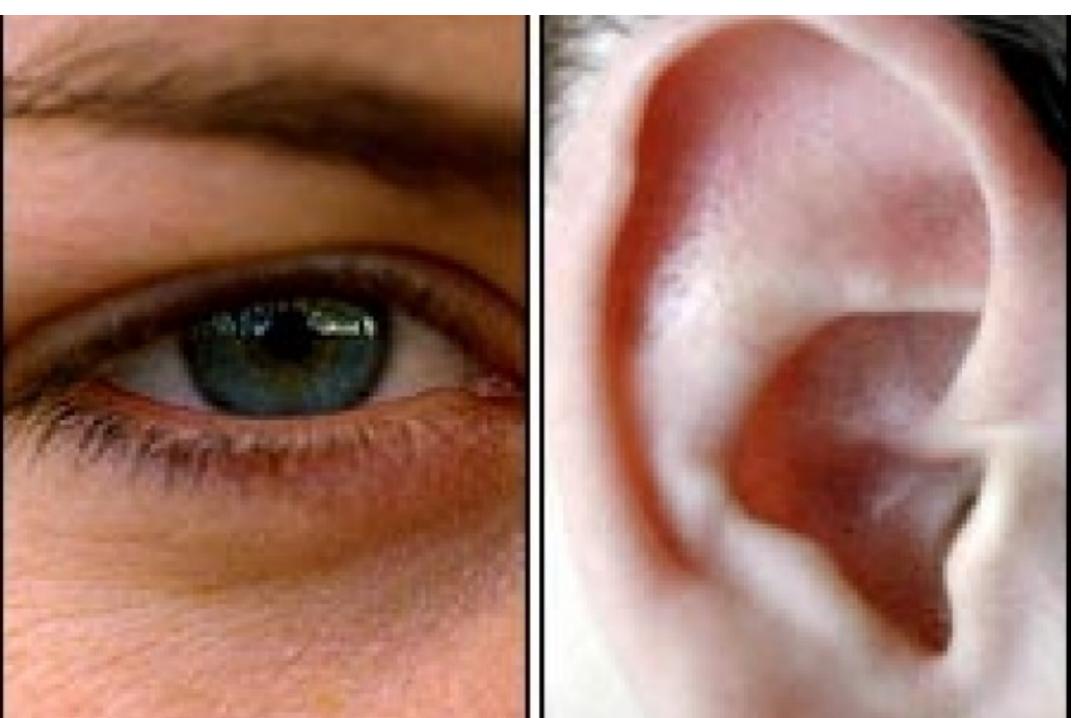
Michael C. Norman, Ph.D., Louisiana Deafblind Project, Rose Moehring, M.A., South Dakota Center for Disabilities, & Julie Durando, Ed.D., Virginia Partnership for People with Disabilities

Between 1765-1785 large groups of French Canadian settlers from Acadia, Canada migrated to what is now the southern most part of Louisiana. This group, isolated form others in the Louisiana territory, established what is celebrated world wide as the "Cajun" culture.

