. However, there was not a corresponding peak in the CVI data reported, nor was this increase in reported CAPD sustained in subsequent years. However, this may in part be due to the recognition of auditory neuropathy now being seen as a separate condition, outside of CAPD.

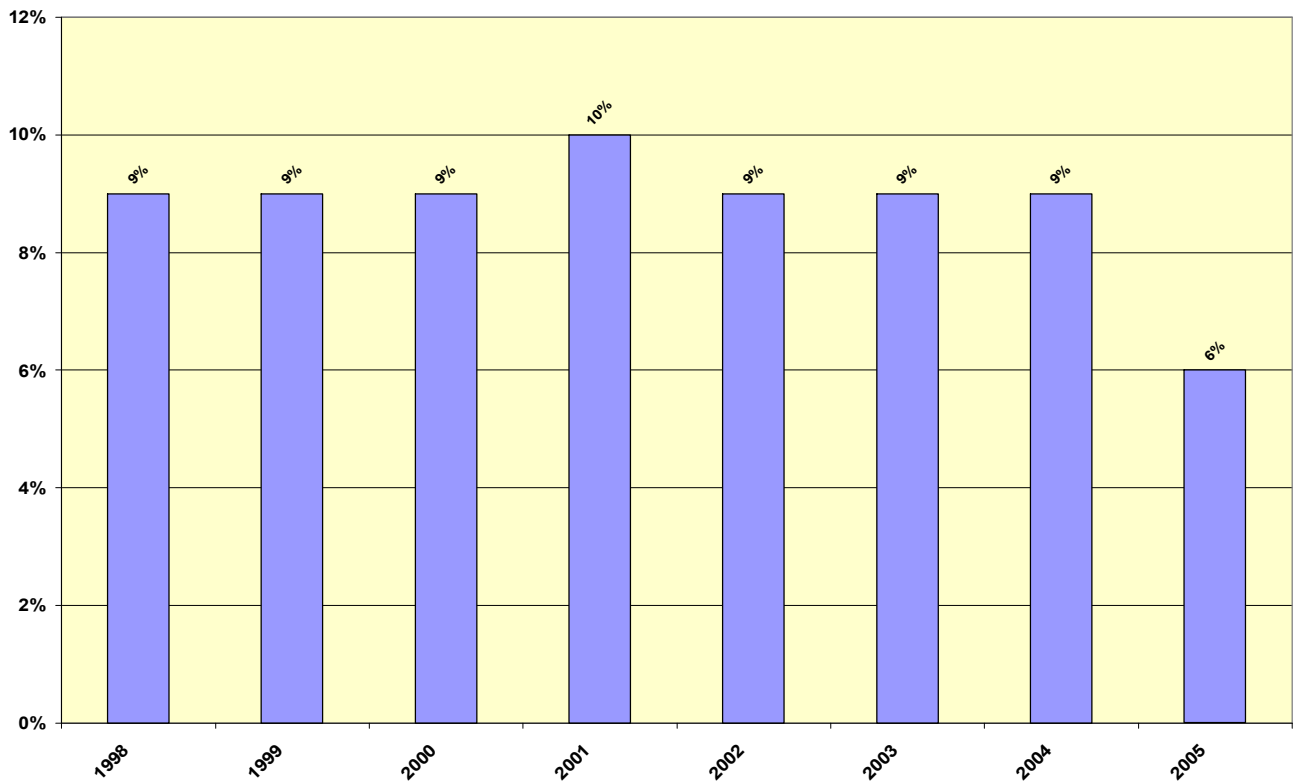


Figure 15: Percent of Students reported with Central Auditory Processing Disorders (CAPD)

Beginning with the 12/1/2007 Census, the *Primary Classification of Hearing Impairment* data element will also be replaced with *Degree of Documented Hearing Loss*. CAPD is currently a separate data collection element.

ADDITIONAL IMPAIRMENTS

In addition to the types and degrees of vision and hearing impairment, projects are also asked to provide information related to an individual’s additional disabilities. Specifically:

1. Physical impairments
2. Cognitive impairments
3. Behavioral Disorders
4. Complex Health Care Needs
5. Other impairments

Not surprisingly, over 90% of children and students reported on the Census are identified as having one or more additional disabilities. The types and combinations of these additional disabilities are consistent across all age groups and ethnicities, although they do appear to be reported more often in those children and youth with more severe vision and hearing losses. Figure 16 illustrates the percentage of additional impairments reported from 1998-2005.

Sixty-six percent of those reported as deaf-blind on the Census are reported as having a cognitive impairment, (the most frequently reported additional impairment), followed by physical impairments (57%) and complex health care needs (38%). Somewhat surprisingly, based on the limited communication skills of the majority of those reported on Census, less than 9% are reported to have behavior challenges. This may be attributed to the emphasis placed on functional behavior analysis and assessing the communication intent of one’s behavior during the last ten years. Nearly 30% are reported to have an additional impairment under the “Other” category.

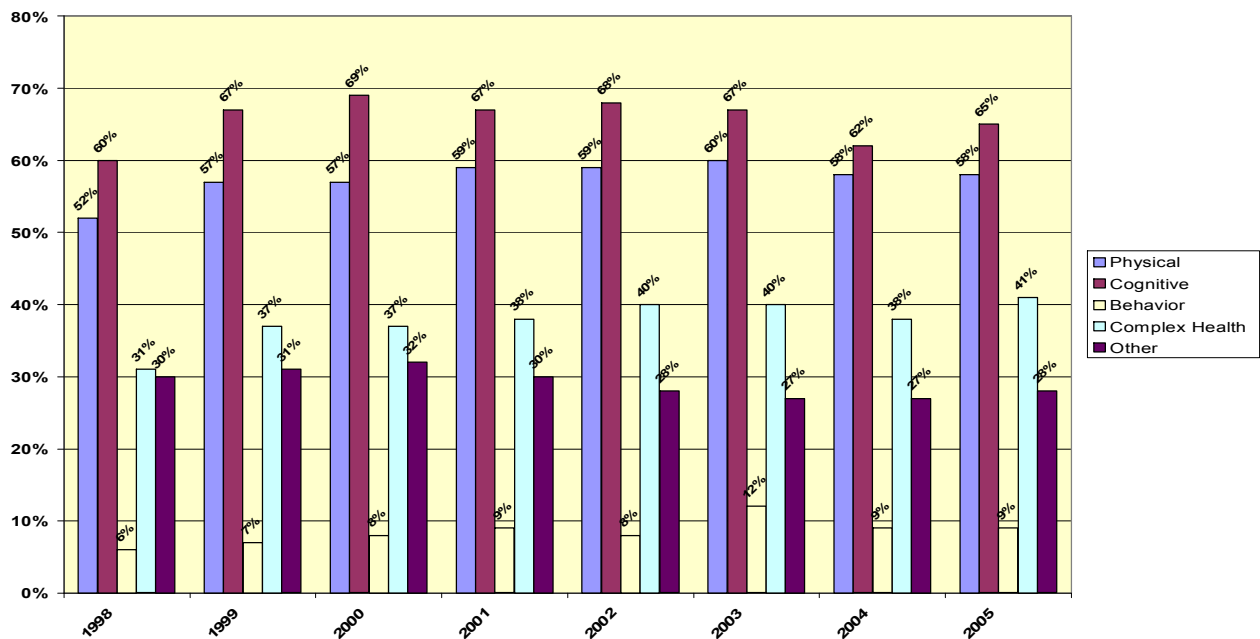


Figure 16: Percent of students reported with additional impairments across years

Figures 17-21 illustrate the percentages of the additional disabilities reported.

