



Early Identification of Young Children with Deaf-Blindness

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Based on the work of . . . Dr. Sarah Cawthon, M.D.



What is Deaf-Blindness ?

- ◆ “.....the term ‘deaf-blind’, with respect to children and youth, means having auditory and visual impairments, the combination of which creates such severe communication and other developmental and learning needs that they cannot be appropriately educated in special education programs solely for children and youth with hearing impairment, visual impairment, or severe disabilities, without assistance to address their educational needs due to these dual, concurrent disabilities.” (IDEA)



The Challenge of Deaf-Blindness

- ◆ The challenge faced by people with both hearing loss and vision is much greater than just the sum of the two losses. The problem is not additive, but multiplicative.
- ◆ $(-vision) \times (-hearing) = (challenge)^2$

(Davenport, 1992)



Early Identification

- ◆ Learning about a vision and/or hearing loss early is critical...skills that could be attained early could be more difficult to attain later in life (Newton, 2001)



Recommended Screening Stages

◆ Vision

- Birth
- 6 months
- 3 to 4 years
- At regular intervals 5 years and older

◆ Hearing

- Birth
- Every 6 months until age 3
- At regular intervals after age 3

American Speech and Hearing
Association

American Academy of
Ophthalmology & American
Academy of Pediatrics



National Census Data

◆ Age	◆ Number
◆ Birth - 1	97
◆ 1 - 2	223
◆ 2 - 3	355
◆ 3 - 4	426
◆ 4-5	396
◆ 5 - 6	376



Primary Identified Etiology

◆ Heredity Syndromes/Disorders	3,607
◆ Pre-Natal/Congenital Complications	1,836
◆ Post-Natal/NonCongenital	1,525
◆ Prematurity /Low Birth Weight	1,194
◆ Unknown Etiology	2,012 1

N= 10,174

2007 National Deaf-Blind Census



The Ability to Learn

- ◆ Learners who are deaf-blind are not limited by what they can learn but by how and what we teach them using effective strategies



Impact of Vision and Hearing Loss on Development

- ◆ **Motor skills:** Difficulties with motor fluency and feeling secure during movement activities
- ◆ **Cognitive skills:** Concept development is compromised. Incidental learning is limited.
- ◆ **Social-emotional skills:** Social cues are missed resulting in difficulties learning how and when to interact with others.
- ◆ **Adaptive skills:** Learning how to meet one's own needs for self-care and independence can be challenging.
- ◆ **Communication skills:** Learning to engage in interactions and participate in language opportunities is difficult. Other people must make language accessible to children with deaf-blindness.



Major Causes of Deaf-Blindness

- ◆ Genetic Syndromes-CHARGE, Down, Trisomy 13, Usher
- ◆ Multiple Congenital Anomalies-Hydrocephaly, Microcephaly, Fetal alcohol syndrome, Maternal drug abuse
- ◆ Prematurity and Small for Gestational Age
- ◆ Prenatal Infections-Syphilis, Toxoplasmosis, Rubella, CMV, Herpes, AIDS
- ◆ Post-natal Causes-Asphyxia, Head injury, Stroke, Encephalitis, Meningitis, Tumors, Metabolic disorders (Heller, Kennedy, 1994)