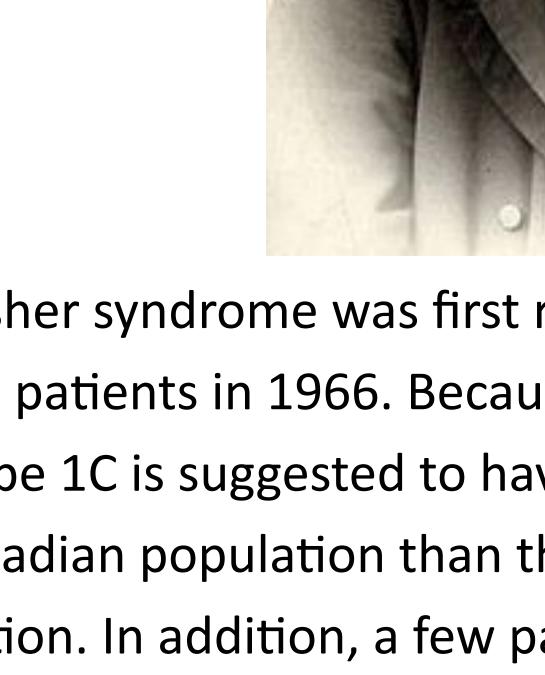
LOUISIANA

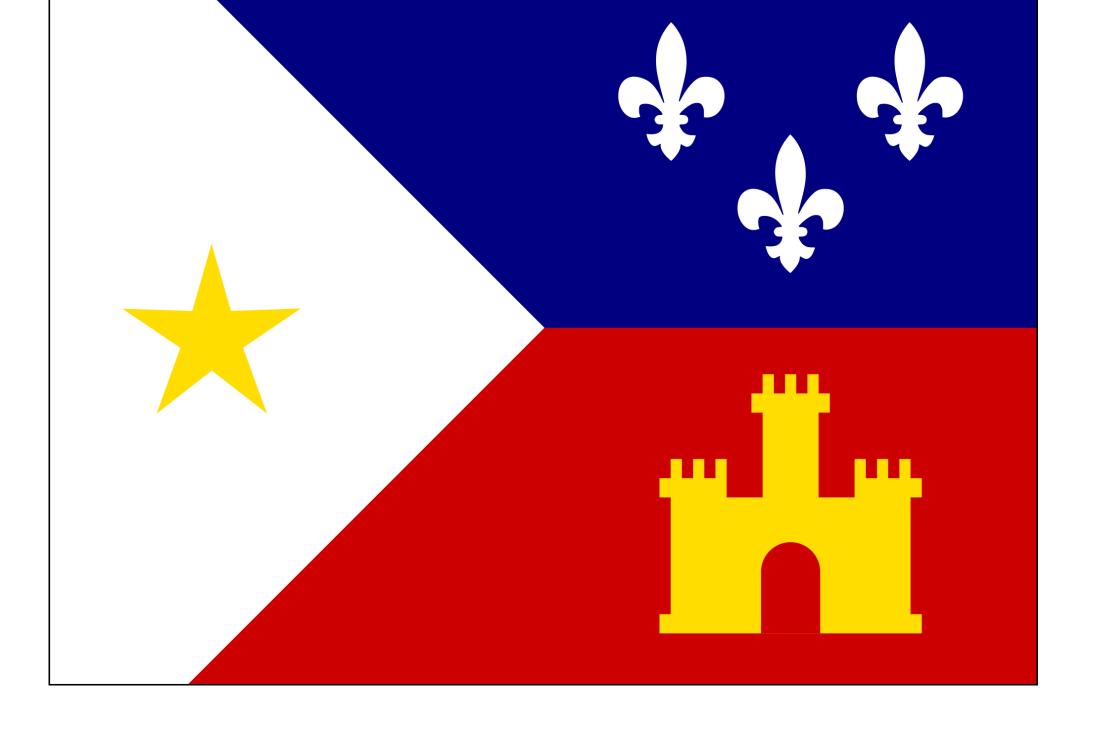




Usher syndrome was first described in 1858 by Albrecht von Gräfe. However, the syndrome was named after Charles Howard Usher, a Scottish Ophthalmologist, who described the syndrome in 1914. The incidence of Usher is estimated at 1:6000 -20000 individuals worldwide. Current reports indicate that Usher accounts for more than 50% of people who are both deaf and blind.

Traveling with this group of settlers was a recessive gene later discovered to result in children born with severe hearing loss who lost their vision in the first decade of their liver — Usher Syndrome. Usher Syndrome is the leading cause of deafblindness in the world and represents 5% of the deafblind population in Louisiana as compared to 1% in other states and territories.

