

The Colorado Census of Children and Youth with Combined Vision and Hearing Loss

Answers to the Most Frequently Asked Questions

In an effort to make the completion of the annual census of individuals with combined hearing and vision problems as clear and simple as possible, the following questions and answers may be helpful.

- 1. What is the census of children who are deafblind?** Colorado Services for Children and Youth with Combined Vision and Hearing Loss project conducts an annual count of all children from birth to age 21 in Colorado who have both hearing and vision problems. Although project staff adds to the census throughout the year, the annual mailing to schools and programs occurs in mid-November and forms are due back to CDE no later than mid-December. Since the information on the census is confidential, only specific data are submitted to the federal government (such as cause of deafblindness and type of school placement), not student or parent names, home addresses, or any other identifying information.
- 2. How long does it take to complete the necessary paperwork?** The project staff has worked hard to streamline the form for ongoing students so that it takes a short time to review and complete each form. For students who new to the census, the paperwork will take more time as the form must be completed in full for the first time.
- 3. Why is the census so important?** The census is important for many reasons. Funding for specialized outreach services is dependent on having accurate information about how many infants, children and youth in Colorado have both hearing and vision problems. When the state and national legislatures approve funding - and state and federal agencies allocate the funds - census information is one factor that is used to determine priorities and needs. In addition, all identified children and youth, their families, and their service providers are eligible for free technical assistance from the Colorado project.
- 4. What exactly is meant by the term *deafblind*?** A functional definition of deafblindness is: "If an individual (birth through age 21) has combined hearing and vision problems that are significant enough to require considerations (such as specialized adaptations, modifications, and strategies) when presenting information or interacting with the child, the child is eligible to be included on the census and receive services from our project." It will be important to have medical / audiological information to substantiate the vision and hearing loss, as well as functional sensory assessment data to inform school district personnel as to educational effects of the dual sensory loss.
- 5. What if a child has multiple disabilities that happen to include vision and hearing problems?** Many children who are deafblind have additional disabilities, including developmental delay, physical challenges, serious health impairments, and so on. Please complete a census form for all students that have hearing and vision problems, regardless of the presence or absence of additional disabilities.

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6. **What if the hearing and/or vision problems are cortical in nature?** Children with sensory impairments that are cortical in nature, such as cortical visual impairment and/or central auditory processing disorder or auditory neuropathy, should be placed on the census. These students usually require adaptations and modifications to their educational programs. In addition, the hearing and vision problems must be considered when developing effective, communication programs for these individuals. When in doubt, refer to the functional definition of deafblindness in question #3 above.
7. **What if deafblindness is not listed as a student's primary disability condition on her or his Individualized Education Program (IEP)?** If a learner has combined vision and hearing loss, he or she should have the label of deafblind on his or her IEP. It can be a primary or secondary label.
8. **Does including a child on the census obligate the school program to provide services such as vision, hearing, orientation and mobility, etc.?** No. Individualized needs and services are determined by the family and educators through the Individualized Education Program (IEP) or Individual Family Service Plan (IFSP) process.
9. **Why is a child's diagnosis included on the census?** Knowing the reason that a child has combined vision and hearing loss is important for a number of reasons. First, it allows project staff to make important connections between families. For example, parents of a child with Cockayne Syndrome might contact our office and ask if there are other parents of children with the same syndrome in their area. The census allows us to make these family-to-family connections (with parent permission, of course). This data is also reviewed from a national perspective (with data from all 50 states) to determine which causes of deafblindness are on the increase or decrease, if there are geographic clusters of students with similar conditions, and so on.
10. **What if my administrative unit or agency does not currently have any students who are deafblind at this time?** It is possible that smaller administrative units may not have any students with combined hearing and vision problems. Statistically, we know that there should be about one child who is deafblind for every 4,200 students in a district. Another guide we use is that there are approximately two students who are deafblind for every 1,000 receiving special education services. Project staff is available to assist in identification efforts.
11. **What if I don't know all the information requested on the census form for a particular student?** Please give us as much information as you have. Don't worry if you are missing some information, such as the date of the student's last vision exam. It is more important that we have an accurate count of students. Project staff will work with you to complete the missing information.
12. **Who should complete the census form?** The project has contact people in almost every administrative unit or educational agency. Contact Tanni Anthony to learn who the contact person is in your administrative unit or agency.

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- 13. What if I have a question about the census that hasn't been answered here?** Please contact Tanni Anthony at <anthony_t@cde.state.co.us> or by telephone at (303) 866-6681.