

## Take CHARGE with Total Communication

### Pre-Submitted Questions and Answers

6/4/2024

1. **What is the best communication approach for CHARGE students that are hearing impaired (cochlear implants don't help hearing) and are low functioning?**
  - a. Consider **Active Learning** principles
    - i. An educational approach that emphasizes that individuals learn best through active participation, geared for early learners at the 0-48 month developmental level regardless of chronological age
      1. We need to adapt student's environments to give them access
    - ii. Activity and play help to engage the brain and encourage concept development
      1. Play is how children learn, make sense of the world, and explore - It's hard work!
    - iii. Encourage spontaneous attention by providing motivating activities
    - iv. <https://activelearningspace.org/>
  - b. **Foundational Communication Skills**
    - i. **Cause and Effect**
      1. Refers to the idea that an action causes a reaction. In this way, we realize we have an impact on our environment.
      2. Examples: Hitting a switch to turn something on; Signing "more" to get more chips to eat
    - ii. **Gestures**
      1. Actions, movement, facial expressions, and/or behaviors that are used with communicative intent
      2. Examples: Waving hello or goodbye; Turning head away to refuse food; Reaching out
    - iii. **Engagement**
      1. Displaying interest and maintaining/sustaining attention to an activity
        - a. Independently or with others
      2. Examples: Playing peek-a-boo with a partner; Clapping in unison to a song; Repeated or sustained playing with one object or material
    - iv. **Joint Attention & Social Reciprocity**
      1. When people have a common focus on an object, event, person, place, etc.
      2. Requires the ability to gain, maintain, and shift attention

3. Knowing how and when to initiate or respond to others' social interactions.
    - a. Via multiple modes, e.g., babbling, gestures, actions, facial expressions, words
  4. Refers to paying attention to people versus objects
  5. Examples: Child follows a parent's pointed finger in a picture book and shifts their gaze between the picture and his parent as if to say, "I see the picture too!"; Turn-taking during play, Conversations, Co-active movement
- v. **Initiation**
1. Unprompted and purposeful sending of a message to communication partner
  2. Examples: Intentionally grabbing a partner's hand and bringing it to a toy to request item; Reaching out and engaging with world around them; Independently obtaining a partner's attention and using a communication device to make a request
- c. There is no one size fits all! We believe in **Total Communication**
- i. **Accepting** any mode a student chooses to use to communicate (actions, vocalizations, sign)
  - ii. **Exposing** to multiple different modes of communication in case they pick up on one over another. Keep in mind that what modality they use to express themselves, may not be the modality they use to understand information.
  - iii. Typically we do start at presenting **whole objects** to students since those are the most concrete. They can see and feel the object if auditory is not their main mode or if they are deaf. Depending on how their understanding of objects develops we may move them to partial objects (more portable), photos, a device, etc! However, it is all student specific.
  - iv. We also use **sign language** and **tactile signs** when communicating with our students.

**2. Please show examples of what a day of total communication could look like for socialization in school and community.**

- a. Example: Social Group Time. If it is time for social group, the student will likely be presented with their schedule. This varies for each student, but in this example let's say their social group symbol is a puppet (whole object) which is an activity they often do during group. Then they arrive to social group and sign hello to greet the group. Then maybe they see a toy on the table and reach to take the toy. Then they may use AAC or shake hands to say bye to the group. Perhaps on the way back from group they sit on the ground and cry to express they are tired and need a break.

- i. In this example alone there are examples of these communication modalities the student uses: use of whole objects, sign, actions, gestures, AAC, vocalizations.
  1. This means they are a **multi-modal communicator** and benefit from Total Communication. Imagine if their teacher, SLP, family only ever verbally communicated with them and didn't give them access to object symbols, AAC, or sign. They wouldn't have been able to demonstrate any of the communicative skills they presented here! We want to give them the best chance at robust communication skills and may not be sure what they will pick up on the most so we expose them to all possible modes.