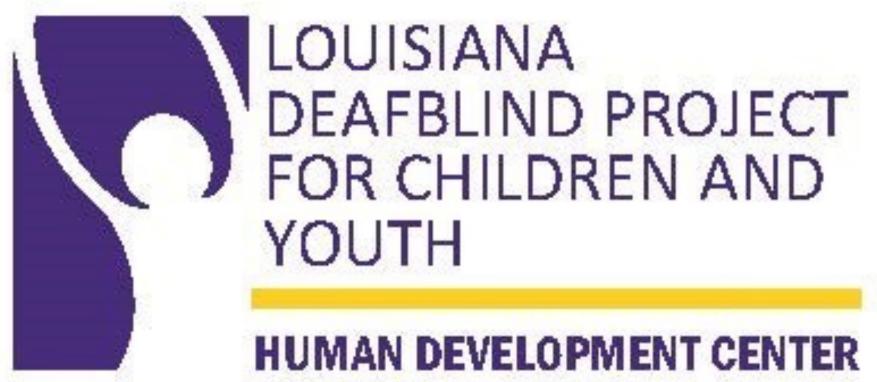




Usher syndrome was first reported n Louisiana Acadian patients in 1966. Because of founder affect, Usher type 1C is suggested to have a higher incidence in the Acadian population than the general American population. In addition, a few patients with Usher type 2 have been reported within the Acadian population

Honoring and celebrating the ethnic, cultural and geographic diversity of our citizenry while assuring equal access & opportunity to all continues to challenge communities across the United States.

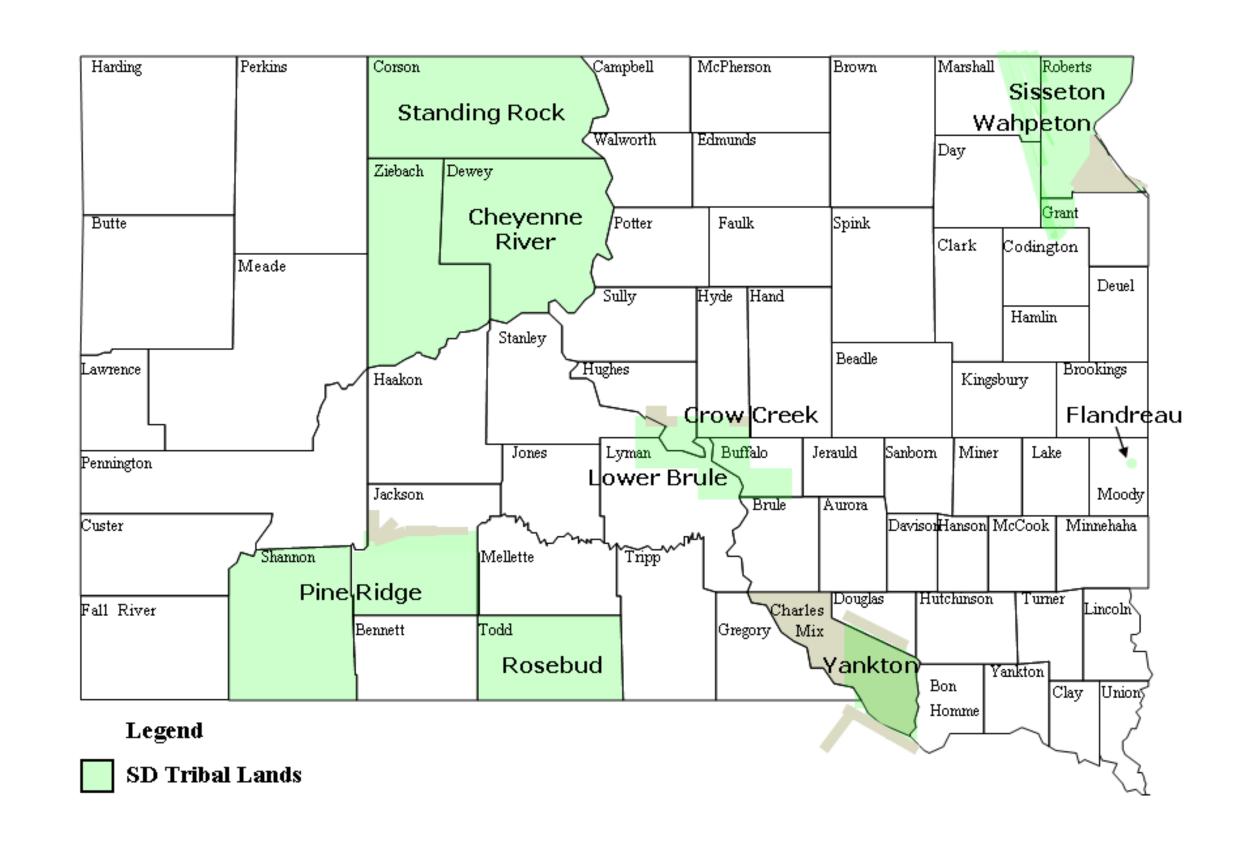
Assuring equal access and opportunity is the primary mission of the Louisiana Deafblind Project for Children and Youth.



