

News Alert



SOUTH CAROLINA DEAF-BLIND CENSUS

Each year in South Carolina and in all states across the nation, a census is taken to determine who is identified as having deaf-blindness as of December 1 of that year. Census results are submitted to the federal Department of Education. The Census gathers demographic and educational data as well as information about the underlying condition causing the deaf-blindness. The definition of deaf-blindness used by the Interagency Deaf-Blind Project in South Carolina is as follows. *A combination of visual impairment and hearing loss that causes severe communication and other learning needs. A person with deaf-blindness cannot be appropriately educated without assistance to address educational needs related to both sensory impairments.* Census forms were revised and streamlined this year to gather information needed for the SC Interagency Deaf-Blind Project and to make the data collection form easier to complete. Incomplete forms were corrected through follow-up telephone calls. This report provides an overview of the results of the spring 2004 census.

Table 1. Age Categories

Age Range	Frequency
Birth through 2	21(28%)
3 through 5	14(19%)
6 through 17	34(47%)
18 through 21	4(6%)
Total	73(100%)

Seventy-three children, youth, and young adults are listed on the 2004 deaf-blind census for South Carolina. The location where each person on the census is receiving services and the agency providing those services is indicated on a map in Figure 1. According to the census, persons with deaf-blindness can be found in 30 of the 46 counties across the state. Six counties have four or more persons on the deaf-blind census. Twenty-seven students (37%) are in the Piedmont region, 20 (27%) in the Coastal region, 18 (25%) in the Midlands region, and 8 (11%) in the Low Country region. These young people range in age from a few months through 21 years old. As can be seen in Table 1, most (72%) are public school aged (3 through 21) and almost half (47%) of the 73 people on the census are under five years of age.

Sixty percent of those on the deaf-blind census are male and 40% are female. One person (1%) on the census is Asian, 34 (47%) are African American, and 38 (52%) are white. As can be seen in Table 2, all of those on the deaf-blind census live at home with their birth, adoptive, or foster parents.

Etiology of Deaf-Blindness

Deaf-blindness is typically caused by one of four conditions or disorders. As can be seen on Table 3, the leading cause in South Carolina is hereditary or chromosomal syndromes or disorders (27%) followed by pre-natal or congenital complications (22%). Third is post-natal or non-congenital complications (18%) and the fourth is complications of prematurity (15%). No specific cause has been

Table 2. Living Arrangements

Living Setting	Frequency
At home with birth/adoptive parents	65(89%)
In a home with extended family	5(7%)
In a home with foster parents	3(4%)
Total	73(100%)

identified for 18% of the children, youth, and young adults on the census.

Based on the etiology of their conditions; it is not surprising that most of the children, youth, or young adults on the deaf-blind census have other impairments in addition to deaf-blindness. Sixty-nine percent have a physical impairment, 85% have a cognitive impairment, 53% have complex health care needs, 3% have behavioral disorders, and 11% have other conditions. These other impairments make addressing the educational needs of children with deaf-blindness even more challenging.

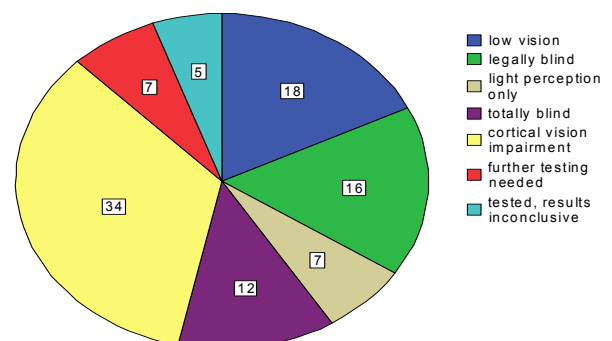
Table 3. Etiology of Deaf-Blindness for those on Deaf-Blind Census

Category	Etiology	Frequency
Hereditary/Chromosomal Syndromes and Disorders 20(27%)	Aicardi Syndrome	1(1%)
	Charge Association	4(5%)
	Crouzon Syndrome	2(3%)
	Dandy Walker Syndrome	1(1%)
	Down Syndrome	1(1%)
	Goldenhar Syndrome	1(1%)
	Hallgren Syndrome	1(1%)
	Waardenburg Syndrome	1(1%)
	Other Hereditary Disorder or Syndrome	10(14%)
Pre-Natal/Congenital Complications 16(22%)	Congenital Rubella	1(1%)
	Congenital Toxoplasmosis	2(3%)
	Cytomegalovirus	5(7%)
	Hydrocephaly	5(7%)
	Other prenatal/congenital Complication	5(7%)
Post-Natal/Non-Congenital Complications 13(18%)	Asphyxia	2(3%)
	Encephalitis	1(1%)
	Meningitis	2(3%)
	Severe Head Injury	2(3%)
	Tumors	1(1%)
	Other Postnatal Conditions	5(7%)
Complications of Prematurity		11(15%)
No Determination of Etiology		13(18%)
Total		73(100%)

