

MANY WAYS TO HAVE A CONVERSATION

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Background

This topic was presented at the 10th International CHARGE Syndrome Conference in Orlando, Florida, in July 2011. This is a modified article as the original presentation included several video clips.

This article demonstrates that students with CHARGE can have meaningful conversations in unique ways. Four case studies are presented, each illustrating that every child learns to communicate in his or her own distinctive manner. There are common strategies and modes that each child can access.

The message throughout is that regardless of age, cognitive level, and degree of hearing and/or vision loss, the use of Total Communication (multiple modes) is critical to the development of language and communication. It is the responsibility of the team (professional staff and families) to assess and to make a determination about the primary modes of communication to be used by all members, keeping in mind the primary needs of the child.

Total Communication

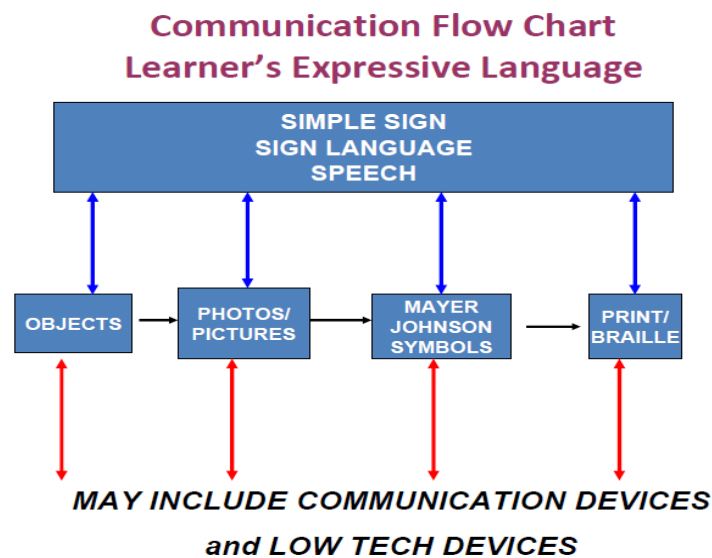
The children in the Deafblind Program at Perkins School for the Blind have access to Total Communication as part of the overall philosophy of the Program. Total Communication, as implemented by the Program, is defined as:

The use of any means of communication—sign language, speech, fingerspelling, lipreading, writing, gesture, pictures, and/or objects—to assist people in the learning of language and to encourage their communication.

Given the nature of the children in our Program, we have expanded the definition to include a larger continuum of communication modes that our students can access, including technology.

Through observation of many children with CHARGE syndrome in the Deafblind Program, we have seen that these students can develop ways to communicate. In some cases, students have developed their own unique communication style; others need more support and structure to foster spontaneous and more formal communication. We have also observed that all students with CHARGE learn to communicate using components of the Total Communication definition. Some students' communication is delayed, and therefore they do not communicate at the expected developmental level. We know that if we are persistent and consistent, then students can learn over time and become more formal communicators.

As you will see from the tables that represent each student's communication level, they do learn and they do communicate. It seems that the use of a visual system supports the learning of sign language and its subsequent use over time. In addition, some students maintain the use of a visual system simultaneous to using sign language.



This flowchart represents the expressive modes of communication that are typically used with children with hearing impairments and children with CHARGE syndrome. It appears through observational data that many children with CHARGE also benefit from additional supports. As you can see from the chart, this can include objects, photos/pictures, Mayer-Johnson symbols, line drawings, print or Braille, and more recently, an array of technology options.

Technology is an added component and can include a variety of communication devices such as voice output, an iPad using a variety of applications, etc. More recently, we have introduced the iPad for specific use as a communication tool.

Case Studies

The following case studies demonstrate a developmental progression where the progression is delayed. Some students use speech, and their language development follows a more typical progression. We have observed that although students with CHARGE follow a progression, it is individualized and therefore the modes of communication are also individualized.

Case Study #1: EF

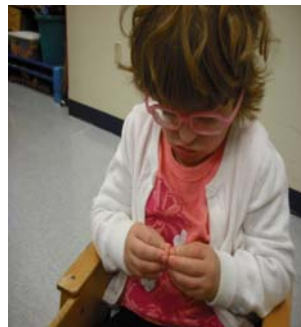
Overview

- EF is 4 years old and has been in the Deafblind Program for 2½ years.
- EF has bilateral profound sensorineural hearing loss. She is legally blind and has bilateral optic nerve colobomas.
- EF is developmentally delayed.
- EF participates in a preschool curriculum.