DEAF-BLINDNESS BY THE NUMBERS



South Dakota is primarily a rural state which covers 75,811 square miles. It takes about 6 hours to go from the eastern to the western part of the state. There are nine reservations in SD. It's population of 869,660 people and is mostly comprised of Caucasian (84.9%), American Indian (9%), and Hispanic (3.8%). SD has a strong agricultural base and is a leader in the production of corn based ethanol. SD has a fair amount of tourism, being best known for the Black Hills and pheasant hunting. SD is known as the land of infinite variety, which is reflected in its weather, scenery, and economy.



Limited access to medical services and high poverty rates, especially in remote areas of SD, impact healthy pregnancies White 7.5 and are barriers to on-going medical services. This is especial-Black 8.2 ly true on reservation areas, resulting in some American Indian Hispanic 8.9 children (with severe disabilities) being served in a large resi-Asian/Pacific Islander 9.1 dential setting, far away from their families. American/Alaska Native 10.9



American indian: Prevalence American Indian

	Non-Al	ΑΙ	Significance	
Depression	5.14%	8.51%	0.02	
Anxiety	7.40%	8.60%	0.49	
PTSD	5.24%	13.34%	< 0.01	
Alcohol Misuse	42.51%	42.65%	0.99	
3 or more ACEs	17.40%	49.80%	<variable 0.01<="" td=""></variable>	
University of South Dakota				
Sanford School of Medicine				
Center for Disabilities Deaf-Blind Project				
Rose Moehring, Project Director				
Rose.moehring@usd.edu				
605-357-1437				



The SD Deaf-Blind Project serves 30 children who have combined hearing and vision loss. The leading known causes of Deaf-Blindness in SD are:

- CHARGE Syndrome
- Down's Syndrome
- . Prematurity
- . Traumatic Brain Injury

n

Disparity index State rank #25

In SD, the preterm birth rate among American Indian/Alaska Native women is 43% higher than the rate among all other women (March of Dimes 2012-2014).

Other Influencing Factors on Reservation Areas

Differences in prevalence between American Indian & non- Higher Rates of Mental Health Disorders (Depression, Anxiety, PTSD)

> Higher Prevalence of Alcohol Use - Related to Binge Drinking High Rates of Drug Use