CHARGE Syndrome

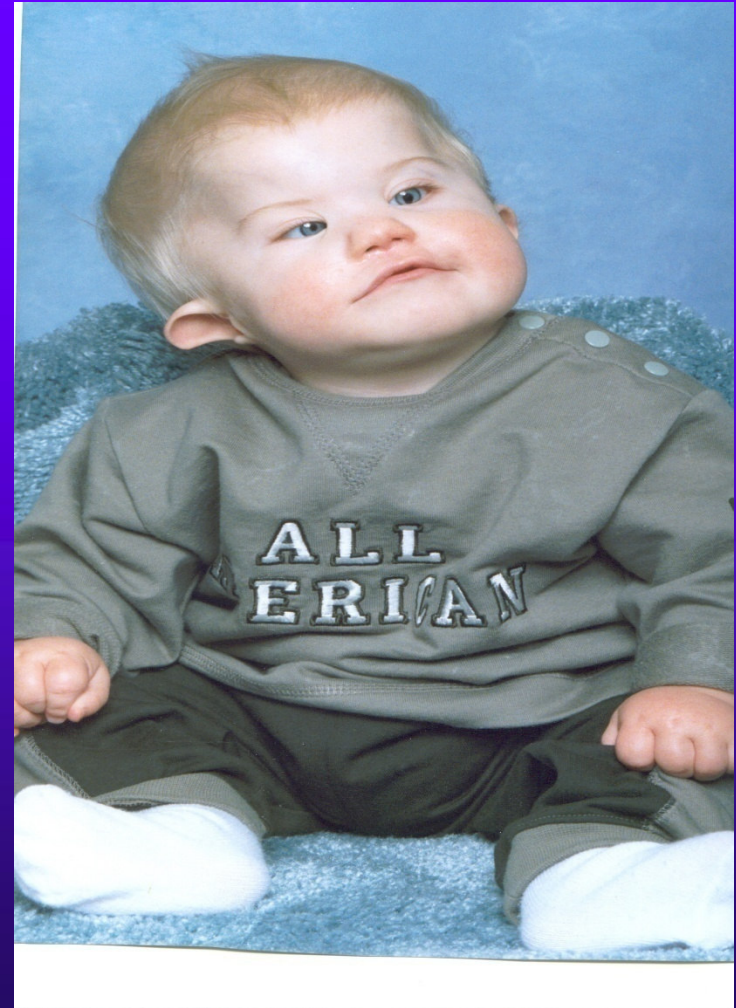
- ◆ Coloboma
- ◆ Heart Abnormalities/Malformations
- ◆ Atresia of the Choanae
- ◆ Retardation of Growth &/or Development
- ◆ Genital &/or Urinary Abnormalities
- ◆ Ear Abnormalities/Hearing loss

(Charge Syndrome Foundation, Inc., 2003)



CHARGE Syndrome

- ◆ Coloboma of the eye(85 %)
- ◆ Ear malformations(85 %)
- ◆ Facial palsy(40%)
- ◆ Cleft Palate(25%)
- ◆ Choanal atresia(60%)



Down Syndrome

- ◆ Flattened face and occiput
- ◆ Upward slanting of the eye with an extra skin fold at the medial aspect of the eyes (epicanthal folds)
- ◆ Small ears
- ◆ Open mouth with protruding tongue



Trisomy 13

- ◆ Small head (microcephaly)
- ◆ Gross anatomic defects of the brain (holoprosencephaly)
- ◆ Cleft lip and palate
- ◆ Extra fingers or toes (polydactaly)





Usher Syndrome

- ◆ Combination of progressive vision loss (i.e., Retinitis Pigmentosa) and severe, congenital hearing loss
- ◆ There at least 3 types that have been identified
 - Difference in types is related to degree and pattern of hearing loss and whether balance or developmental delays exist
- ◆ In order to determine the type of Usher Syndrome or whether a person has Retinitis Pigmentosa alone, a thorough evaluation is needed.

(National Eye Institute, 2004)



Other Notables

- ◆ Alport
- ◆ Alstrom
- ◆ Apert
- ◆ Cockayne Syndrome
- ◆ Crouzon
- ◆ Goldenhar Syndrome
- ◆ Hallgren Syndrome
- ◆ Hunter Syndrome (MPS-II)
- ◆ Kearns-Sayre Syndrome
- ◆ Mucopolysacharidosis
- ◆ Morquio Syndrome (MPS IV)
- ◆ Norrie
- ◆ Refsum Syndrome
- ◆ Sarcoidosis
- ◆ Strickler
- ◆ Turner Syndrome
- ◆ Waardenburg Syndrome