### 3. What are your thoughts on Pro Tactile ASL for the deafblind?

- a. Pro Tactile communication is a method to convey environmental information and emotions tactilely. As seeing and hearing individuals, we have the ability to take in other cues in our environment - what is happening around us - while we engage with something 1:1. For example, while I am having a dinner conversation at a restaurant, I am able to notice that someone at a far table is using their napkin, the set up of all the tables and waiters around the space, or the little child at a table next to me is crying. I can observe all of this incidentally, but I am still engaged with the conversation I am having. Pro Tactile communication allows a deafblind individual to experience all that is happening around them, just as the seeing/hearing person does.
- b. There is a level of cognition that is needed in order to understand and process the Pro Tactile information that is being transmitted - the individual has to have a sense of abstract language and be able to hold a lot of information at once, while maintaining attention to the task at hand. Pro Tactile also assumes a strong language foundation with social competencies, so all of these environmental aspects can be communicated quickly and with meaning. It is a reciprocal system as well.
- c. This is an **individualized consideration**.
- d. Additionally, we have to be mindful of tactile defensiveness, which could be part of an individual's profile, when deciding if Pro Tactile communication is the most appropriate for that student. Are there other methods that can capitalize on the tactile aspect of communication without making the individual uncomfortable?
- e. This should be explored more in our field. It could be a useful tool for some students, but we would like more research around the use of Pro Tactile communication with our student population who have varying degrees of cognition, language foundations, and memory. The benefits of explaining who is in the room using a tactile sense (or other modalities depending on what works

best for the individual) could potentially add a more understanding and social benefits for individuals with CHARGE.

**4. How could VOR affect visual ASL acquisition? What are some accommodations that could help with issues in this area?**

- a. The vestibulo-ocular reflex (VOR) keeps us steady and balanced even though our eyes and head are continuously moving when we perform most actions. When we make a head movement, our eye muscles are triggered instantly to create an eye movement opposite to that of our head movement at the exact same speed to readjust the visual world, which, in turn, stabilizes our retinal image by keeping the eye still in space and focused on an object, despite the head motion.
- b. Oftentimes, our students with CHARGE rely on this movement to sustain **visual attention**. We have students that experience VOR behaviors and still are able to access in-the-air signing, depending on the intricacies of the signs and movement patterns.
- c. It will be necessary to **collaborate** with OT, SLP, and TVI to decipher impacts of VOR on Sign acquisition.
- d. Some **strategies** to consider
  - i. Reduce the use of complex signs as needed
  - ii. Use tactile sign language to capitalize on other senses that can receive information.
  - iii. Incorporating Total Communication methods can support language development through a variety of modalities including visual learning for ASL in those with VOR behaviors.

**5. We would like help with developing expressive communication and expressive signing, but we have difficulty with stimming.**

- a. “Stimming“ is a natural expression of self-regulation and can serve various purposes, such as managing emotions, releasing energy, or promoting concentration.
- b. Consider consulting with an **Occupational Therapist (OT) or a Behavior Specialist (BCBA)** to discern the motivation behind this behavior (sensory, seeking, babbling, releasing energy, etc.). Then the team can come up with a plan to address that while providing access to functional communication.
  - i. This could mean using a more total communication approach, like incorporating other AAC systems.
- c. It is always best to **model and allow for individual exploration of signs and AAC**. This is all part of the learning process. Sometimes individuals may need

to perform the same action multiple times to build memory and motor planning memory.

- d. Consider communication temptations
  - i. Find what is highly motivating to them and place it somewhere out of reach or in a box where they need to symbolically request help or the name of the motivating item to receive it.
  - ii. This will be key in fostering the understanding of cause and effect of communication and could promote the functional use of signs or other communication modalities.

**6. Our son uses Total Communication and does not have an ASL interpreter in school—he has had an IT in the past, is this important?**

- a. This is a very **individualized consideration**. Some questions to ask would be:
  - i. Does he receive and understand language when presented ASL?
  - ii. Is ASL a beneficial supplement to how he is receiving his information?
  - iii. What has he shown to prefer or respond more to - ASL, Verbal Speech, Visual AAC methods, Combination, etc.
  - iv. At what level is the signing ability?
    - 1. For example, can ASL be supported with the SLP or aids through training because the individual's language levels are at the 1-3 word phrases, and they rely on total communication, rather than ASL alone.
  - v. Has the Intervener (IT) been helpful in the past? Would that support be necessary?
    - 1. An intervenor facilitates the interaction of the person who is deafblind with other people and the environment. The intervenor provides information about the environment and what is happening (using receptive language through ASL), assists the individual who is deafblind to communicate (using expressive language through ASL), provides or develops concepts where necessary, confirms actions, assists with life skills and most importantly, assists the individual to achieve as much independence as possible within their situation.
    - 2. It will also be important to consider how independent and autonomous the individual can be with an Intervener. Another aspect to think about is that if the individual is really accessing total communication, an Intervener may not be the best to support development of communication and language, given the need for multimodal communication systems. Interveners typically use only ASL.

