

**W**hen you want to be understood by those around you, you share with them. Often, individuals with disabilities have a harder time sharing their world. Augmentative and Alternative Communication (AAC) can open a door for them. AAC includes any form of communication other than oral speech. In fact, we all use it in some form throughout our day, by making gestures, facial expressions, writing and other non-verbal means of getting our needs, thoughts and feelings across to others.

### “HOW CAN I TELL YOU THAT I AM NOT STUPID?”

**Chaya Rosen**

Yisroel is a bright child with typical intelligence. He knows just what he wants to say, but because of his severe apraxia of speech, he cannot. Lacking the ability to successfully coordinate his oral muscles, Yisroel developed an intricate sign language of his own. With patience and love, his family learned his signs. Yisroel was successfully able to convey many of his needs and emotions, opening a window to his world.

Later on, in school, Yisroel learned how to use a computerized assistive communication device. The family reached out to a local organization that lent the family the expensive device, so that Yisroel could communicate at home too. “At the end of the six-month period, when I went to return the device, I told the staff that I felt like I was returning my child’s mouth,” shares Yisroel’s mother. In the interim, Yisroel reverted to communicating fluently in “Yisroel” sign language.

“It was an adjustment for us to go back to using a device,” says Yisroel’s mother when they finally receiving insurance funding for a communication device. But it was simple to personalize, and now Yisroel can describe events, identify people, places and things and communicate with others. He uses complete and grammatically correct sentences and navigates the device completely on his own. “He prepares sentences before making a phone call and often delights his grandmother with telephone calls during which he can share anything with her, using his trusty tablet.”

“Of course, I removed any boards that were not appropriate,” relates Yisroel’s mother with a wry smile. “Yet I left a board that contained some ‘insulting’ words, as I wanted him to be able to express himself as all children do. Recently, I came home to find Yisroel chasing his older sister with his tablet in hand, repeatedly pressing a particular insult. But I was glad he was able to communicate in that way.”

Yisroel uses his tablet at school to answer his teachers, but unfortunately does not often use it with his peers. “His friends do not have the patience to wait for him to formulate sentences on the tablet. It’s especially difficult to expect them to listen to him while they are playing sports and running around, as ten-year-old boys often are,” explains Yisroel’s mother.

Yisroel is an independent young man, who goes on errands, shops at the grocery store, and rides buses alone. He does not always take his tablet along with him. He makes himself quite understood with his hands and facial expressions. “The difficult part is having people treat him like a baby, or talk down to him. They smile at him, pat his head and speak slowly. That’s unnecessary.” Yisroel’s mother sighs.

“Communication is the Essence of Human Life”

Janice Light

## COVER STORY

### INFORMATION ABOUT AAC

#### WHO USES AAC?

According to the American Speech-Language-Hearing Association (ASHA) more than 2 million people in the United States have a severe communication disorder that impairs their ability to talk. With correct training and guidance, AAC can be used for individuals with a wide range of special needs who struggle with speech delays or communication disorders.

- Cerebral Palsy
- Apraxia
- Autism
- Developmental Delays
- Down Syndrome
- Brain Injury

#### HOW DO I KNOW WHAT IS BEST FOR MY CHILD?

The options available today are as widely varied as their users. They range from no-tech to low-tech to high-tech and can be used at home, in school and on the road.

#### LOW-TECH AAC

**Picture or symbol cards, boards or books.** They can be personalized with actual photos of places, people and things in the child's life.

**Signing and gesturing.** This portable mode of communication has a downside because caregivers and family need to “translate” for strangers

**Speech buttons, boards or devices.** A speech button can be programmed to say a certain word when pressed, like “yes”, “no” or “more”. When used with a board then the button pressed under the photo of his friend can say “May we go visit Yitzy?”

#### HIGH-TECH AAC

**Computers, iPads and Apps.** Various communication devices and programs that use the same principles as boards and can be customized in myriad of ways.

**Speech Generating Devices.** Communication can be typed or a “talker” can be activated and controlled by moving the cursor with eye gaze, head pointing or use of a switch.

*A list of AAC Information Websites, helpful Facebook pages and You Tube Channels are available from A Voice Discovered. This Non-Profit Organization was started in 2013 by Traci Peplinski, a speech and language pathologist specializing in working with people with complex communication needs.*



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## A SIGN OF LIFE

Chaya Rosen

It was dinner-time. Children of various ages sat around the table, with spills, arguments, and some eating all going on. Eli, who has Down syndrome, was quietly eating his dinner. Eli always was a quiet little boy – along with the Down syndrome and accompanying speech delays, Eli also had moderate hearing impairment and was scheduled to be fitted for his first pair of hearing aids.

Suddenly a distant roar came from the open window. Our neighbor had probably started mowing his lawn, as he tended to do in the evening. No one paid much attention.

No one, that is, but Eli. He leaped to his feet and started signing excitedly. *Motorcycle*, he signed. *Motorcycle*.

Instantly we all grew silent, with only the roaring breaking the stillness. We stared at Eli and then at each other. “Within a few moments, my mother and I had erupted in tears and were both covering our Eli with hugs and kisses,” shares Leah, Eli’s sister. “Despite the fact that he was two years old and non-verbal, Eli had communicated with us. It was a wondrous moment.” At that second, they had realized that Eli, even though he did not yet inhabit the world of spoken words, was a person – a thinking, hearing, feeling person, who listened to the world around him despite his hearing impairment and made connections, and wanted to communicate them.