Level of Impairment

Periodic evaluations and reevaluations of hearing and visual impairment are required to participate in special education. The level of impairment is assessed during these evaluations. Functional hearing and vision exams are sometimes conducted on students with sensory impairments to determine the practical implications of their impairments. Functional vision examinations were conducted on 50 of the students on the deaf-blind census and 45 had a functional hearing examination. Figures 2 and 3 show the levels of impairment for all of those on the deaf-blind census. As can be seen in Figure 2, about 12% of those with visual impairments could not be assigned

Figure 2. Primary Classification of Visual Impairment

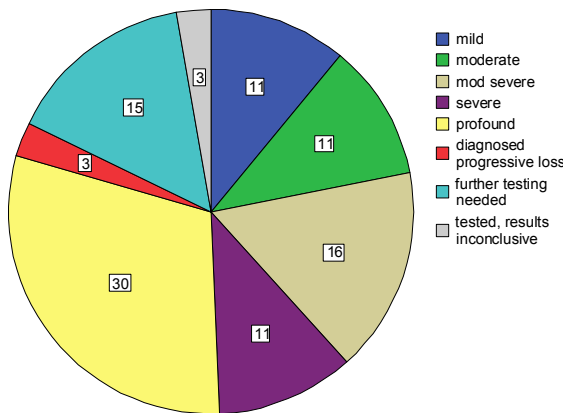


a level of impairment and will need further evaluation. Just under half of the students on the deaf-blind census have some vision (41%). As can be seen in Figure 3, just under half (49%) of those on the census has some level of hearing and about 18% had inconclusive results or needed further testing.

Category of Disability

At the time of enrollment in special education, a primary disability category is determined for each student. Funding received for the student is determined by the primary disability as well as the types of services to be provided.

Figure 3. Primary Classification of Hearing Impairment



have a disability category, and those between three and five can remain non-categorical.

As can be seen on Table 4, only five of the students on the census have deaf-blindness as their primary disability. Most have mental retardation as their primary disability followed by hearing or visual impairments. Students under three do not

Table 4. Disability Categories of People on the Deaf-Blind Census

Disability Category	Frequency
Under 3/Not Applicable	19(26%)
Mental Retardation	15(21%)
Hearing Impaired	13(18%)
Visually Impaired	6(8%)
Non-Categorical	6(8%)
Deaf-Blind	5(7%)
Multi-disabled	4(5%)
Other Health Impaired	3(4%)
Orthopedic Impairment	2(3%)
Total	73(100%)

Educational Setting

Table 5 describes the setting in which the students on the deaf-blind census are currently being educated. Most of the children in elementary and high school are educated in a separate classroom. Two attend a regular class and receive additional help from an itinerant teacher. Some of the students are educated at the School for the Deaf and Blind in Spartanburg (a public residential school). Six students are too medically fragile to attend school and are educated at home or in a hospital setting. Most of the very young children are in the home-based early intervention program. After they reach the age of three and become eligible for public school services, most attend a program in an early childhood special education setting and a few continue to receive home-based services.

Table 5. Educational Setting of Students on the Deaf-Blind Census

Educational Setting	Frequency
Separate Class (6 through 21)	18(25%)
Home Based (Birth through 2)	16(22%)
Public Residential Facility (6 through 21)	12(16%)
Early Childhood Special Education Setting (3 through 5)	10(14%)
Homebound/Hospital Environment (6 through 21)	6(8%)
Home-Based Program (3 through 5)	4(6%)
Program for Developmental Disabilities (birth through 2)	2(3%)
General Education Class (6 through 21)	2(3%)
Home/Center-based Program (birth through 2)	1(1%)
Reverse Mainstreaming Program (3 through 5)	1(1%)
Missing	1(1%)
Total	73(100%)

Summary

The Deaf-Blind Census provides valuable information to Interagency Deaf-Blind Project staff as they plan services for students with dual sensory impairments. Additional support is critical for these students due to their challenging and complex educational needs.