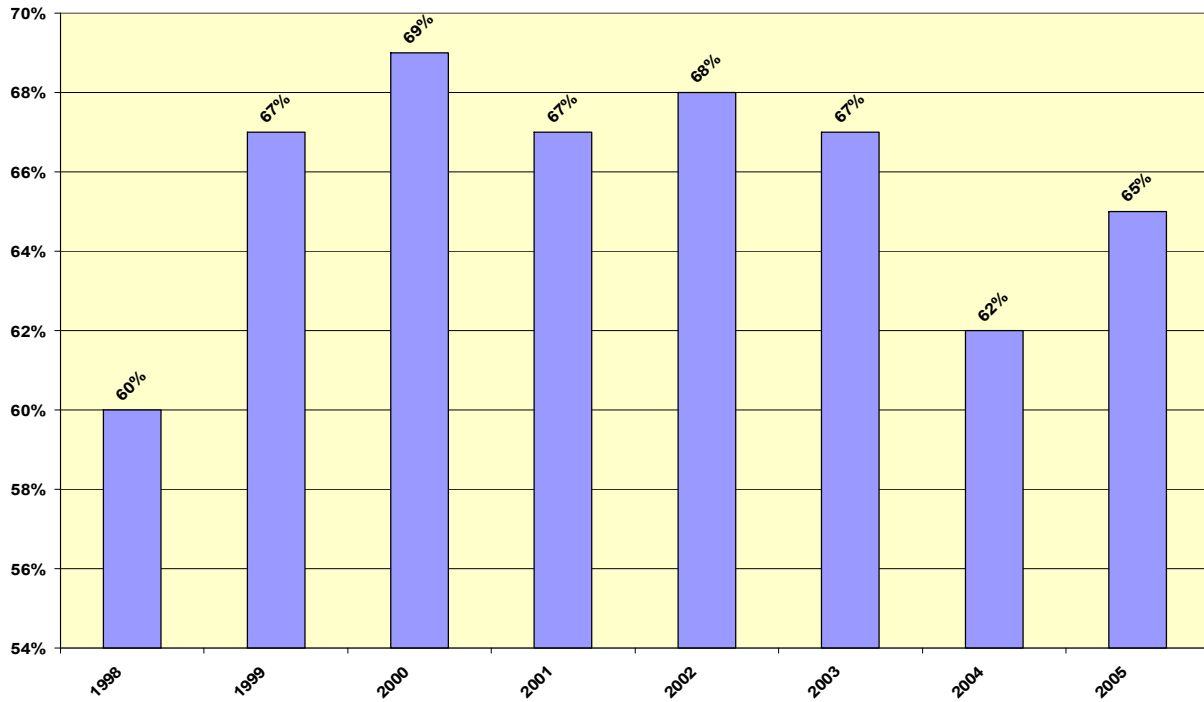


Figure 17: Percentage of those reported with additional cognitive impairments

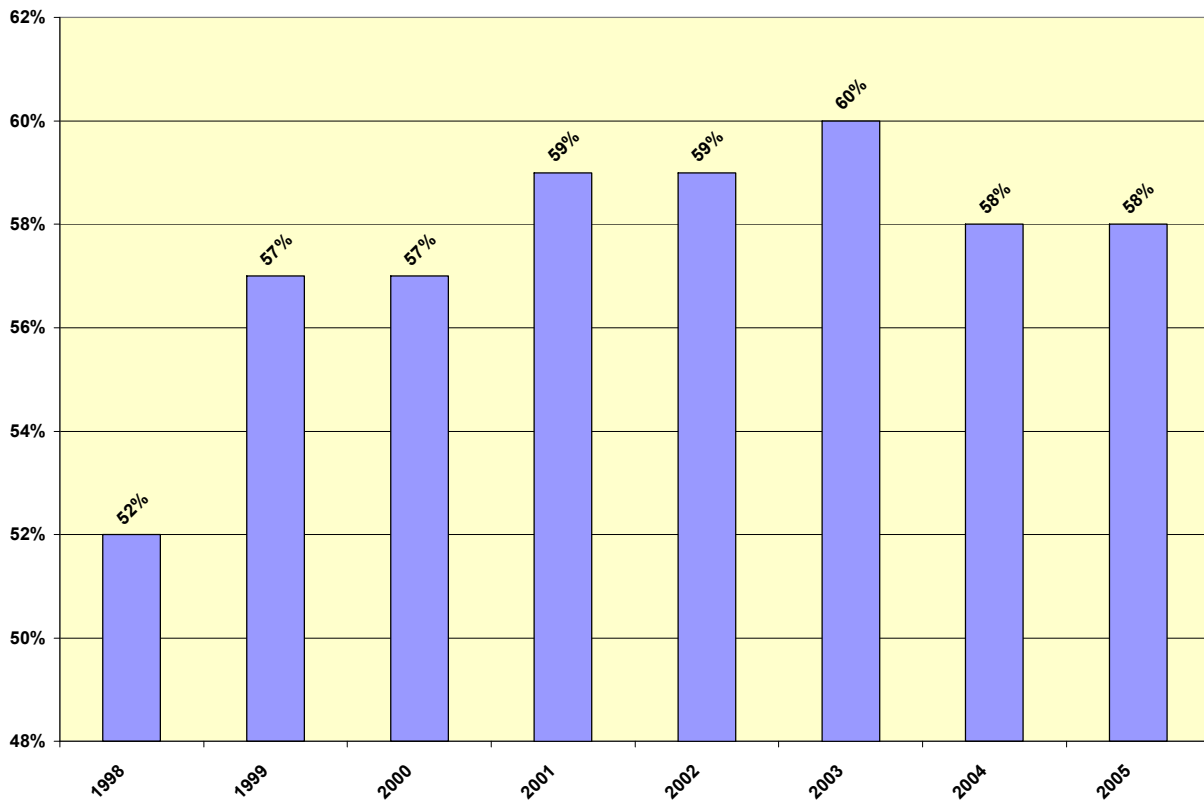


Figure 18: Percentage of those reported with additional physical impairments

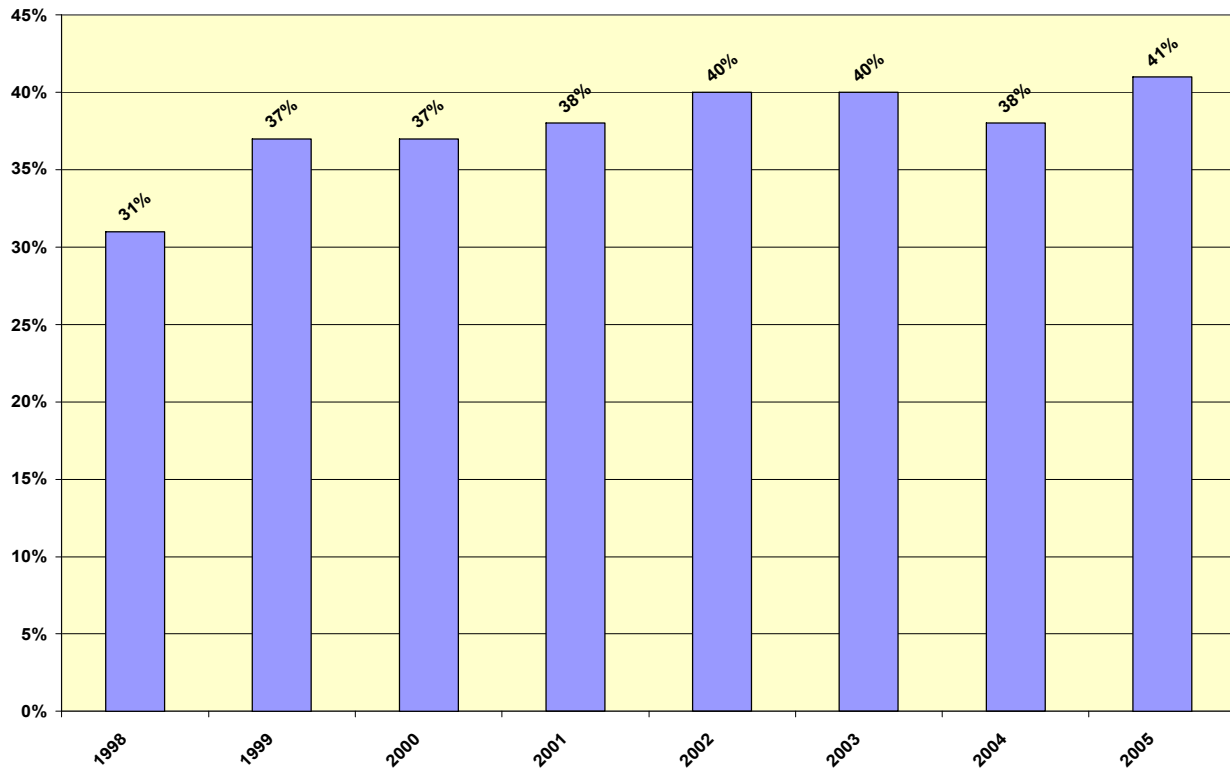


Figure 19: Percentage of those reported with additional complex health care needs