EF's Total Communication

EF uses Total Communication:

- To label an object
- To reject and accept
- To get information and talk about a book/literacy
- To indicate the beginning and the end (finished)
- To express an emotion
- As a part of her calendar system



COMMUNICATION PROFILE: EF

| | RECEPTIVE | EXPRESSIVE |
|--|--|---|
| Speech | Mimics vocalizations (vocal play) | <ul style="list-style-type: none"> • Attempts initial sounds in words • Uses vocal phrases with varying intonation (social exchanges) |
| Gestures | Responds to gestures | <ul style="list-style-type: none"> • Uses body language to make requests (help) • Attempts to mimic body movements |
| Simple Sign | Responds to locatives (in, out, on, off) | <ul style="list-style-type: none"> • Imitates hand and body movements during social interaction and song • Attempts signs when modeled |
| Sign Language | <ul style="list-style-type: none"> • Demonstrates understanding for action sign words (sit, give, eat) • Knows the meaning for many signs (schedule, words, objects, name) | Has emerging sporadic sign language |
| Objects | Objects paired with sign increase understanding | Selects objects from field of two to match with a picture |
| Photos/Line Drawings/MJ Symbols | <ul style="list-style-type: none"> • Uses photos paired with object symbols in schedule • MJ symbols enhance main idea in literacy activities | <ul style="list-style-type: none"> • Currently working on choosing MJ symbol to label main idea in books • Chooses MJ symbol to match with object in circle |
| Print/Braille | <ul style="list-style-type: none"> • Access to print in books • Enjoys tactile books and pre-Braille books | <ul style="list-style-type: none"> • Introduction to upper- and lowercase letters • Access to books with variety of elements |

| | RECEPTIVE | EXPRESSIVE |
|------------|--|---|
| Technology | Cause/Effect games on touchscreen computer | <ul style="list-style-type: none"> • Uses switches for literacy repeated • Story time |

EF demonstrates joint attention with sustained eye contact when she is physically supported and when the topic is highly motivating to her. EF is supported during her literacy activity/book reading, seated in a Rifton chair with a boppy pillow across the front of her body. This helps her to feel secure, be well supported, and protects her when she attempts to either bang her elbow or hit her head. The pillow also serves as a place to rest her arms. Given these supports, EF can focus on the activity of reading the book. Several self-regulation strategies are in place in order to assist her with these behaviors.

In lieu of the video, the scenario is described below.

EF is participating in a literacy activity with a peer. She is seated in a chair that offers her maximum support so that her posture is appropriate and, as a result, her hands are free to sign, to turn the page in the book, and to match objects to pictures in the book. The teacher who is reading aloud includes the use of simple sign language with close attention to labeling objects, use of verbs, and expression. EF is able to generalize her language and communication skills to book reading.

At the beginning of the scenario, EF has her head on the table; she is listening to the teacher reading aloud. The book is *The Very Hungry Caterpillar*. EF shows that she knows the book by her facial response when she is shown the book. When it is her turn, the teacher signs, "EF...your turn;" and begins to read and sign the next page in the story.

EF is asked to imitate the sign for "apple." She does so with some accuracy and then reaches out for the object "apple." She then is asked by the teacher to find the "same." She holds the apple and, with support, puts the apple on the picture of the apple in the book. At this time she is told it is "X's turn." She sits back and watches the pages being turned in the book. When her peer has taken his turn, the literacy activity is "finished" for the day.



EF is told the book is “finished,” and she is shown the “finished” bucket. She places the book and the apple in the “finished” bucket. She then approximates the sign for “finished.”

The teacher simultaneously uses her voice and sign language as well as a visual system of pictures for EF. This is a good example of Total Communication used successfully as part of a literacy activity. The focus is literacy, but the communication is a conversation about the story.

Case Study #2: DS

Overview

- DS is 8 years old and has been in the Deafblind Program for 2½ years.
- DS has colobomas, a profound hearing loss, and a cochlear implant.
- DS is developmentally delayed and has access to an Early Academics curriculum.

