



# Texas School for the Blind & Visually Impaired

## Outreach Programs

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### Discovering How to Connect and Communicate with My Granddaughter

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*Abstract: This article discusses connection and communication between a grandparent and her grandchild with CHARGE syndrome. The author discusses the benefit of attending conferences and how implementing the “Triple C Concept” has improved her communication and relationship with her granddaughter.*

As a grandparent and caretaker of my granddaughter with special needs, I often ponder what I can do to help her live a full and happy life. Ki (pronounced “Kee”), who has CHARGE syndrome, is now six years old and thriving in more ways than we ever imagined. I used to wonder how it would even be possible to connect with this person that seemed to be so locked up in her own little bubble and hard to reach. I’ve discovered that attending conferences focused specifically on Ki’s challenges and needs has been very helpful. Bonds are built and much is learned through sharing experiences and having conversations with other families in the same situation.



Figure 1 Ki brushes her doll's teeth.

Recently I attended a conference to learn more about how to communicate and connect with my granddaughter. Ki is non-verbal but rapidly learning how to sign. She expresses frustration in her face and with body language when I don’t understand her or provide what she wants. Ki, like any other person on this planet, wants to be heard and feel validated. At this particular conference, I learned some things that resonated with me. Giving choices and waiting for responses has greatly improved our communication, and inherently, our relationship. I’d like to share a few more ideas that seem to be working very well.

How can we connect and communicate with someone who may seem unreachable? There are three things that can help promote progress in our quest to include these special people in our lives and build their confidence: Create Opportunities, Challenge the Individual, and Offer Choices. (We could call this the “Triple C Concept”).

## Create Opportunities

Create opportunities to communicate with the person. It can be mimicking their sounds and/or movements, using gestures and signs, holding their hand, talking to them as if there are no barriers, or any other respectful action to help them react to your effort. Ki loves it when I mimic her sounds and movements. In her world, I am speaking her language, and she feels connected when I notice her and what she's interested in. When I gently touch Ki's chin, she realizes it's time to focus and pay attention to what I am saying. When I need her to do something, I take her hand and she automatically knows to follow. She appreciates being spoken to at her age level. Since she looks like a three-year-old and often doesn't make eye contact, I catch myself speaking to her as if she's a toddler. It's important for me to remember that her brain is most likely functioning as the six-year-old that she is.

Our favorite "created opportunities" each day are made by including Ki in practically everything we do. We make sure to find ways that she can participate in what's going on, even if it means just having her in the same room so she is exposed to new activities. This helps Ki know we love her and that she is part of our family. Taking Ki to playscapes and kid-friendly events sparks a lot of excitement, and her spunky personality just beams. She tries to keep up by pushing herself to do things that the other kids are doing. Her mobility and social skills improve with every outing because she's motivated and happy.



Figure 2 Ki and her mom pose for a photo at the International CHARGE Syndrome Conference 2019 in Dallas, Texas.



Figure 3 Ki and her dad at home

## Challenge the Individual

Challenge the person with things to improve their coordination, speech, knowledge, creativity, etc. This gives them opportunities to feel important and proud of themselves as they accomplish new skills. Ki loves when she is the designated person to push buttons for the elevator, be the "light switch flipper," or pull the chain for the ceiling fan. Asking Ki for help with chores like unloading the dryer and putting groceries on the pantry shelf makes her feel like she has important jobs like everyone else in the family. While these jobs improve her sense of belonging within the family, they also challenge her coordination and communication skills.

Playing games and watching educational programs on technology are a great way to promote creativity and challenge problem-solving skills to increase knowledge. One of Ki's favorite activities is playing Mahjong on my iPad. Our little genius can find matching patterns almost as fast as I can. I also like to record Ki echoing words that I prompt her to say, and in turn, she's infatuated with viewing these videos over and over. While watching her videos, Ki gets so much joy out of mimicking herself and practicing the words again and again. I'm constantly surprised to find selfies, fun photos, and entertaining videos on my phone that our Little Missy has taken or created when I wasn't looking.

Having moments to be creative with crafts or playing with water encourages endless discoveries. It can be messy but well worth it. Ki's favorite water activities include swimming, playing with bubbles while washing her hands, and standing on a chair next to Nana to rinse and stack the dishes. Of course, there's more playing in the water than stacking dishes!

## Choices

Choices are extremely important and give a person a chance to feel like their opinion matters. Susan Bashinski, Associate Professor of Special Education at East Carolina University, teaches us that too often WE make choices for people with special needs. This doesn't give them a chance to think for themselves. Chris Sense, who also has CHARGE, taught us that, "we should always assume that special needs people CAN communicate." We want to acknowledge our children with special needs, give them chances to make decisions, and allow them to explore options. It's up to us to learn what a non-verbal person's responses are through their own sounds and movements. Don't forget that in most cases, response time is different for everyone. WAIT for that response! Refrain from rushing to move on and making the decision for the individual. If you find that you get a response different from what you expected, honor that decision. Eventually, the individual will learn through their own trial and error what they really do like and prefer. People need to feel validated and know that their choices matter.

Honoring her choices makes Ki happy and boosts her cooperation and confidence. The motivation to progress improves immensely. Some of the simple choices that can set Ki's mood for the day are choosing her outfit and hair accessories when getting ready in the morning. She also likes to have a say in what foods are put on her plate for her swallowing therapy and which bites she will take next. This stimulates her brain through problem-solving and presents her with opportunities to communicate. Most importantly, this gives her a sense of control and helps her realize she is being heard and that she has worth.



Figure 4 Ki and her doll sit together to play on her iPad.



Figure 5 Ki and her family pose for a photo at the International CHARGE Syndrome Conference in Dallas, Texas.

I hope this information is helpful for other parents, grandparents, and caregivers. When my granddaughter was born six years ago, I wondered if this would even be possible. It IS possible! I truly believe in my heart that we CAN connect and communicate with these tender beautiful angels on earth. Through trial and error, we discover daily what works and what doesn't. We are amazed at how much we are still learning as Ki gets older. Thank heaven for conferences! These events are rich with information and support and improve our ability to "understand her" along our journey as we help raise such a complicated

and yet sweet spirit. For us, the Triple C Concept makes so much sense. It results in giving our loved ones with special needs a voice and a chance to feel loved and validated. These

individuals do notice the time we invest in them, and hopefully feel valued. They deserve as much of a chance to belong in this world as we do and long for it! Let's be proactive and help them to not only be seen, but heard.



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