Deaf-Blind Census Report

Based on students enrolled as of 12/1/2003

Cynthia Flynn, Ph.D.

TRAINING UPDATE

The SC Regional Deaf-Blind Education Teams (RDBET) began their initial training August 3rd and 4th in Columbia. These regional teams are comprised of early intervention staff, teachers of the visually impaired, teachers of the hearing impaired, and orientation and mobility specialists from the SC School for the Deaf and the Blind (SCSDB). RDBET members were chosen from the on-campus program in Spartanburg as well as the statewide SCSDB Division of Outreach Services.

The training was conducted by Dr. Terry Rafalowski Welch. Dr. Rafalowski Welch, one of the authors of *Hand in Hand: Essentials of Communication and Orientation and Mobility for Your Students Who Are Deaf-Blind*, is the former Director of Washington State Services for Children with Deaf-Blindness, and a former teacher of children who are deaf-blind. Her publications include a guide on early intervention for families of children who are blind and numerous articles on services for children who are deaf-blind and their families.

Dr. Rafalowski Welch presented an in-depth introduction to deaf-blindness, the early effects of deaf-blindness, learned helplessness and communication strategies

The next training for the "RDBET" staff will be held in Columbia on October 18, 2004. The focus will be communication and mental disabilities.

Lynda Smith, Statewide Director of Early Intervention Services and a Project Coordinator for the SC Interagency Deaf-Blind Project, will attend the Annual Project Director's Meeting in Washington, D.C. October 14-16, 2004. This year's keynote speaker will be Karen Erickson from the University of North Carolina. The agenda includes sessions on early literacy, mentoring and expanding teaching strategies. There will also be an overview of the Deaf-Blind Grant Site Review process.

MEDICAL ISSUES

USHER SYNDROME – Early detection is critical.

Usher Syndrome is the leading cause of deaf-blindness in adults, but **the symptoms often appear in students as young as 10 years of age.** Usher Syndrome is a genetic disorder characterized by serious hearing impairment, present at birth or shortly thereafter, and progressive vision loss due to Retinitis Pigmentosa. Researchers believe that the loss of hearing is sensorineural deafness and is due to a problem with the sensory (nerve) cells in the cochlea of the inner ear. The vision loss begins later in life, but usually before adolescence. There is no way of knowing the time of onset or the rapidity of the vision loss. Usher Syndrome is a very difficult disease to describe because each case is so different. The changes in hearing and vision are **not** the same for all people who have Usher Syndrome.

The two major types of Usher Syndrome are Type I and Type II. The hearing loss is profound in Type I. In Type II persons, they are often considered hard of hearing and are able to detect low tones better than high tones. Only a small amount of additional loss (about 10 - 20 dB) occurs over a lifetime, and may be related to noise exposure or aging. Type III has not been as well defined as the other two types. A fairly large group of people in central Finland is being studied, and there are a few other cases in other places. The onset of the hearing loss can be anytime from infancy to mid-adulthood. The hearing loss gets steadily worse over 10 - 15 years leading to profound deafness. The audiogram shape is much like Type II, except for "speed-bump" upturn in the higher frequencies.

USHER SYNDROME: Why is early detection important?

If teachers, parents and students are proactive, education can prepare the student with Usher Syndrome for employment and independent living. People with Usher Syndrome, and their families, need time to:

- Adjust to the dual sensory loss, including time for the grieving process, and changes in self-image/self-esteem, communication needs and relationships.
- Recognize the effects of the increased vision loss, and make necessary changes in their educational program (classroom modifications, in-service for staff, sensitivity awareness training, etc.).
- Develop coping skills - both emotionally and physically.

- Make an informed decision about career/vocation. The individual, parents, and teachers can plan for educational and vocational experiences and guidance that take into account the eventual visual difficulties.
- Consider genetic counseling. A diagnosis of Usher Syndrome in an older child allows parents to consider genetic counseling. Persons who have Usher Syndrome may also want to consider genetic counseling. The same may be true for siblings.

The following suggestions may help people with Usher Syndrome in their education and career development.

1. Know that you have Usher Syndrome.
2. Know what your vision is at all times as it changes throughout your life.
3. Find out about educational and career opportunities.
4. Expose yourself to as many careers as possible.
5. Know your own interests, dislikes, talents, and weaknesses.
6. Make choices yourself, whether right or wrong.

