

## **CHARGE Syndrome: Technical Assistance (TA) for Children with Combined Hearing and Vision Loss (Deafblindness)**

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Most children with CHARGE syndrome have varying combinations of hearing loss and vision loss. This is referred to as deafblindness even when there is some residual vision and/or hearing. Children with deafblindness require distinct educational practices to assure that they reach their potential. That is, approaches used with children who only have hearing loss or only have vision loss are not sufficient. Even children with some usable vision or hearing will receive distorted or incomplete information through these senses. To benefit from their education, children with CHARGE require significant support and curricular modifications.

Most children who are deafblind are educated in their local school districts. Because deafblindness is such a low incidence disability, the local district may never have served a student who is deafblind and will lack the local expertise to do so. ***Technical assistance from both state and national Deafblind Projects are the primary way for local districts to get the training and support needed to effectively educate these children.*** Technical assistance is a process of linking and applying state-of-the-art knowledge & practice to the solution of a [developmental] problem. Technical assistance is designed to help clients develop or improve systems, organizations, programs and or products (NECTAC, 1989.)

The state and national projects focused on deafblindness support efforts to train both beginning and veteran teachers about the unique needs of students who are deafblind, about appropriate assessment and effective teaching strategies.

### **State Deafblind Projects**

- serve children and their families in each state. For help finding the project in your state contact DB-LINK (800) 438-9376) [www.dblink.org](http://www.dblink.org) [People and Programs tab]
- offer training, support and consultation to teachers, other educational team members and families
- work with State and Local Education Authorities to help them provide appropriate services for children who are deafblind
- often employ a Family Specialist to provide support and networking opportunities for families

### **National Consortium on Deaf-Blindness (NCDB) <http://nationaldb.org/>**

- works, nationally, to identify the needs of children and youth who are deafblind
- delivers an array of technical assistance to meet the needs of families, service providers and agencies

- strengthens the capacities of service providers and agencies serving children and young adults who are deafblind and their families
- increases the ability of families to effectively participate in their child's education
- links research-based practices to state and local service providers and families

**DB-LINK at NCDB** <http://nationaldb.org/ISDefault.php>

- Facilitates the sharing of information and practices between agencies, organizations and individuals
- Provides resources and personalized service to anyone needing information about or for children who are deafblind through a toll free number (800) 438-9376 and on the web
- Helps parents, teachers, and others by providing them with information to foster the skills, strategies and confidence necessary to nurture and empower children who are deafblind
- Identifies, coordinates, and disseminates, at no cost, information related to children and youth who are deafblind from birth through young adulthood