

CHARGE SYNDROME

What is CHARGE Syndrome?

- A genetic condition caused by a mutation (i.e. change) in the gene CHD7.
- Occurs in approximately 1/10,000 births.
- Leading cause of deaf-blindness in the United states
- Difficulty in one or more of the following areas
 - Senses of hearing, vision, touch, taste, smell, pain, pressure
 - Motor skills and balance
 - Speech and language, learning
 - Feeding and swallowing, breathing
 - Behavior

What areas of communication are affected by CHARGE?

- Speech-how children produce sounds in their language
 - Children may have difficulty producing clear speech sounds due to differences in how the parts of their mouth and face are formed
- Pragmatics-how children communicate in a socially appropriate manner
 - Behaviors such as facial expressions, body language, turn taking, and initiating conversations may be affected
- Expressive language-what children “say”
 - Smaller vocabularies and difficulty forming sentences with the correct grammar (using verb endings such as past tense –ed)
- Receptive language-what children understand
 - Struggles with understanding concepts or following directions

Consequences of Communication Problems

- Needs and wants (e.g. preference for a certain object) may not be met
- Limited ability to interact with family and peers: social isolation
- Inappropriate behaviors



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Role of the Speech-Language Pathologist (SLP)

- Identify how the child with CHARGE communicates
- Define demands of the child's environment
- Specify most effective mode of communication
- Work with other professionals on the child's team (e.g. physical therapist, occupational therapist, audiologist, educator of the deaf, teacher of the visually impaired, and special education teacher)
- Educate family and team members about ways to communicate with the child

Classroom Modificaitons

- Set up face to face activities
- Assign different classroom staff to different areas of the room to provide a variety communication partners
- Provide consistent schedules and routines
- Label items in the classroom (Braille or large print as needed)
- Consult with the vision specialist and adapt materials as needed (e.g. make a prop box with objects to go with a story)

Communication Strategies

- Give child more time to process information
- Repeat information
- Provide short, simple, clear directions
- Be flexible in using multiple modes of communication
- Maintain interaction at an appropriate eye level
- Touch cues to start/stop conversation (e.g. tap on the shoulder)
- Alert child to your presence

For more information about CHARGE Syndrome please visit:

CHARGE Foundation: <http://chargesyndrome.org/index.asp>

National Center on Deaf-Blindness: <https://nationaldb.org>



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