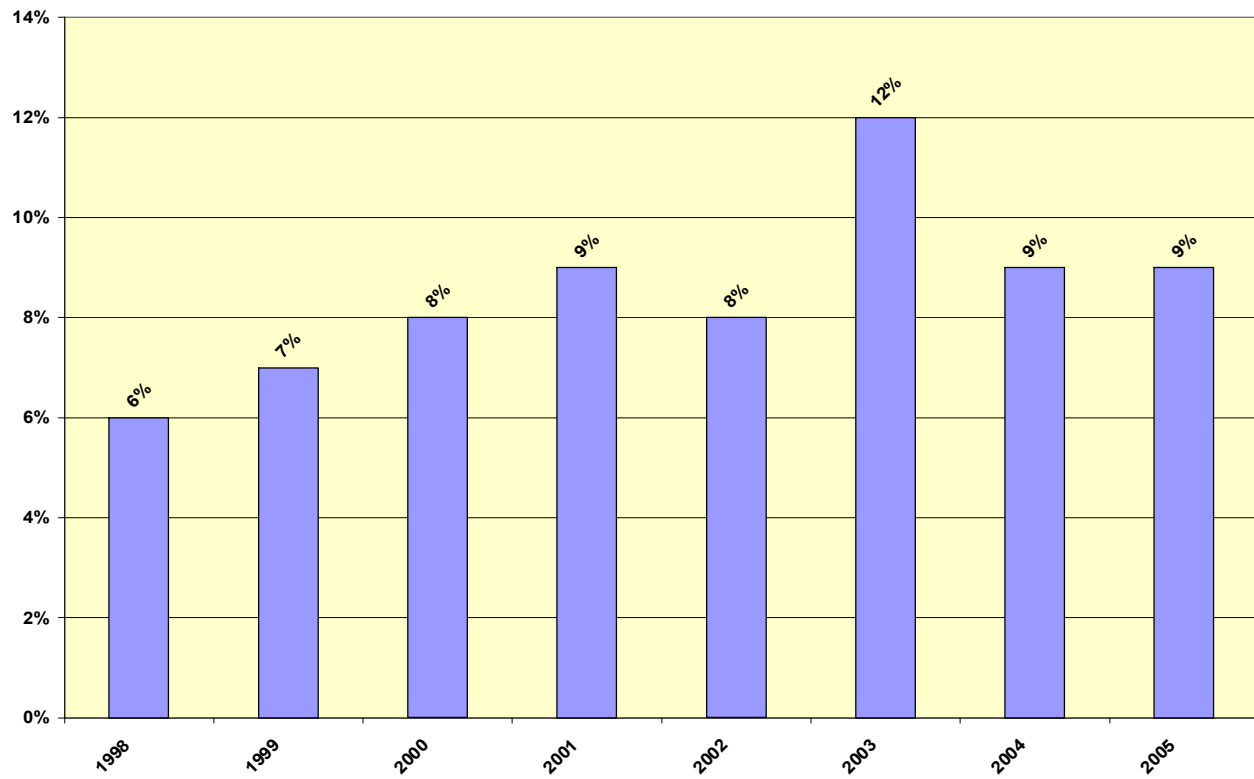


Figure 20: Percentage of those reported with additional behavior challenges

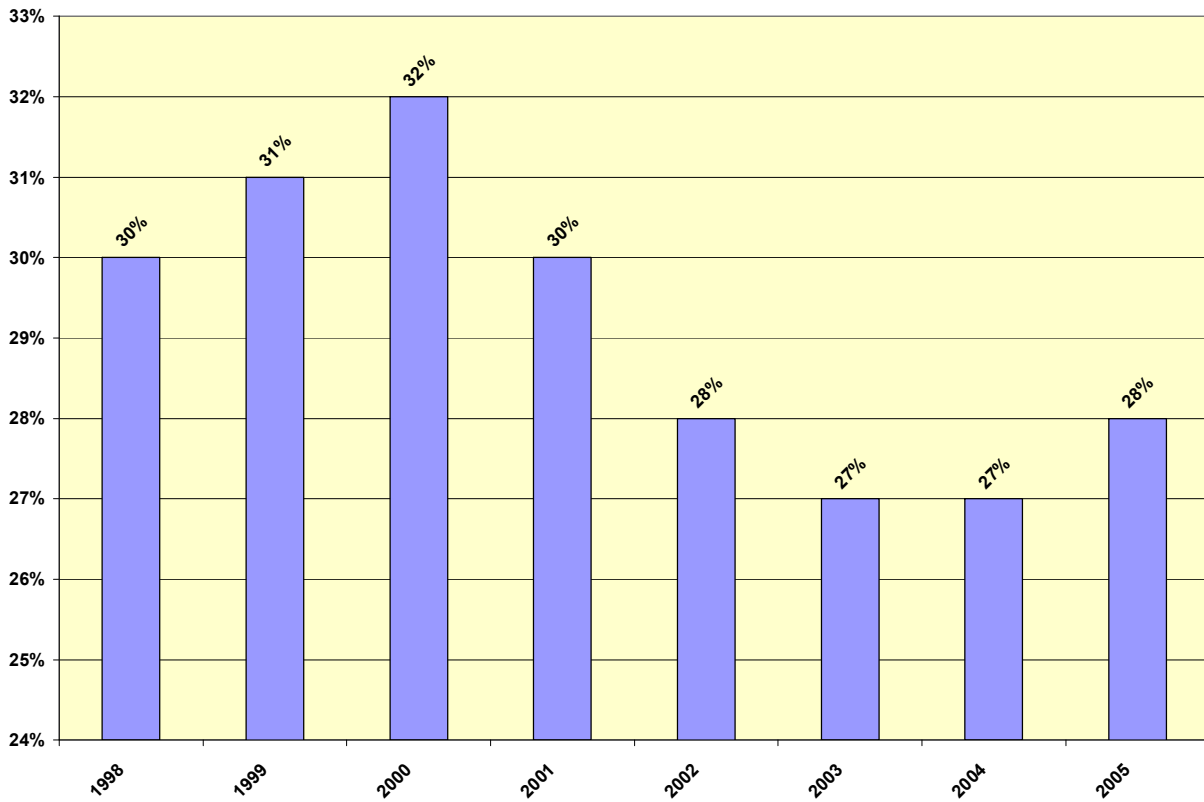


Figure 21: Percentage of those reported with other additional impairments

Beginning with the 12/1/2007 Census, information related to an individuals' communication, speech, and/or language impairments will also be collected, and the physical impairment data element will be redefined as orthopedic and physical impairments.

ETIOLOGIES

The Census requires that projects also identify and code the etiology of the individual's deaf-blindness. Although there are over 100 potential etiologies, in 2005, ten etiologies accounted for over 70% of the individuals reported.

The top ten etiologies include:

1. Heredity (2,107)
2. Prematurity (1,112)
3. Pre-natal complications (790)
4. Post-natal complications (715)
5. CHARGE syndrome (572)
6. Microcephaly (369)
7. Cytomegalovirus (CMV) (334)
8. Hydrocephaly (284)
9. Meningitis (279)
10. Usher syndrome (246)

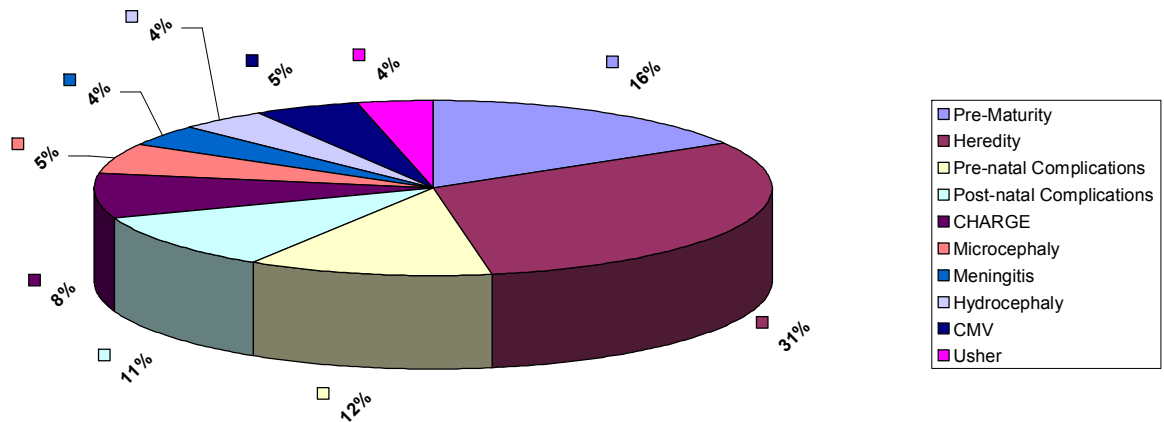


Figure 22: Percentage reported within etiology category in 2005

It is interesting to note that rubella (German measles), which is often cited as raising the national awareness of the unique needs of those with deaf-blindness as a result of the rubella outbreak in the early 1960's, is now reported as the etiology for just 1% of those reported on the 2005 Census.

CHARGE and Usher syndrome have been disaggregated from the Heredity category and are reported separately. Although the specific order of the top ten has changed little from year-to-year since 1998, with CHARGE syndrome showing the greatest growth, these top ten rankings have been consistent across the years. CHARGE is now the leading single syndrome associated

with deaf-blindness as reported on the Census. It is a recognizable pattern of genetic defects that is identifiable in approximately 2/3 of those genetically tested.

The acronym CHARGE refers to:

- C- Coloboma of the eye
- H- Heart defects
- A-Atresia of the choanae
- R-Retardation of growth and/or development
- G-Genital and/or urinary abnormalities
- E-Ear abnormalities and deafness

Most children born with CHARGE undergo multiple surgeries and require medical, as well as require ongoing early intervention and educational services.

