

## Speech and Language Therapy in CHARGE Syndrome

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Students with CHARGE syndrome benefit from speech and language therapy to expand their receptive/expressive language skills, social/pragmatic language skills and in some cases speech production skills across settings. Assessing and treating a student with CHARGE syndrome differs from typical evaluation and treatment protocols used by speech and language pathologists. It needs to be a team approach, ideally involving the classroom teacher, parents, teacher of the visually impaired, audiologist, occupational therapist, and physical therapist. The SLP needs to integrate the visual, auditory, sensory, behavior, and educational information for each individual student based on the assessments from the respective disciplines.

A **Total Communication** approach works best for these students. *Total Communication* means incorporating spoken language, vocalizations, objects, tangible symbols, body language, gestures, sign language, tactile sign language, photographs, line drawings (e.g., Mayer-Johnson picture symbols), and written text/Braille depending on the individual student's profile. The total communication approach should be used to convey information to the student and for the student to use *to communicate*. It should be stressed to parents that learning sign (often the easiest for a child to learn first) does not mean a child will not learn to speak – use every available means of communication!

The speech and language pathologist needs to look at the student with CHARGE syndrome as a whole person, taking into account structural, anatomical, and physiological characteristics of the syndrome, as well as the positioning, sensory needs and behaviors of the child. Many times a student is unable to attend and/or to carry out a task because of the features of CHARGE. This can be misconstrued as non-compliance or lack of understanding when it is neither. For example, when presented with a novel activity, the student may want to explore the activity on their terms and may not be able to follow the task requirements until the activity becomes more familiar.

The student with CHARGE benefits from **established routines**, where predictability helps decrease anxiety and thereby ensures better availability for learning. Working closely with the team will allow the speech and language pathologist to establish a positive rapport with the student and allow for maximum communication growth on the student's part.