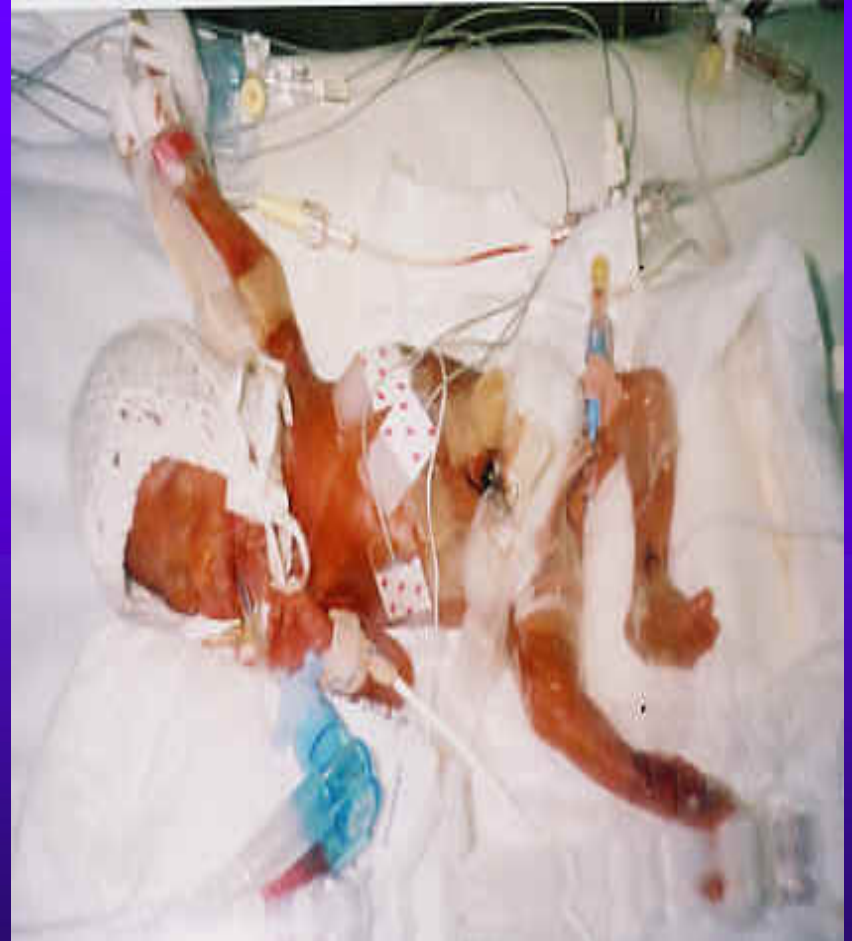


Fetal Alcohol Syndrome (FAS)

- ◆ Alcohol consumption during pregnancy places the fetus at risk of being born with multiple abnormalities. The combined effects of maternal (and possible paternal) alcohol consumption on the infant/child has been referred to as Fetal Alcohol Syndrome.
- ◆ FAS is the most common cause of mental retardation

Prematurity

- ◆ 4.3 % have serious visual defects (retinopathy of prematurity being one of the more common causes)
- ◆ 2 % have serious hearing impairments





Rubella a Success Story !

- ◆ Rubella is no longer a major public health threat in the U.S.A. In the 1960's an epidemic caused approx. 100,000 cases of Congenital Rubella Syndrome (CSR). Much of our educational advancements of working with the deaf-blind came from this era. In 1969 the vaccine came out that has virtually eliminated this from our population. In 2004 there was only 9 cases of Rubella reported, and no cases of CSR.
- ◆ So keep those kids vaccinated!



Meningitis

- ◆ Meningitis is an infection of the meninges
- ◆ If the cause is viral, it's usually self limited and treated symptomatically
- ◆ If the cause is bacterial, severe damage and/or death can occur



Physical Indicators of Hearing Loss

- ◆ Cleft lip or palate
- ◆ Malformation of the head or neck
- ◆ Malformations of the ears
- ◆ Heart Malformations
- ◆ Kidney problems
- ◆ Frequent earaches or ear infections
- ◆ Discharge from ears

(Chen, 1997; 1998)



Collaboration is Critical

- ◆ Unique demands are placed on families who have a child with a vision and hearing loss
- ◆ Many professionals will be involved with a child who has a hearing or vision loss
- ◆ Successful transitions require careful and respectful teamwork
- ◆ Appropriate monitoring of child progress requires all members to watch carefully

(Chen, 1997; Miles, 1995)



- ◆ It is critical that families and educators have access to training and support for assessment and education of infants, children, and youth who are deafblind.
- ◆ Each state has a federally funded technical assistance project to provide training and support.



Resources

- ◆ DB-Link-National Information Clearinghouse on Children who are Deaf-Blind <http://www.tr.wou.edu/dblink>
- ◆ NCDB (National Consortium on Deaf-Blindness) www.tr.wou.edu/ncdb
- ◆ Helen Keller National Center for Deaf-Blind Youths and Adults
<http://www.helenkeller.org/national/>



- ◆ For information
- ◆ National Consortium on Deaf-Blindness:
Phone: 800-438-9376
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