DS’s Total Communication

DS uses Total Communication to:

- Get information about his schedule
- Have a conversation about his calendar/schedule system
- Indicate a preference/make a choice
- Express an emotion (happiness about the next activity)
- Access an iPad to express choices, my turn/your turn, and more to continue an activity, and uses sign language as well as speech

COMMUNICATION PROFILE: DS

| | RECEPTIVE | EXPRESSIVE |
|----------------------|---|---|
| Speech | <ul style="list-style-type: none"> • Clothing items • Door • Open/closed • On/off • Bathroom • Stand up • Sit down • Take • Responds to Ling sounds | <ul style="list-style-type: none"> • Vocalizes • Imitates |
| Gestures | <ul style="list-style-type: none"> • Follows • Points | <ul style="list-style-type: none"> • Points • Moves adult hands • Uses facial expressions |
| Simple Sign | | Imitates new signs |
| Sign Language | <ul style="list-style-type: none"> • More • Finished • Help • Sit/stand • Eat/drink • Hello/goodbye • My turn • Bathroom • Books • Thanks • Medicine • Shoes • On/off • Pay attention | <ul style="list-style-type: none"> • More • Finished • Help • Sit/stand • Eat/drink • Hello/goodbye • My turn • Bathroom • Books |
| Objects | Uses object for support | Makes choices using objects |

| | RECEPTIVE | EXPRESSIVE |
|--|---|---|
| Photos/Line Drawings/MJ Symbols | <ul style="list-style-type: none"> • Schedule is combination of MJ symbols and photos of therapists • Sequence boards with MJ symbols | Makes choices using pictures and MJ symbols |
| Print/Braille | Print exposure on all schedule pictures and literacy activities | |
| Technology | <ul style="list-style-type: none"> • Cochlear implant • iPad | <ul style="list-style-type: none"> • Touchscreen computer and BIGmack switch for computer • Recently introduced to iPad |

DS has a receptive vocabulary of approximately 20 words. He is also developing an understanding of a larger variety of symbols. He communicates using the signs that he knows in context of an activity. He also uses communication boards that are made up of Mayer-Johnson symbols. He is able to point to the symbol representing what he wants. He does not yet use signs in a conversation. He has joint attention when both pictures and signs are used with him. His self-stimulatory behavior can interfere with joint attention. Through observation, he does better when both the sign and symbol are used simultaneously and when the communication “look at me” is emphasized. He demonstrates a happy face when his communication has been understood and reinforced.

In lieu of the video, the scenario is described below.



DS is shown using his portable calendar system. The teacher bends down to DS’s eye level for eye contact. She signs and verbally tells him, “X is finished.” DS then places the activity symbol on the back of his book, placing it in an envelope (similar to the “finished” bucket). The teacher then shows him the next page of his calendar system, and signs and says, “It is time for arts and crafts.” DS looks at the photo, takes a few minutes to respond, and then moves in the direction of the arts and crafts table. He has a strap on his

portable calendar system, which he places on his shoulder. He then takes the system to the next activity independently. The activity is in the same room, and he is able to go without staff support.

Case Study #3: MM

Overview

- MM is 12 years old and has been in the Deafblind Program for 6 years.
- MM is legally blind as a result of colobomas and has profound hearing loss.
- MM has a moderate level of intellectual delay and participates in an Early Academics curriculum.

MM’s Total Communication

- Sign language
- Gestures
- Facial expressions
- Mayer-Johnson symbols in a communication book format with simultaneous use of sign language and gestures

COMMUNICATION PROFILE: MM

| | RECEPTIVE | EXPRESSIVE |
|--|-------------------------------------|---|
| Speech | Deaf | N/A |
| Gestures | Understands basic gestures | Understands basic gestures to make his needs known |
| Simple Sign | Simple sentences | Alphabet, numbers |
| Sign Language | Understands approximately 100 signs | <ul style="list-style-type: none"> • Signs a few simple “want” sentences • Less than 50 words |
| Objects | Uses objects for support | Makes choices using objects |
| Photos/Line Drawings/MJ Symbols | MJ symbols and photos of people | MJ symbols and photos, usually prompted (given choices) |

| | RECEPTIVE | EXPRESSIVE |
|---------------|---------------------------------|---|
| Print/Braille | Understands about 100–200 words | Uses about 50–100 words (schedule words, colors, numbers, days of week) |
| Technology | Uses PODD computer | Emerging use of PODD in conjunction with iPad |

In lieu of the video, the scenario is described below.