Figure 23 illustrates the increase in those reported with CHARGE syndrome in the last eight years.

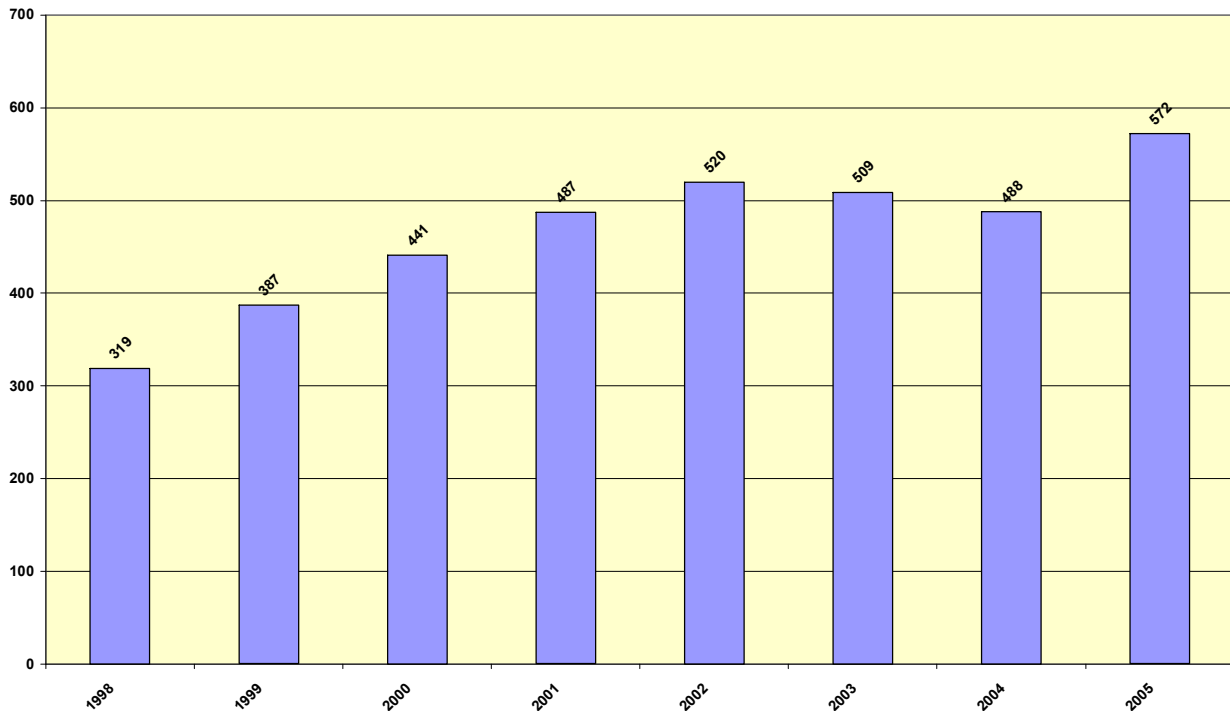


Figure 23: Increase in the number of children and students reported with CHARGE syndrome since 1998

EARLY INTERVENTION AND EDUCATIONAL SETTINGS

In previous years, Part C Early Intervention Settings and Part B Educational Settings (3-5 and 6-21) were a single, combined Census reporting element. Prior to the December 1, 2006 count, projects reported the educational setting code from the appropriate age subcategories that best described the individual's education setting. These settings, and their respective definitions, were based on previously used OSEP reporting requirements and definitions.

The previously used educational setting categories used for the Census have been revised and are now three discreet reporting elements describing:

- Early intervention settings (birth through 2)
- Early childhood special education settings (3-5)
- School-age settings (6-21).

These new settings, and their respective definitions, are based on the changes reflected in OSEP's Section 618 reporting requirements, and are based on the percent of time a student spends in a regular education setting. The use of these new settings became optional with the 2006 Census, and their use will be mandatory beginning with 2007 Census. It is important to note that the descriptions within each of these three reporting elements are now completely revised based on federal changes and do not easily crosswalk with those previously used for the 3-21 year old age groups..

Educational settings used prior to 2006 for reporting infants and toddlers (B-2) receiving early intervention services

For children served in Part C early intervention programs, nine possible early intervention settings were provided and projects were required to select the setting that was most reflective of the setting in which the child was reported on the state's Lead Agency, Part C Child Count.

Potential early intervention settings included:

- Programs designed for children with developmental delays or disabilities
- Home
- Combination of center based and home based early intervention
- Service provider locations
- Daycare/childcare settings
- Hospitals (inpatient)
- Not receiving early intervention services
- Residential facilities
- Other

In the summer of 2006, *NTAC* cross-walked the previously reported early intervention settings to the new OSEP settings and the 1998-2006 data that follows reflects analysis within these new

settings. In addition to the three OSEP categories, “Not receiving early intervention services” has been used as a reporting option for Census reporting purposes.

Thus, the currently reported early intervention settings include:

- Home
- Community-based settings
- Other settings
- Not receiving early intervention services

These settings are federally defined as:

- Home, where early intervention services are provided primarily in the principal residence of the child’s family or caregivers.
- Community-based settings, where early intervention services are provided primarily in a setting where children without disabilities typically are found. These settings include but are not limited to child care centers (including family day care), preschools, regular nursery schools, early childhood center, libraries, grocery stores, parks, restaurants, and community centers (e.g., YMCA, Boys and Girls Clubs).
- Other Settings, where early intervention services are provided primarily in a setting that is not home or community-based. These settings include, but are not limited to, services provided in a hospital, residential facility, clinic, and EI center/class for children with disabilities.

As seen in Figure 24, the vast majority of infants and toddlers with deaf-blindness have received early intervention in their home since 1998, averaging over 70% across the years. The provision of home-based services peaked at 78% in 2000 and by 2005 has gradually decreased to the 70% mean.

An average of 27%, ranging from a high of 38% in 1998 to a low of 20% in 2000, of infants and toddlers reported have received early intervention services in “Other” settings. These included programs designed only for children with developmental disabilities, combination home and center-based programs, as well as residential, clinic and hospital facilities.

Only 2% of those reported received services in community settings such as daycare or child care centers, preschools or other community settings and 1% of the children reported as deaf-blind by the projects were not receiving early intervention services or reported to be in a in a state or local Part C lead agency setting.

It is important to note that no information related to the frequency of services received in an early intervention setting, regardless of the setting, are collected by the projects or reported for the Census. Anecdotal reports suggest great variability in the frequency of services from one visit a week to one visit a quarter. Nor is the type of early intervention service collected or reported by the projects.

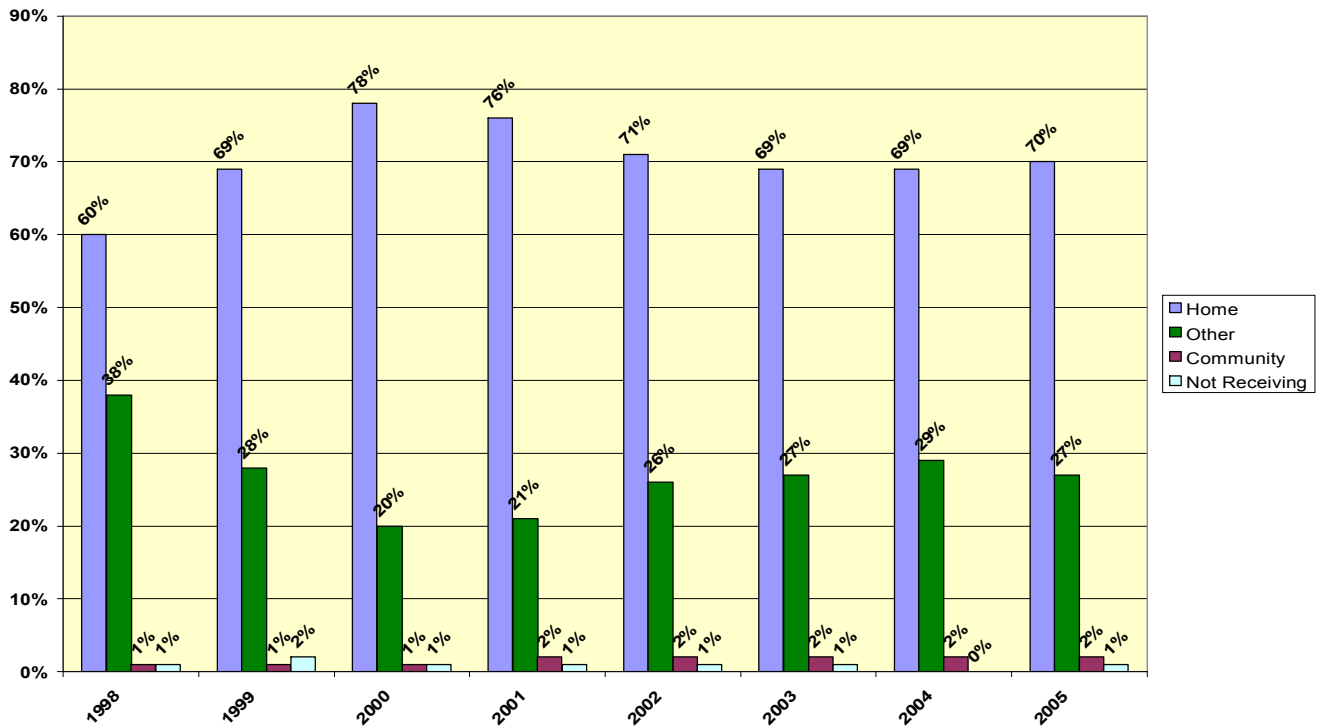


Figure 24: Settings in which early intervention services were provided

Figures 25 and 26 illustrate the percentage of infants and toddlers served in their home, as well as in “Other” settings from 1998 through 2005.