- b. It is likely important to have access to sign language in some capacity - We would want to be **cautious about visual abilities** and access to pure ASL by the Intervener or others. ASL is a visual language that relies on subtle body movements and facial expressions to convey messages and grammatical markers. Would maintaining a total communication approach be more appropriate with Signed English paired with verbal speech (so signs match the verbal speech in word order and grammar)?
- c. Depending on the level of proficiency, it may be beneficial to list ASL as the primary language on the Individualized Education Program (IEP) so you can advocate for an ASL interpreter or staff training.

**7. How to know when, if ever, to stop ASL support when the school team says the student can “hear”?**

- a. We want to provide access to a **total communication approach** so individuals can use a variety and preferred modalities to understand and express language. The team should have on-going consult with the SLP and Audiologist in addition to educators and family. We want to take into account the individual's motivation and ease of access. It will be important to consider what mode they use receptively, but that may not be what they use expressively, so we may need to keep ASL to support expressive and/or receptive language development.
- b. A question we would want to know is, how much ASL is the individual picking up on? How responsive are they to the signed supports?
  - i. We have students with functional hearing who use ASL for a variety of reasons: preference, ease of access, comfort, efficiency, etc.
- c. Above all, we want to **follow the individual's lead!** Have they reduced their signing and are more verbal? Have they expressed in some way that they no longer want to sign?

**8. How to integrate total communication when our SLPs don't support it**

- a. A place to start would be to educate the SLPs and team members on understanding the **impacts on learning that sensory processing challenges have** for individuals with CHARGE; specifically, what senses are challenged and what senses can be capitalized on to experience the world around them.
  - i. Individuals with CHARGE **experience sensations differently**
    - 1. Five senses
    - 2. Proprioception (awareness of body in space and in motion)
    - 3. Vestibular Sensation
    - 4. Interoception
  - ii. Impacts how individuals interact with the world around them
    - 1. **Incidental learning** (learning by observing) is often limited and

students rely heavily on **experiential learning** (learning by doing) which is more functional for them

- iii. Energy levels may fluctuates
  - 1. Individuals may not know what exactly is wrong, and can't effectively communicate this, so it can be a difficult communicative task to teach - they may not have the feeling OR they do not know what the feeling is, what caused it, and problem solving and how to communicate this
- iv. An important task for SLPs will be to figure out how to address this skill so individuals can build self-advocacy skills.
- v. Consultation with the **Occupational Therapist (OT)** will also be crucial to understand the individual's sensory processing needs and how to support them in communicating about it, and for maintaining comfort.
- b. It will also be imperative to educate the SLPs and team members on understanding the **impacts on learning that behavior challenges have** for individuals with CHARGE
  - i. Often Times it is the very strong feelings that are conveyed through unwanted behaviors - I don't like/want, I'm too excited, I need help, you're not understanding me, I'm hurt, this isn't what I'm used to
  - ii. BCBA's maintain safety in the moment first, then work with SLP to create plan for functional communication of these emotions
    - 1. What is the **function of the behaviors**
      - a. Attention Seeking
      - b. Escape
      - c. Tangible Gains
      - d. Sensory Seeking or Aversion
- c. The next step would be to educate the SLPs and team about what is **Total Communication** in general and why it is needed to support communication of sensory and behavioral impacts
  - i. Total Communication is using and honoring a combination of verbal speech, sign language, symbols (picture symbols or tactile symbols), meaningful use of whole objects, facial expression, communication devices, print/braille, and more.
  - ii. Since Total Communication is individualized to fit the expressive and receptive needs of an individual, it is more of a philosophy rather than a methodology (i.e., it may look different for everyone).
  - iii. Total Communication is an "all hands on deck" approach to learning language

## 9. How we can improve communication in kids with CHARGE?

- a. Hopefully our presentation answers this question!

**10. What recommendations do you have for working with a pre k student with CHARGE?**

- a. Please refer to our answer for Question 1, and hopefully our presentation will answer this!

If there are other questions, please feel free to reach out to us. We'd be happy to talk through them!

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