

CHARGE Syndrome Information: Occupational Therapy (OT)

Anna Shinkfield, OTR/L

When working with a student with CHARGE syndrome, many of the typical occupational therapy treatments/strategies need to be altered or modified.

For example, it is beneficial for the student if sessions are set up with:

- A set routine from session to session
- A visual schedule [pictures or symbols] in order for the child to decrease anxiety and to anticipate what will come next
- Provide a “finish bucket” for the child to place the completed activities in
- Provide minimal visual and auditory distractions
- Set-up sensory breaks throughout the session

Every student with CHARGE is unique and requires a full team evaluation to determine what adaptations and modifications are likely to be most successful. Ideally, the full team would include parents, classroom teachers and aids, speech language pathologists, physical therapists, and other educational specialists. In addition, information provided by numerous medical specialists (e.g. ophthalmology, audiology, neurology, cardiology) should be available and taken into account. If possible, a behavior specialist should be part of the team. A behavioral specialist may offer suggestions for ways to set up the environment, as well as how to address any negative behaviors.

Some of the conditions present in CHARGE which might benefit from OT attention.

- bone and muscle malformations of the hand
- increased tightness and shortening of the muscles in the shoulder area
- low tone resulting in loose joints
 - difficulty holding a pencil or pen
- upper body hypotonia
 - tiring more quickly when compared to their peers
- decreased shoulder mobility (many cannot lift their arms above shoulder level)

These abnormalities may inhibit the child’s ability to complete many activities, including activities of daily living (ADL’s), finger spelling and signing, handwriting tasks, and other fine motor classroom activities. It is important to consider what is being asked of the child, and if they are physically able to perform that task. Knowing the limitations of each child is critical in planning activities for that child.

Another area that may need to be tailored differently for a child with CHARGE syndrome is the basic structure of their day. In order for them to be involved in their schedule, and to anticipate and be prepared for what comes next, try to keep to a set routine during the day and for therapy sessions. Collaboration with the SLP and other therapists is encouraged to incorporate the most successful means of total communication for setting up the schedule.