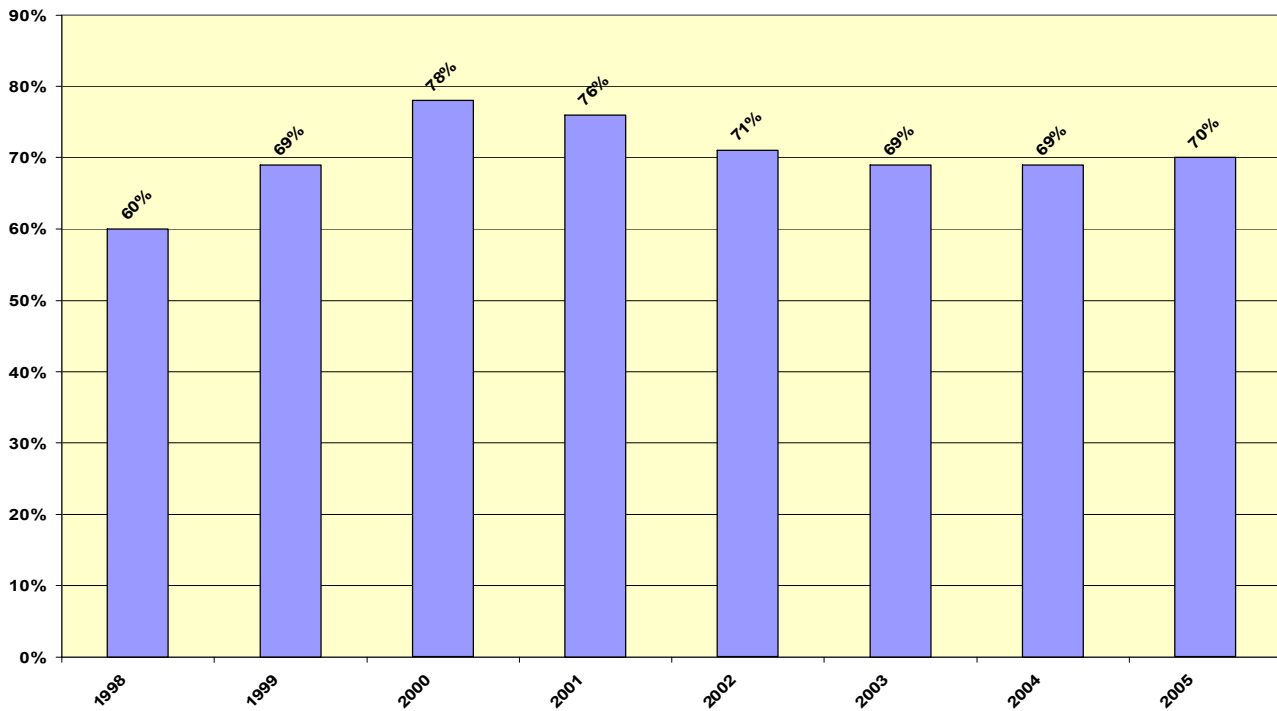


Figure 25: Percent of infants and toddlers served in their home

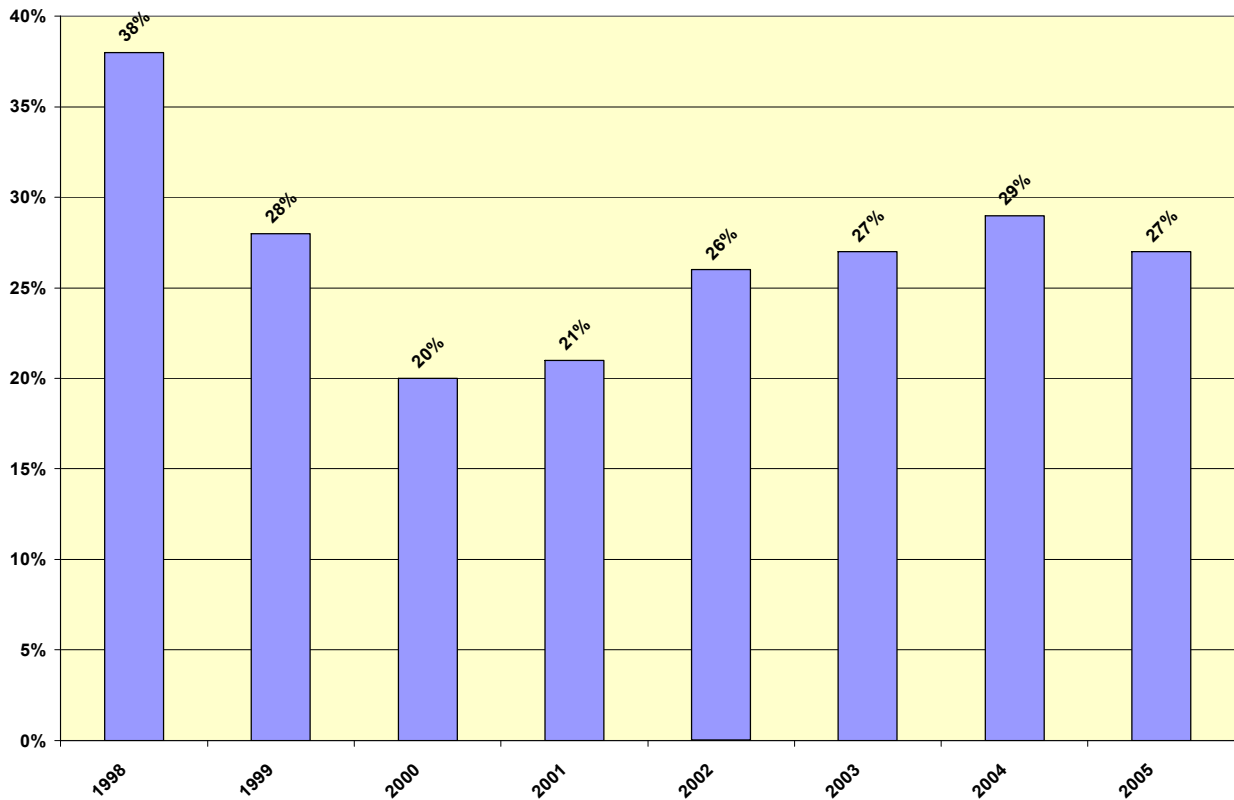


Figure 26: Percent of infants and toddlers served in “Other” settings

Educational settings used prior to 2006 for reporting preschoolers (3-5) placed in early childhood special education programs

For children placed in early childhood special education, nine potential settings were provided and projects were required to enter the setting under which the individual was reported on the State Department of Education Part B, IDEA Child Count.

These settings:

- Early childhood settings
- Early childhood special education settings
- Combination early childhood and early childhood special education settings
- Home
- Residential facilities
- Separate schools
- Itinerant services outside the home
- Reverse mainstream settings
- Other

Figure 27 illustrates all settings in which preschoolers with deaf-blindness were served from 1998-2006. The vast majority of preschool-aged children (3-5) with deaf-blindness have received their services in separate settings while very few have received services in fully integrated settings.