> > Lack of Primary Care Provider

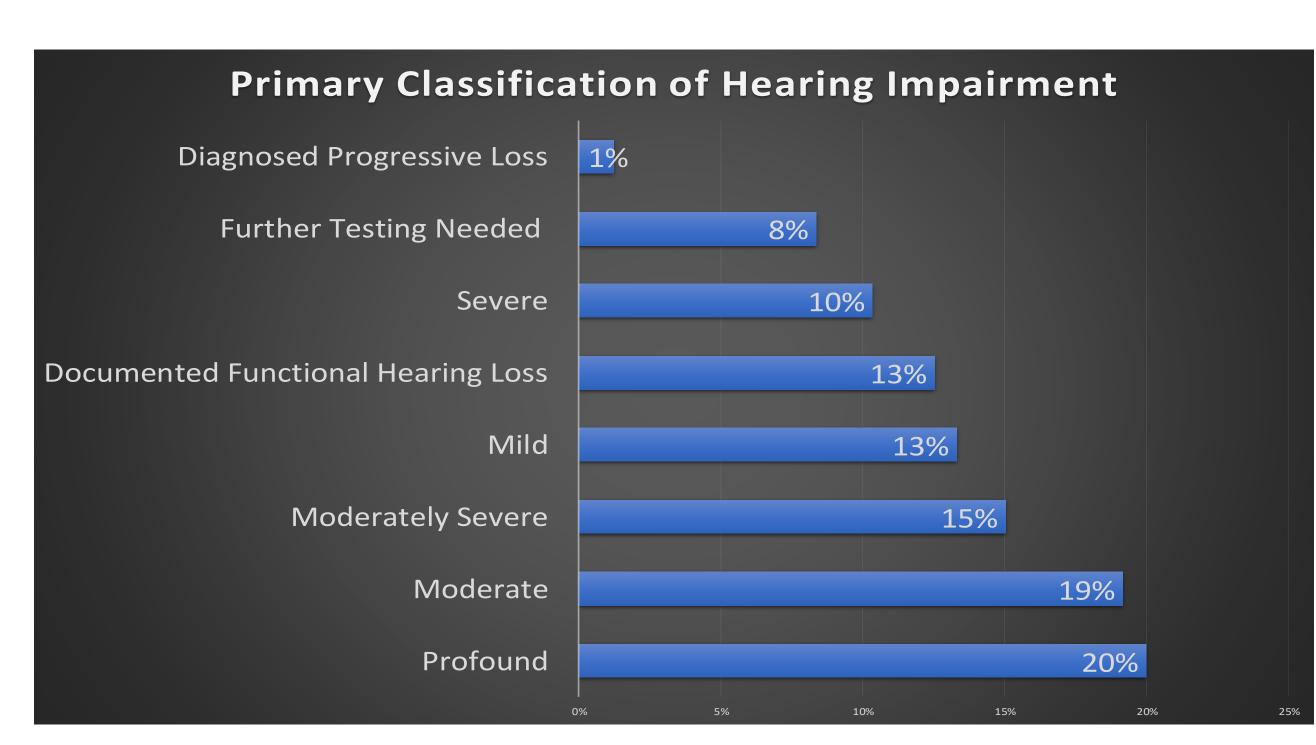
High Rates of Adverse Childhood Experiences