“We began signing with Eli when he was about 6 months old. It took a very long time until he caught on. We would show him Baby Einstein signing clips on the computer and practice the signs over and over and over again.” Leah says. Once Eli was a year old and started daycare, they signed with him there, too. Slowly, he started signing. *Eat* was first, followed by *more*, *drink*, *play*. Then *all done*, *mommy*, *daddy*, *outside*, *shul*, *daven*, *car*, *truck*, *music*, *hot*, *happy*, *sad*...the signs came fast and furious after their slow start. “Within a year,” Leah says, “although Eli was still not speaking (though once he got his hearing aids he started saying words), he was communicating fluently with over 200 signs, including all the common colors, animals, and people in his life.”

Leah elaborates: “Without the signs, we would have never known just how smart Eli was. He proved that his memory was excellent, as was his understanding: signing “shofar” when someone remembered something that happened on Rosh HaShana, signing “elephant” when someone requested a trip to the zoo during vacation, and recognizing all the colors, various animals, and correctly recognizing and signing different types of vehicles, including car, truck, bus, boat, motorcycle and airplane. He was polite and friendly, signing *please*, *thank you*, and *sorry*. All before he was 3.5 years old.”

Today Eli is much older and after being fitted with hearing aids he was taught to communicate verbally. Signing as an alternative method of communication helped him communicate before he was able to speak. It opened a window to his world and allowed him to share himself.

*Chaya Rosen is a writer and author of “Our New Special Baby”. This book tells a touching and heartwarming story of three young children’s acceptance of their new baby brother, born with Down syndrome.*

### AAC FUNDING RESOURCES

There are many funding sources that may be available for a person with complex communication needs. Below is a list of websites with detailed information about the funding process and funding options.

#### AAC FUNDING HELP

[www.aacfundinghelp.com](http://www.aacfundinghelp.com)

- Speech generating device (SGD) Funding Solutions from the Assistive Technology Law Center provides information about various funding sources
- Links to report samples and templates
- Links to letters of medical necessity
- AAC report coach

#### ASSISTIVE TECHNOLOGY INDUSTRY

ASSOCIATION (ATIA) [www.atia.org](http://www.atia.org)

#### AMERICAN SPEECH LANGUAGE AND

HEARING ASSOCIATION (ASHA) [www.asha.org](http://www.asha.org)

#### AAC REHABILITATION ENGINEERING

RESEARCH CENTER

[www.aac-lerc.psu.edu](http://www.aac-lerc.psu.edu)

### COMMONLY USED FUNDING METHODS

- Medicaid
- Medicare
- Private Insurance
- Tricare
- Tri Counties Regional Center (state of California)
- Deaf and Disabled Telecommunications Program
- School Districts
- Grants
- Private Pay

*A Voice Discovered provides funding through a grant program and also offers education and information. A parent support group, a lending library and advocacy for people with complex communication needs are all provided because A Voice Discovered believes that all people, regardless of the severity of their disability have the right to have access to proper technology, therapy, and support to be able to communicate to the best of their ability. *



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*Linda Kroenke a board member and parent liaison of A Voice Discovered shares with Building Blocks her experience using AAC with her son Judah.*

### **WHAT WAS IT LIKE TO COMMUNICATE WITH YOUR CHILD FOR THE FIRST TIME?**

Judah is 8 years old and has severe Cerebral Palsy. Like any child, communication began very gradually. He began with opening his mouth in response to my question “do you want more?” while holding a spoonful of baby food. That open mouth became his sign for “more” and then we taught him to use it to mean “yes.” Around the age of 3, we had to come up with some sign that could be used to mean “no.” We sang “If you’re happy and you know it...” and got creative with our commands. “If you’re happy and you know it, close your eyes...” We realized that Judah could close his eyes on command, so that became “no.” If he blinks hard several times, it means “NO!!!!” We taught him to use a speech generating device (or “talker”) that he controls by moving the cursor with his eye gaze.

I can say that each time he communicates something new or unexpected, I feel like stopping everyone around me and making them see how amazing it is! Like any proud mom, I take pictures of the exciting moments as they happen. I’ve been taking pictures of his computer screen when he says something I want to remember. Recently, he was pouting and sad, so I asked him why? And his response was “because vacation is over.” That may sound simple, but for a child with complex communication challenges, it is HUGE!!! I also got a picture of him telling me he loves me all in his own without any prompting. I had told him that I would be taking him to the bathroom so the screen says “Let’s pee.” And he then typed “I love you” spontaneously. It makes me laugh to look at the screenshot.

### **HOW HAS COMMUNICATION CHANGED YOUR UNDERSTANDING AND RELATIONSHIP WITH YOUR CHILD?**

If Judah could not communicate at all, I think our relationship would be heartbreaking. Not knowing what he needs or wants is still a challenge because his communication is still improving and he has such great physical limitations. But I know how to ask him questions and I know how to read his facial expressions so we can usually get our point across to one another. When Judah has all the language in front of him on his “talker” device, he can say so much more! It really allows his personality to shine. With his talker, he can show the world the funny, sensitive, smart boy that he is.

### **WHAT MESSAGE WOULD YOU LIKE TO GIVE TO PARENTS OF NON-VERBAL CHILDREN?**

Communication is so much more than speech. If your child cannot speak, there are likely complicated reasons why. But finding a way to communicate should be the highest priority. More important than any other therapy or appointments. Our non-verbal children need to be able to speak up for themselves to prevent abuse, to tell a doctor what hurts, or to make a friend. So much of the progress my son has made came from trial and error, so I say keep trying and surround yourself with other parents who can share what they have tried.