

Educational Needs of Children with CHARGE Syndrome

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Educating a child with CHARGE is very complex. When developing an educational program many components should be considered. These include the following topics:

COMMUNICATION

Most children with CHARGE have both vision loss and hearing loss (dual sensory impairment: deafblindness). Most benefit from a **total communication** approach. Total communication means incorporating anything and everything: gestures, simple signs, print/Braille, facial expression, symbols, and PECS (Picture Exchange Communication System) in addition to speech and sign language. The modes for each child are highly individualized and the entire team (including the family) needs to participate in developing and consistently instituting the plans.

SENSORY LOSSES AND THE IMPACT OF VISION AND HEARING LOSS

It is important for the team to take careful notice of the functional vision of the child as well as the hearing loss, the impact of hearing loss on communication and the total effects on day-to-day functioning. Determine the communication bubble! [The communication bubble includes how far out and how well a child sees and how far out and how well a child hears. It also needs to take into account things like lighting, ambient noise and other factors.] Many types of accommodations will likely be necessary in the educational setting and these should be written into the child's IEP. Consultation with vision and hearing specialists can be helpful in determining appropriate accommodations.

CURRICULUM

Curriculum should be challenging, and both age and content appropriate. Children with CHARGE are very capable. Due to communication challenges and delays in using expressive language, their overall cognitive ability is often, if not usually, underestimated. In fact, many children with CHARGE are very clever, have an impressive capacity to learn information, to retain ideas and to do well in academic subjects. They have specific learning needs, can benefit from specific teaching strategies and must be challenged through access to a highly motivating and flexible curriculum. They benefit from a curriculum that incorporates a variety of skills across a variety of settings. As goals are achieved, other skills can be added to enhance knowledge and growth.

ENVIRONMENTS

Children with CHARGE often require frequent sensory "breaks." Some types of break examples of breaks might include:

- bean bag chair
- soft cushion on the floor
- magazines and books in a comfortable space

- quieter room with low lighting; small space with three walls and comfortable seating
- swings of different types
- weighted blanket or vest

There should be adequate space within classrooms or nearby to ensure access for the child who needs time to relax, to do something that calms and allows time to be quiet (see article by David Brown). Fatigue can quickly overcome a child. The ability to take a quick “break” is critical for the child to be able to maintain a calm demeanor. A flexible schedule that allows for “breaks” is important; staff should be aware of “signals of behavior” and how to respond to the child; anticipation of the need for a break is a key to minimizing the behavioral outbursts and creating a successful educational environment for a child with CHARGE!

Physical environments can be arranged to motivate and intrigue the child with CHARGE. By having a flexible environment that can change and grow, optimal learning can take place. For example:

- Having a space that reflects the likes of the student, such as hanging pictures of their favorite people including characters can make the work or relax space inviting.
- Having some environments or spaces created with intriguing materials that peek the interest of the student can make learning fun.
- Rotate materials to keep the child interested and motivated.
- Using creative imaginative ideas can change an ordinary space into anywhere in the world. For example, the science area can become a space ship to our solar system.

TEACHING STRATEGIES FOR CHILDREN WITH CHARGE SYNDROME

As far as possible, these ideas should be integrated into all educational settings and across all environments:

- Strategies for structuring activities
 - Organizational skills – work in an organized manner (left to right, top to bottom), using checklists
 - Negotiation – allow the child to feel as if he/she is in control. Give a variety of choices as well as use first, then, strategies.
 - Sharing – foster peer-to-peer interactions. Encourage turn taking as a precursor for conversational communication.
 - Motivation – select activities that are interesting to the student. Use materials that are interesting and rewarding.
 - People preferences – give choices of WHO should do tasks/lessons with the student whenever possible.

- Partial vs. Full Participation – have the child do as much of a task or activity as possible to feel successful. Avoid setting up for failure by having an activity that has too many steps or is too long.
- Functional Activity – in all activities, ask yourself “will this skill or activity be useful in the future?”
- Modeling – engage the child by modeling the steps in an activity
- Choice making – allow for choices across settings. Let the child feel in control. Choices may be limited or guided, but must be offered.
- Age appropriate content/curriculum – all content and curriculum should be based on age and cognitive abilities. Don’t underestimate the cognitive abilities of these children! Both factors should be considered when planning.
- Active vs. Passive learning – alternating activities between quiet (sitting-desk work) and movement oriented (delivery jobs, getting things, physical education class, recess, etc.)
- Clear expectations/Limit setting – set clear, firm limits that remain consistent. Give the child time and opportunities to learn these expectations.
- Follow Student’s Lead – allow students to be leaders, watch and see what interests them. Incorporate these ideas into lessons.
- Natural routines environment – teach in environments in which activities naturally occur.
- Variety of exciting content – although routines and structure are important, keeping the content dynamic is critical for the student with CHARGE!
- Task analysis – break tasks into smaller steps that allow the child to feel successful.
- Sensory techniques
 - Awareness of hands/touch – allowing others to touch for signaling, (tapping) tactile signing, etc.
 - Signals: Verbal/Auditory/Visual – gesturing to gain attention, using voice or sound cue to gain attention
 - Prompt levels hand-under-hand – use an adults’ hand as guides under the child’s as a less invasive technique.
 - Sensory breaks – allow pause time during activities and in between activities.
- Timing
 - Beginning-middle-end – make sure all activities have a clear beginning, middle, and end that are at the student’s level of understanding.

- Structure and routine – having predictable schedules and routines play to the strength of the child with CHARGE.
- Pause time for response – WAIT, WAIT, WAIT, allow the child with CHARGE to respond in a manner they are most comfortable.
- Curriculum
 - Child centered curriculum – the child should drive the curriculum, the curriculum should not drive the child.
 - Expanding environments – some children with CHARGE need to start activities in “smaller” environments (less physical space or less cluttered). As they mature and grow environments can become bigger (physically) and more challenging.

What Every Student with CHARGE Needs to Know:

- Social Skills (how to be an effective communicator)
 - How to be a part of a group – as member that is accepted by the group
 - How to Negotiate – how to get their point across and know when to surrender
 - How to take turns & share – to take the appropriate amount of turns in a conversations—BE a listener as well as a speaker signer.
 - How to help out – be part of a family by doing chores. In school have school jobs.
- Cognitive Skills
 - How to be organized – work, think & execute in an organized manner
 - How to anticipate activities (calendar system) – know exactly when the order things will happen
 - How to cope with behaviors – know when & what to do when on “sensory” overload or stressed.
 - How to make choices – know that here are choices & the choices may be from a “set” group. Know that all choices are not possible at all times.

****See teaching strategies*****