Follow these suggestions and then make a decision for what you want to do. Try it. If the decision is not right for you, change to another decision and try it. The practice of trying out educational and job opportunities is the best way to find out what is right for you. * (from Hearing-Vision Impaired Programs at Gallaudet University).

Another reason for early detection is that the gradual decrease in vision may go unnoticed by the individual, and they may continue activities (driving, crossing streets, work under hazardous conditions) that cannot safely be done anymore. Proper modifications may make the activity safe to continue.

The school system may also need to consider taking steps to ensure they are providing timely and appropriate services to students with Usher Syndrome (and their families). It is important that the students have positive feelings about themselves and their school experiences. They also need to learn to make optimal use of their vision. This may include:

- Low vision assessments
- Specialized training for staff
- Monitoring of the student's needs
- Counseling and support for the student, and their family
- Establishing Usher Syndrome Support group (through summer camps, national events, Networking, Parent Group, etc.)
- Classroom and environmental modifications

What are some of the behavioral symptoms that teachers, parents, and others may see that suggest Usher Syndrome?

Night blindness
Glare sensitivity
Difficulty with contrast
Restricted field
Problems with visual acuity
Balance problems

Clumsiness

(Llewellyn Jones, "Understanding Usher Syndrome," July 2004, Asheville, N. C.)

An Open Letter to Our Parents: What We wish You Had Known

"...Having Usher Syndrome is both difficult and a challenge. Having vision problems that have gotten worse or can leave us blind is extremely stressful. Some of our parents didn't tell us what was wrong with us. Some did say there was an eye problem but still didn't tell us the details or explain anything to us. Finding out from friends, or a doctor, when we know that our parents knew this was happening to us left us angry, frustrated, and feeling like we have been treated like babies."

"...Most of us felt we knew that we had a problem sometime between the ages of 10 and 12, but there was no one to tell or talk to, even after visits to the doctors."

"...The staff at the schools need to be trained very well and trained over and over again so they know what is going on and so they understand. Someone should look at the school setting to see how they can make it brighter and safer for us."

"...We felt very embarrassed by the cane; at the same time, we feel it was absolutely necessary to begin to learn about it and maybe it should have started even younger."

Usher Family Support, Fall 1994

THE SC DEAF-BLIND INTERAGENCY PROJECT LISTSERV

The South Carolina Deaf-Blind Interagency Project Listserv is now available. To join the listserv, send a request to SCDeafBlind@scsdb.k12.sc.us. Include your name and school or agency affiliation. If you are a parent or an adult who is deaf-blind, not associated with a school or agency, please include your address and telephone number. DB-LINK, NTAC, and Teaching Research provide support for this LISTSERV.

THE SC DEAF-BLIND INTERAGENCY PROJECT RESOURCE LIBRARY

Video: *Hand in Hand: It Can Be Done!* This video offers essential information on how families, teachers, and other educational team members can work effectively together with children who are deaf-blind to deliver successful educational programs.

The Deaf-Blind Resource Library is located at the SCSDB Midlands Regional Outreach Center (MROC) in Columbia. For a list of the materials currently available for loan, please call Annette Hammond at (803)896-9794 or email SCDeafBlind@SCSDB.k12.sc.us. New acquisitions will be available on the website link.

For information on publications such as the DB Link Newsletters, *Deaf-Blind Perspectives*, or a "New Teacher Packet", contact DB-Link (800) 438-9376 or email dblink@wou.edu.

POINT TO PONDER

Communication is the exchange of a message between two or more people. Everyone communicates in many different ways and for many different reasons. Communication can be **expressive** or **receptive**. Children who are deaf-blind may never learn to talk. However, they can express themselves to you. They can receive messages from you. Through communication children can make changes in their world.

Kathleen Stremel (DB Link, Aug. 2000)

The **definition** of deaf-blindness used by the Interagency Deaf-Blind Project is South Carolina is as follows.

A combination of visual impairment and hearing loss that causes severe communication and other learning needs. A person with deaf-blindness cannot be appropriately educated without assistance to address educational needs related to both sensory impairments.

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For an alternate format of the *News Alert*, please email <SCDeafBlind@scsdb.k12.sc.us>



Regional Deaf-Blind Educational Team Training – August 2004 – Columbia, SC
Top: Chuck Klocko and Nancy Decker demonstrate hand-under-hand assistance.
Bottom: Paul Moton and Modenia Davis demonstrate sighted guide travel.

Deaf-blind Census 2004: Service Provider and Location of Each Student