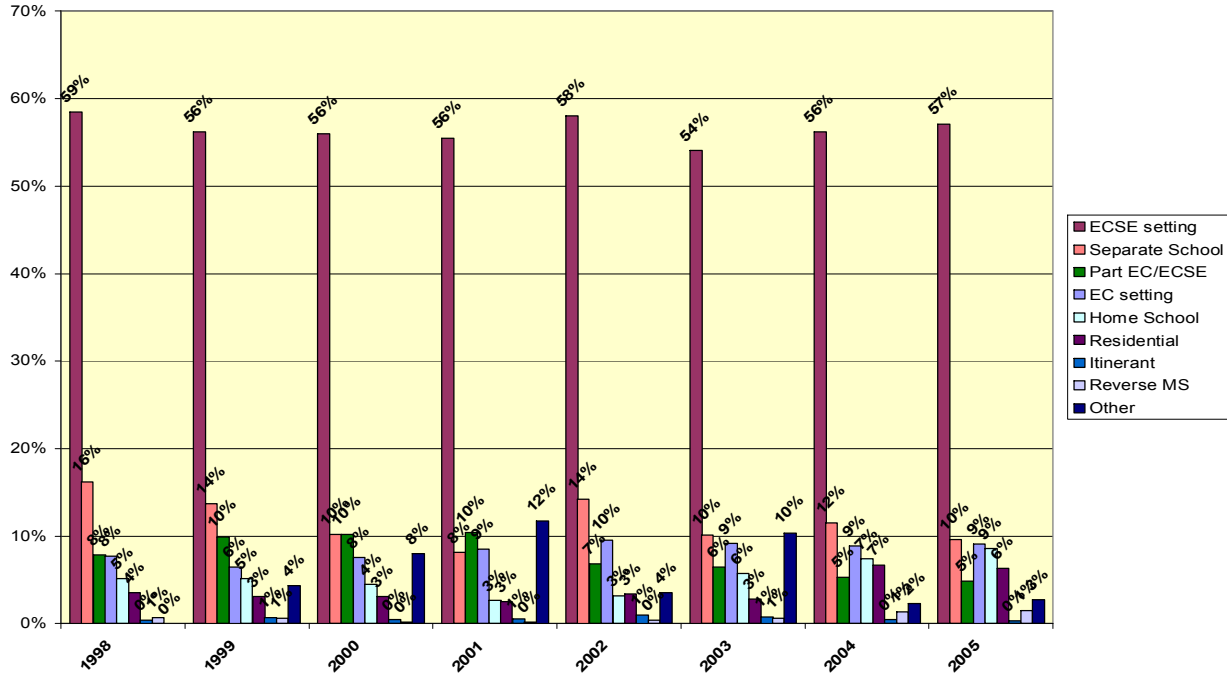


Figure 27: Settings in which early childhood special education services were provided

As seen in Figure 28, since 1998 over 72% of preschoolers have received their services in separate early childhood special education programs, separate schools and residential facilities.

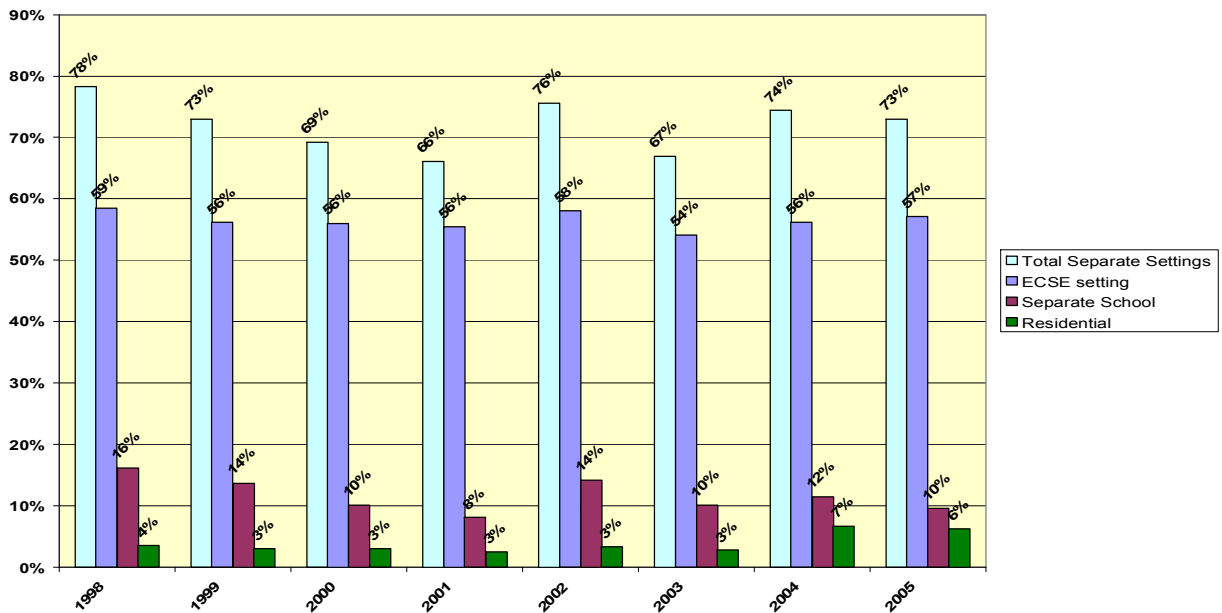


Figure 28: Separate settings in which early childhood special education services were provided

In contrast, less than 20 % were served in fully or partly integrated settings including regular early childhood programs, combined early childhood/early childhood special education programs or in reverse mainstreamed settings. Five percent of the preschool-aged children received their early childhood special education program in their home. Obviously, early childhood inclusion remains as an area in need of ongoing systems development and technical assistance.

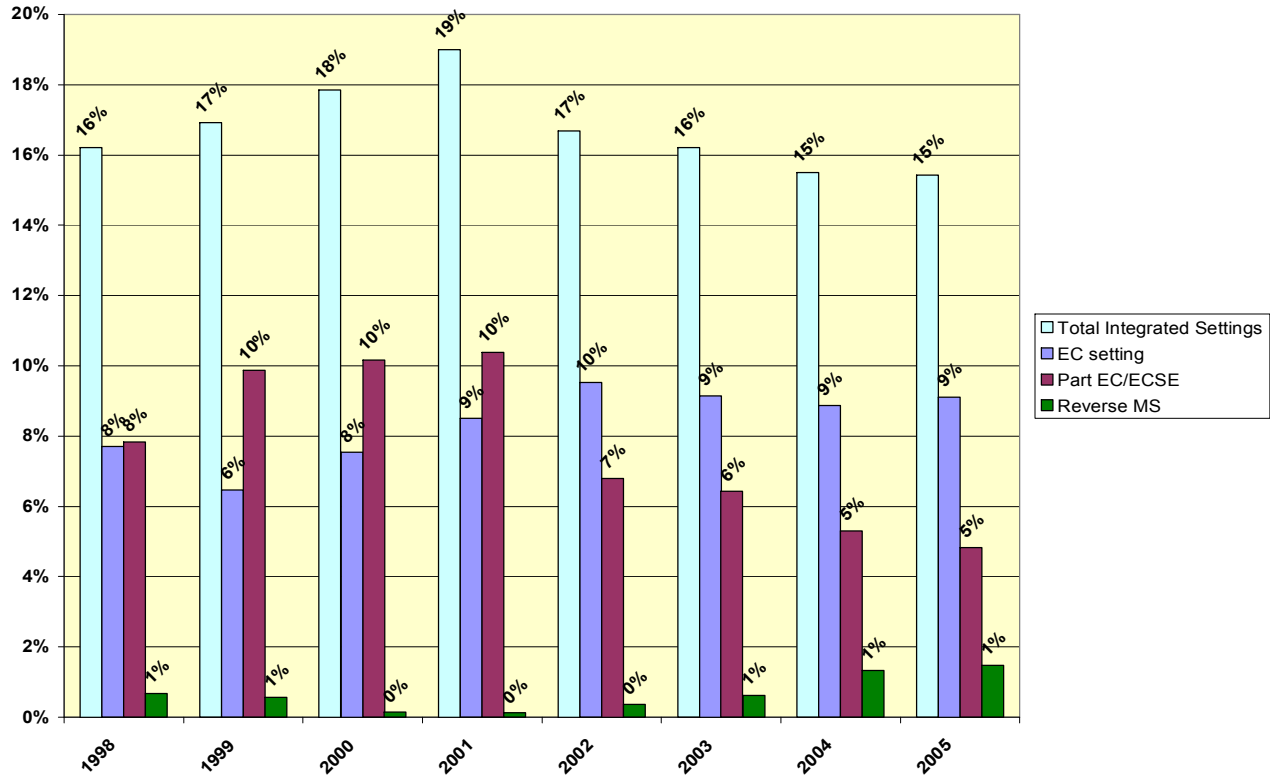


Figure 28: Integrated settings in which early childhood special education services were provided

Educational settings used prior to 2006 for reporting school-aged students (6-21)

For school-aged (6-21) students, 13 potential settings were provided and projects were again required to enter the setting under which the individual was reported on the State Department of Education Part B, IDEA Child Count.