MM is using his calendar system, which is made up of Mayer-Johnson symbols. MM develops his own schedule from a model and places the symbols and printed words in the correct order in his calendar. The photo demonstrates the form of his book. The skills he uses include reading both the print and the symbols and then identifying them with the master schedule. He also works in a highly organized manner, going from left to right and making sure that all of his symbols are lined up precisely. Once this process of developing his daily calendar is completed, he proceeds to the next activity. MM is independent in regard to following his schedule within the classroom area. Once he leaves the classroom, he needs support because people in the hallway, shapes he likes to explore, and the general busyness of a hallway easily distract him.



MM has a very strong receptive sign language vocabulary. He does not use the signs he knows as part of his calendar system without the support of the visual system. Once shown the visual system, he will sign the name of each activity. He will sign spontaneously or imitate the signs, but he does not typically use a two- to three-word utterance without the support of the symbols or without prompts. MM is a good example of an impressive ability to read, understand context, and demonstrate independence in the implementation of his calendar system. He continues to learn new signs and new concepts but continues to need visual supports for success in communication.

MM has had consistent access to sign language paired with MJ symbols, photos, and line drawings. His use of spontaneous sign language continues to be well below his receptive comprehension. He has joint attention but prefers symbols to faces. He has access to a complex communication book that has layers of MJ symbols. He uses this book with ease and knows the location of topics, quickly finds topics, and communicates clearly what he wants to say. We hope that exposure to an iPad will assist in the development of his overall communication.

In addition, MM will imitate or “label” the sign once the visual system is available to him. MM has demonstrated that he is a very successful visual learner in all areas of the curriculum. He is very interested in complex shapes/geometry and creates complex visual images using the computer software program Clicker Draw.

Case Study #4: WE

Overview

- WE is 17 years old and has been in the Deafblind Program for 12 years.
- WE has profound hearing loss and vision loss.
- WE has moderate/severe intellectual challenges.

WE’s Total Communication

WE uses Total Communication to:

- Talk about his experiences in the community
- Describe his experiences in great detail using gestures and sign language
- Take turns in conversation
- Continue the conversation through gestures and signs [e.g., Can I talk about the other favorite topics that I like (that were not part of the experience)?]

COMMUNICATION PROFILE: WE

| | RECEPTIVE | EXPRESSIVE |
|----------|---|---|
| Speech | | N/A |
| Gestures | Understands gestures, mime storytelling | Uses gestures to tell stories, acts out/mimes |

| | RECEPTIVE | EXPRESSIVE |
|--|---|---|
| Simple Sign | | Will use what he knows when trying to recall a sign |
| Sign Language | Able to understand sign except for fingerspelling | <ul style="list-style-type: none"> • Signs very well • Struggles to answer questions • Often talks about preferred topics (e.g., Disney, Garfield) |
| Objects | | |
| Photos/Line Drawings/MJ Symbols | Uses MJ symbols for new or unfamiliar activity paired with a word | <ul style="list-style-type: none"> • Uses choice boards to make choices or to order food • Uses communication cards |
| Print/Braille | Basic familiar sight words | Print with symbol support |
| Technology | iPad for community communication | <ul style="list-style-type: none"> • Computer for communication • iPad for community |

WE has had access to a Total Communication approach since his acceptance into the Deafblind Program. He used gestures, mime, and simple signs to communicate and to describe and tell stories. As he expanded his interest in characters and his social skills, he began to draw and to use MJ symbols to tell his stories and to communicate information.



At this time WE uses almost all of the modes defined in Total Communication. He continues to “fill in” language through use of pictures, gestures, and body language. He is an effective communicator, with sign language now his first mode with supports from additional modes. WE is beginning to use an iPad to inform his communication partner of his choice (food, activity, etc.) He is also trialing its use with employers and community-based communication partners to communicate using a visual system as well as sign language.

Conversation Format: Conclusion

- Each child is an individual learner.
- Each child develops a way to communicate (use of symbols, sign language, speech).
- Each child uses Total Communication in his or her own unique way.
- Many children benefit from a combined system of sign language paired with a symbol system as part of their communication and use these modes for a lifetime.
- New technology can support the development of communication for many children with CHARGE syndrome.

For questions or more information on this topic, please contact:

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