

Dear Florida Early Steps Contact:

The Florida and Virgin Islands (FAVI) Deaf-Blind Collaborative (previously the Florida Outreach Project—FOP) is currently conducting the annual child count of children in the state of Florida with “deaf-blindness.” Deaf-Blindness is defined as BOTH hearing loss and vision loss (diagnosed or suspected).

Young children with any level of hearing loss combined with any level of vision loss are considered “deaf-blind.” In many young children with deaf-blindness, one or both of the sensory losses are suspected but not yet confirmed. Some young children with disabilities have sensory losses of neurological origin. Young eyes and ears may be physically functional, but sometimes the brain is not able to process visual and auditory signals appropriately. Infants and toddlers with deaf-blindness frequently have other disabling conditions, such as: global developmental delays, neurological conditions, intellectual disabilities (formerly called mental retardation), speech and communication delays, behavioral concerns, and/or physical disabilities. Children with diagnosed or suspected hearing and vision losses should be counted as deaf-blind, regardless of other disabling conditions.

A wide variety of etiologies are associated with deaf-blindness. Complications of prematurity are frequently associated with combined hearing and vision losses. Hereditary/chromosomal syndromes, such as CHARGE, Moebius, or Down syndrome, may put young children at risk for combined sensory losses. A list of etiologies associated with deaf-blindness is provided for your information. Any child with BOTH suspected hearing and suspected vision losses should be reported to the deaf-blind registry--whether or not the child's etiology is included in the provided list.

The FAVI Deaf-Blind Collaborative is mandated to collect demographic information on children with both vision and hearing losses from Part C programs. De-identified information on young children with deaf-blindness being served in Florida is then reported to the

federal government. By reporting to the FAVI Deaf-Blind Collaborative on infants and toddlers with combined hearing and vision losses, **you can help families to address sensory losses early and effectively.** Please help us to improve services to young children with combined vision and hearing losses **by reporting the most complete and accurate data available on young children with diagnosed or suspected hearing and vision losses.**

The FAVI Deaf-Blind Collaborative collects data from providers and reports data to the federal government using HIPAA-compliant and FERPA-compliant procedures (Please see <http://deafblind.ufl.edu/census>). 1) When you provide de-identified, HIPAA-compliant data, a child with diagnosed or suspected sensory losses can be added to the Florida deaf-blind registry. 2) When consent has been obtained from a parent or guardian, families and educational providers/teams are then eligible to receive training, consultation, and other assistance from the FAVI Deaf-Blind Collaborative.

All completed forms (attached) are returned to the FAVI Deaf-Blind Collaborative by fax (352-273-8539) or mail, as EMAIL IS NOT A HIPAA-COMPLIANT METHOD.

Please feel free to contact Shelly Voelker, Family & Education Specialist, at 352-273-7534 with questions or concerns about deaf-blindness, deaf-blind census reporting, or the services of the Florida and Virgin Islands Deaf-Blind Collaborative. We gratefully anticipate your assistance with our mission to ensure that all Florida infants and toddlers with diagnosed or suspected sensory losses are identified and served appropriately. Thank you.

Best regards,

Shelly Voelker, Ed.D.

Florida & Virgin Islands Deaf-Blind Collaborative, University of Florida

352-273-7534 or 800-667-4052

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