School-age settings included:

- Regular classrooms
- Resource rooms
- Separate classes
- Public separate schools
- Private separate schools

- Public residential facilities
- Private residential facilities
- Homebound/Hospital programs
- Home school programs
- Post-secondary programs
- Vocational programs
- Not in educational setting
- Other

Since 1998, the vast majority of school-aged students, nearly 80%, have received their services in separate classrooms, schools or residential facilities and only 15% have been served in regular education environments. Less than 1% of school-aged students with deaf-blindness are reported to be served in post-secondary education or vocational settings and 1% is reported as receiving no educational services at all.

Interestingly, there has been little variability in the settings that school-aged students have been served in throughout the years, despite the federal emphasis on the provision of services to students in least restrictive settings and the inclusion of all students in the general education curriculum. As with ECSE placements, school-age inclusion also appears to be an area in need of ongoing systems development and technical assistance.

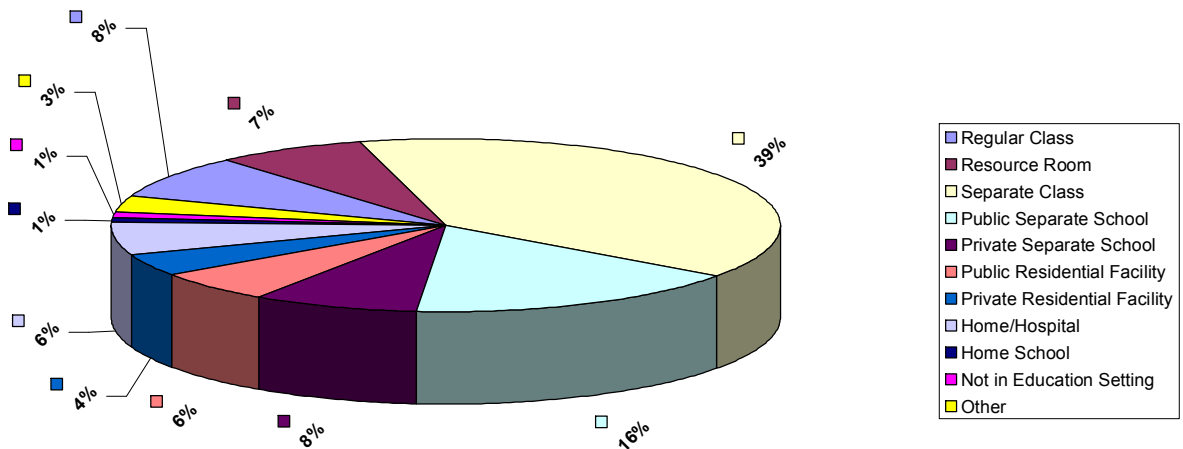


Figure 30: Mean school-aged placements from 1998 through 2005.

Figure 31 illustrates the distribution of separate settings in which school-aged students have been served. On the average, thirty-nine percent of students with deaf-blindness are served in separate classroom settings, 24% are served in private (8%) or public (16%) separate schools and just over 10% are served in public (6%) or private (4%) residential facilities. Six percent of students are served in home and hospital programs and 1% is served in a home school setting. (Note: A Home and hospital program refers to settings in which a child is placed by an IEP team. In contrast, home school is a setting in which a parent voluntarily enrolls their child).

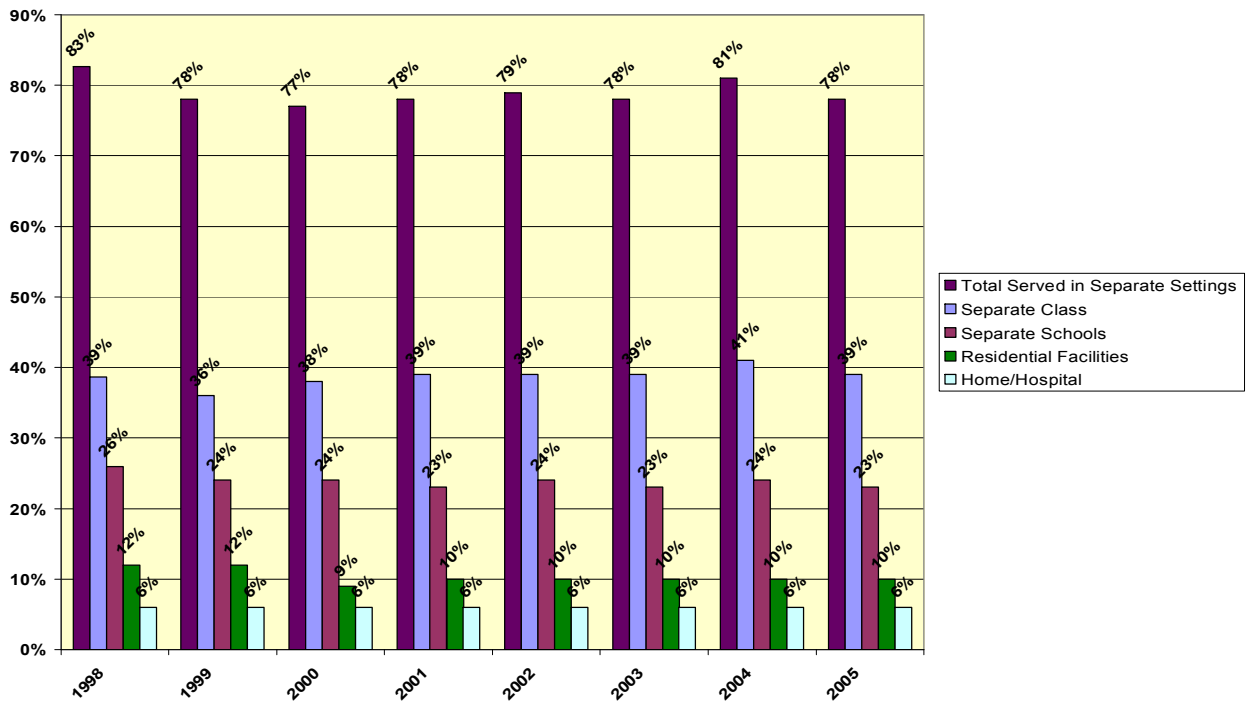


Figure 31: Separate settings in which school-aged special education services were provided

Figure 32 illustrates the regular education settings, both regular classrooms and resource rooms in which school-aged students have been served. On the average, only 8% of school-aged students with deaf-blindness have been served in regular classroom and only 7% in resource settings.

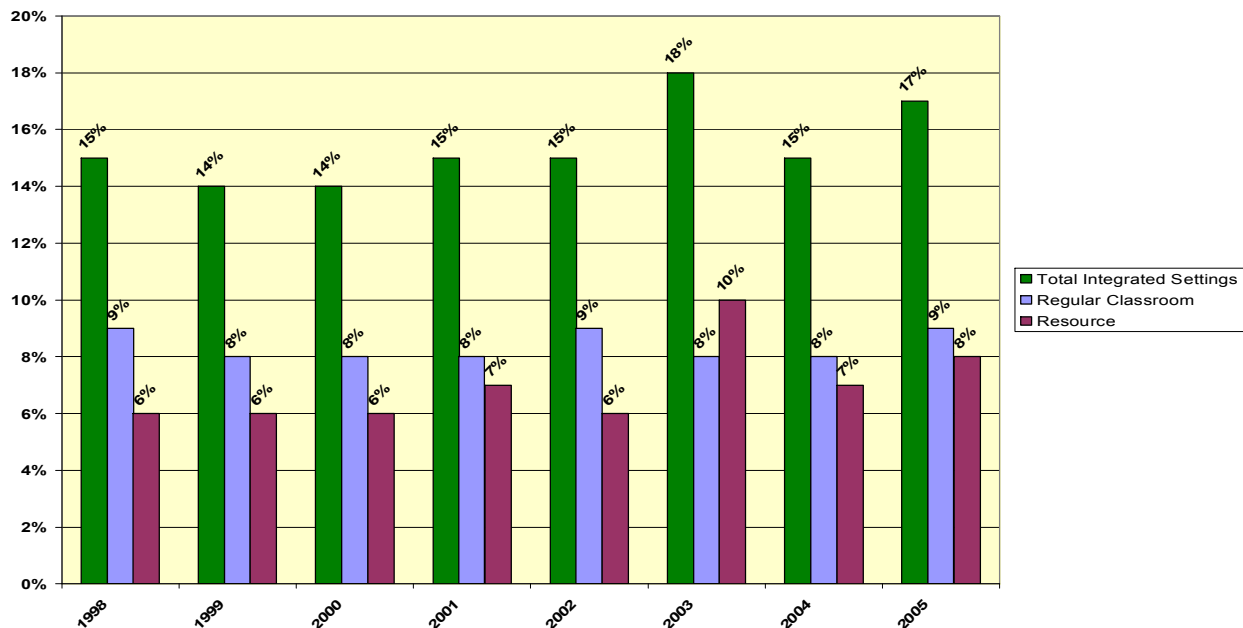


Figure 32: Regular education settings in which school-aged special education services were provided

LIVING SETTINGS

Projects are also required to identify and report the location in which the individual resides during the majority of the year.