*A Focus on South Dakota: A Picture of Health

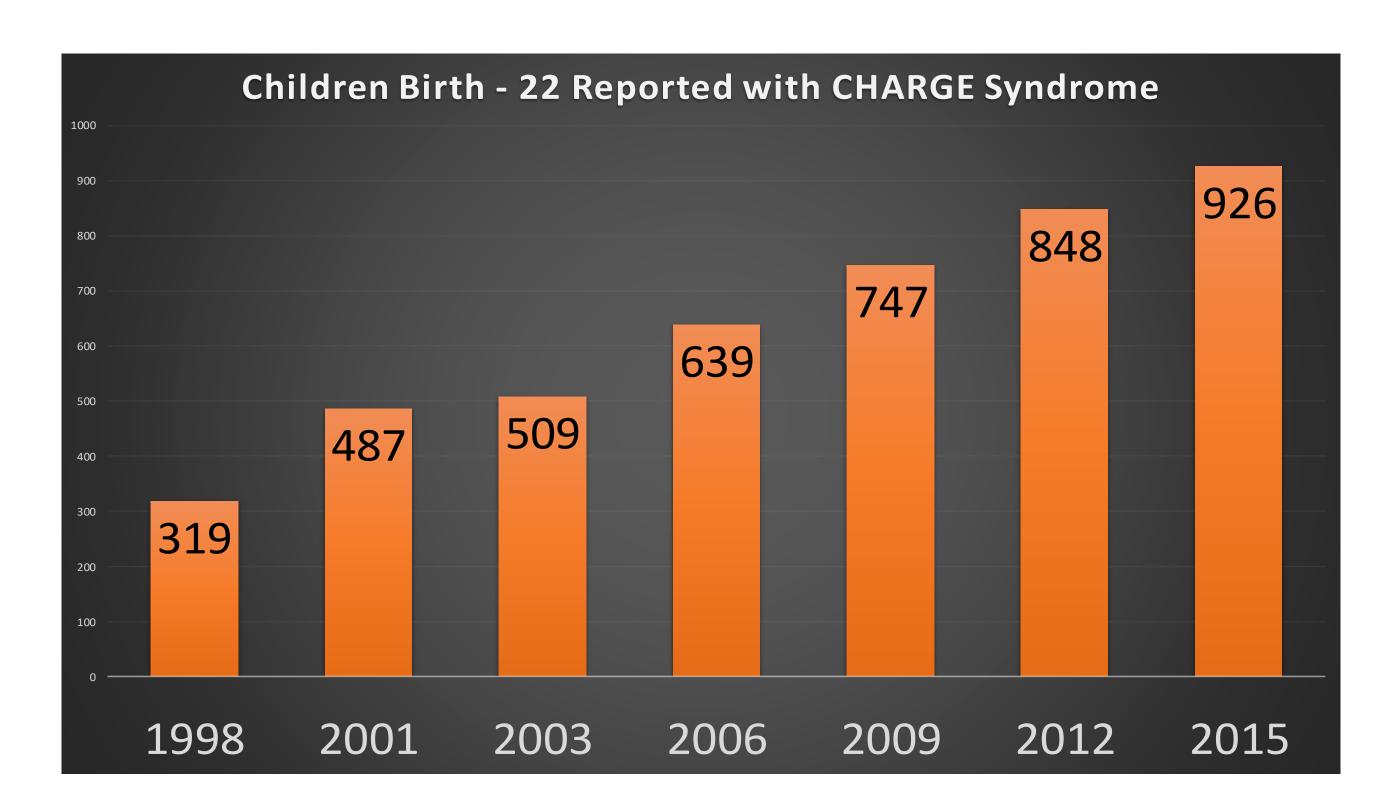
Helmsley Charitable Trust Report May 2016



National Child Count of Children and Youth who are Deaf-Blind, also commonly referred to as the Deaf-Blind Census, was initially requested in 1986 by U.S. Department of Education. It captures children who would be missed by OSEP's annual December 1 counts. Additional information collected includes classification of vision, hearing, additional disabilities, educational settings, assessment, and exiting information. In 2017, 10,000 children and youth were identified between birth and 21 years of age. Details and interactive maps available at nationaldb.org.



More than 70 specific etiologies were identified in the 2017 National Deaf-Blind Child Count, many exceedingly rare. The most prevalent are listed on the chart of Most Common Etiologies. About 19% of the children reported did not have a determined etiology. CHARGE Syndrome has been one of the fastest growing etiologies reported. As illustrated, the incidence has increased more than 290% since 1998.

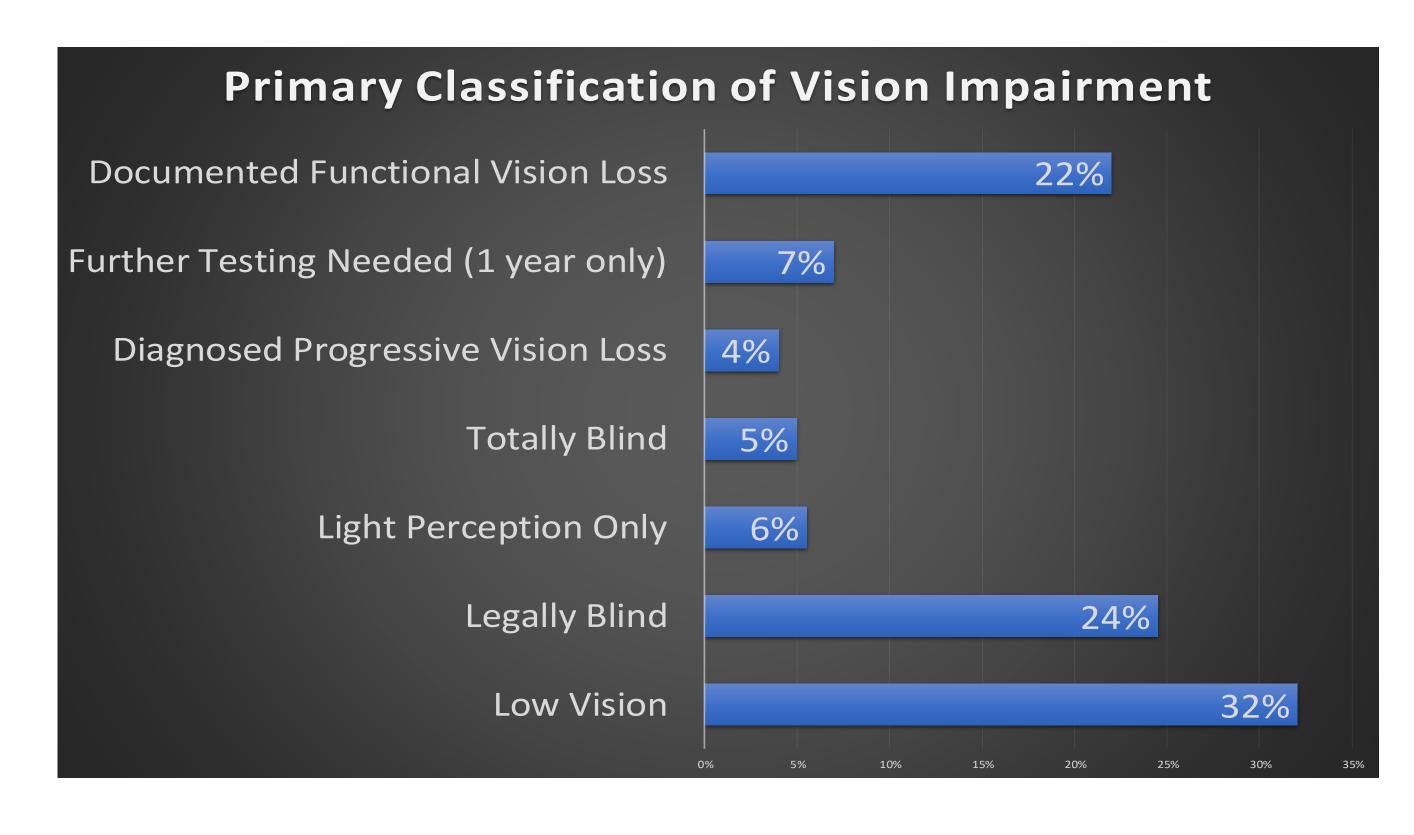


About 30% of children aged 3 to 5 are educated in a regular early childhood education setting for some portion of the day. Across the age span, over 60% of school-age children in special education receive instruction in a regular classroom in their local school at least a portion of their day. Over one quarter (26.1%) of students identified with deaf-blindness participate in statewide assessments tied to regular grade level standards.

NATIONAL



The population of children with deaf-blindness is diverse in many ways. They have varying degrees of vision and hearing. Only one percent have profound hearing loss and total blindness, whereas 99% have some residual vision and hearing. Almost 90% have one or more additional disabilities.



Most Common Etiolog	gies	Total Reported 201
Complication of Prematurity		1,047
CHARGE syndrome		933
Usher syndrome (I,II,III)		329
Down syndrome (Trisomy 21 syndrome)		315
Cytomegalovirus (CMV)		292
Hydrocephaly		214
Microcephaly		206