Nine living settings are provided and they include:

1. Home with their birth or adoptive parents
2. Home with extended family members
3. Home with foster parents
4. State residential facility
5. Private residential facility
6. Group homes with less than 6 residents
7. Group homes with 6 or more residents
8. Apartment, both independent or supported
9. Pediatric nursing home

Figure 33 illustrates the mean living settings reported since 1998. Nearly 80% of those reported live with their birth or adoptive parents, and the vast majority continues to so throughout the time they are reported on the Census. As students age, less than 3% are leaving home and moving to independent or supported settings including group homes and apartments.

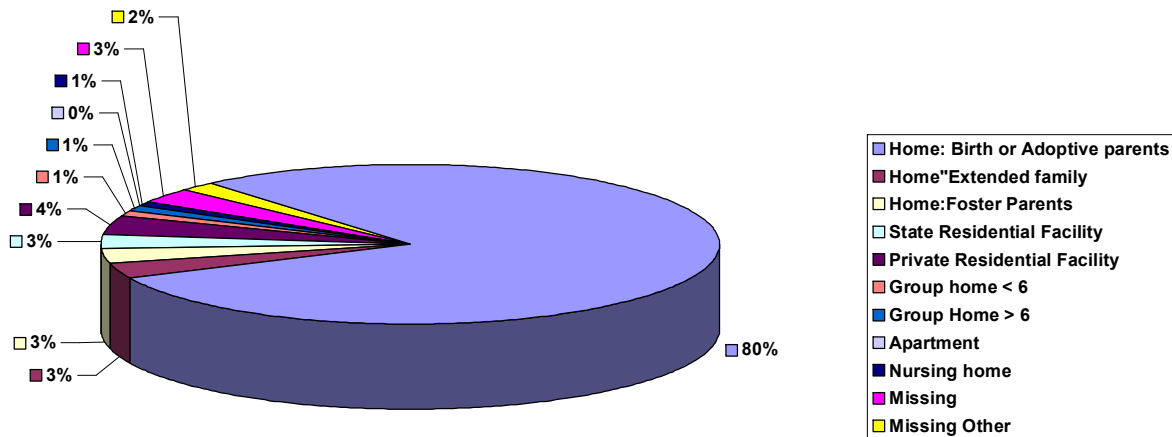


Figure 33: Mean living settings from 1998 through 2005

As seen in Figure 34, there has been little variability in the number of children living in a home setting, although overall, there has been an increase of 5% from 1998, when 84% of those reported were living in a home setting, to the high of 89% in 2005. As seen, the total for home setting includes those children reported as living with their birth or adoptive parents, those living in homes with extended family members and those living in foster care homes.

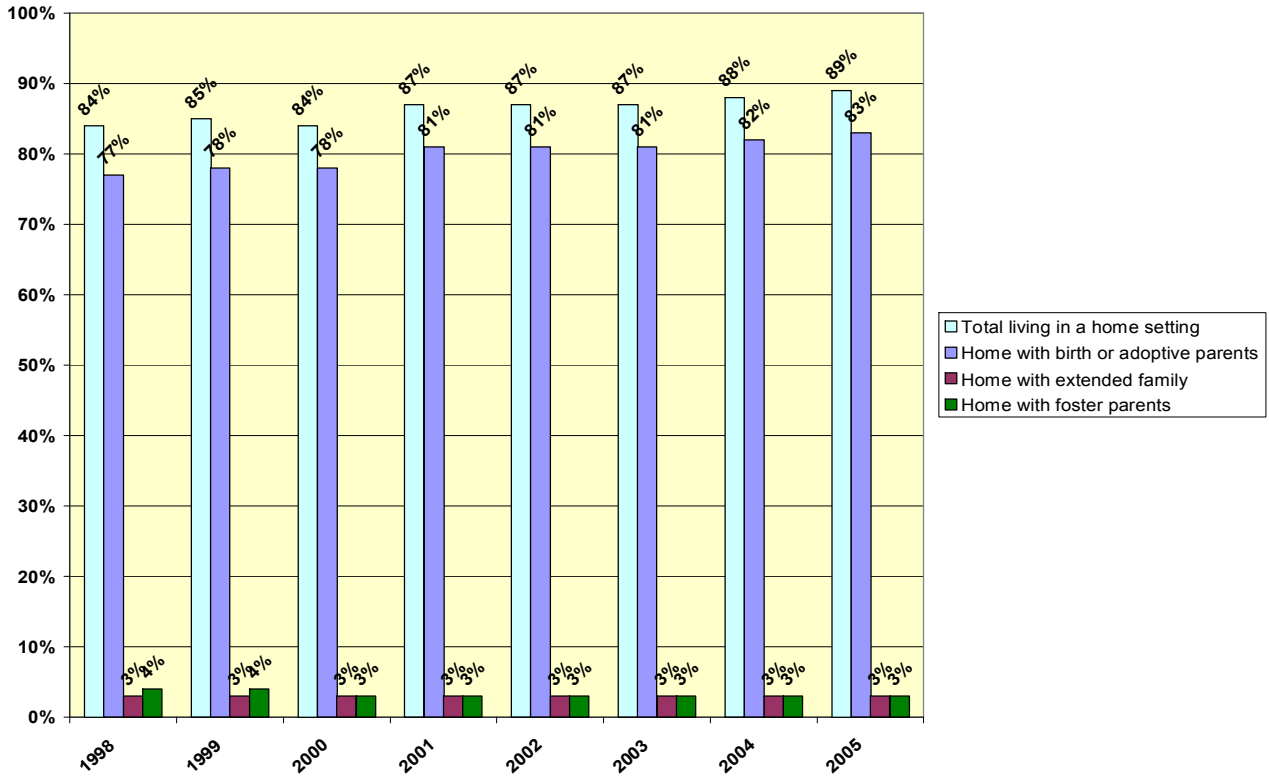


Figure 34: Home settings in which children and students lived

In contrast, less than 6% of children and students with deaf-blindness were reported as living in residential facilities, including nursing homes in 2005, nearly a 4% decrease since the high in 1999.

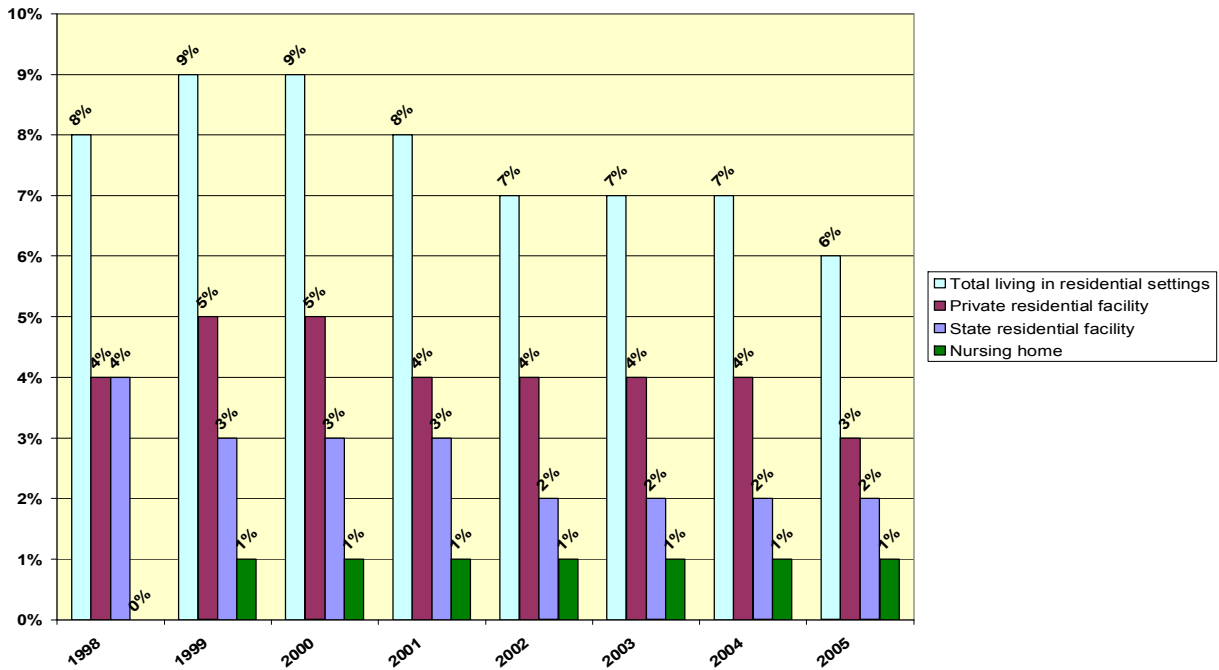


Figure 35: Residential settings in which children and students lived

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