

## The Power of Connection

*by Julie Maier, CDBS Educational Specialist*

People who are part of the world of deaf-blindness – either personally, as a family member, or as a professional – are aware of the importance of social connections and relationships for individuals who are deaf-blind, as well as the challenges of making, supporting, and sustaining those connections. One of my most indelible memories from this past summer occurred in late June near the end of a rather impromptu picnic lunch at San Francisco’s Crissy Field between members of DeafBlind Citizens in Action (DBCA) and a few students from the San Francisco State University Specialization in Deaf-Blindness teacher training program.

DBCA was in the San Francisco Bay Area for their annual retreat and, in addition to their annual planning for the next year’s planned goals and activities, they reached out to make connections with numerous individuals who are deaf-blind or working in the field of deaf-blindness in the local area. DBCA’s mission and advocacy center around their commitment to improving the quality of life for people with deaf-blindness through their ongoing leadership activities; educating others about rights and responsibilities of individual with deaf-blindness; and their ongoing informed involvement in current events related to educational, technological, and national and state legislative developments that affect the deaf-blind community. The two hours we spent with these self-determined, dedicated young men and their interpreters and support providers was so interesting and enjoyable. It was the perfect way to spend one of those rare fogless summer days along a bright blue bay of water looking out towards Alcatraz Island and under the shadow of the Golden Gate Bridge.



*Members of DeafBlind Citizens in Action and students in SFSU Specialization in Deaf-Blindness Program meet at Crissy Field*

One of the first people I met at the picnic was Mussie Gebre, the current president of DeafBlind Citizens in Action. His interpreter supported our conversation about his past legislative advocacy efforts to gain more access for individuals with sensory disabilities and the group's current efforts to develop a Leadership training program to promote self-determination and leadership skills of youth and young adults who are deaf-blind. Mussie's own leadership skills were demonstrated through his informed and committed investment high-priority issues related to individuals who are deaf-blind, balanced equally with his thoughtful humility about his commitment and efforts on the behalf of others. His quiet, reflective nature really shone forth at the end of the picnic when he had the chance to meet a young boy with deaf-blindness, let's call him "*David*", who had accompanied Kayla Kenton, one of the SFSU students, to the picnic.

Kayla had previously served as David's intervener for a few years of his schooling. Although she has now moved on to teach her own class, she still occasionally provides care to David and his brother. It just so happened the day of the picnic was a day she was spending with David. As with most young boys in a wide open space, upon arrival David was much more interested in the things he was experiencing at the picnic—the grass, rocks, dirt, wind, and white canes—than in all of the adult picnickers. Eventually he was introduced to all of the members of DBCA, yet it was his encounter with Mussie that stood out because of the true connection they appeared to make that in their short exchange just before the picnic ended.

As I watched this introduction I first noticed that that Mussie rather quickly picked up on and understood David's trepidation of meeting so many new adults. I also noticed that David seemed to become more interested in Mussie as the minutes passed, as if he sensed this someone who really understood, or "got it", and was willing to give him time and space to interact in a reciprocal way. Mussie signed to David and the rest of us that he remembered when he was young he also often felt nervous and unsure when meeting new people. That seemed to be an important part of the connection that was unfolding — Mussie, a recognized leader in citizen action and advocacy for the deaf-blind community, could recall his own personal childhood memory and relate it to what this child might be experiencing. Perhaps David sensed this too.

As I thought more about this encounter later that evening, it occurred to me that another essential piece of this successful connection was the support both Mussie and David were provided. For David the support came from the presence of a trusted intervener who supported David through total communication, in that she used both signed communication and speech. She was also fluent in ASL and easily understood Mussie and his interpreter as they signed and was able to share that with David at his individual level of communication.

Mussie's support was two-fold. First, there was trusted interpreter present who used tactile sign to interpret the conversational exchanges. The second support was the presence of Mussie's friend, Amy Parker (from the National Center on Deaf-Blindness and a DBCA Board Member), who thought to provide audio description of the scene and David's actions and expressions so that Mussie, who is completely blind, could get a more complete picture.

So as the interpreter and intervener provided communication support, Amy provided detailed audio descriptions, which she asked the interpreter to share with Mussie...



*knee now and looking at your face.”*

*“Mussie, David is looking at your hand, but it doesn’t look like he is ready to touch it yet. He seems a little nervous and is leaning against Kayla.”*

*“Now he seems more excited. He is smiling a little and rubbing his hands up and down on his stomach.”*

*“Mussie, he is moving closer and reaching out to touch your cane. I think he might almost be ready to meet you.”*

*“He is moving closer to your right*

The interpreter faithfully relayed the audio description Amy was providing in real time and it was this full description of the scene, interpreted through tactile sign, that allowed Mussie to be fully aware and involved in this exchange at every level—the physical, social, and emotional levels. The parts of the interaction he was missing by not being able to see David’s expressions or actions were easily replaced through excellent audio description. The portions of interaction that both Mussie and David missed due to hearing loss were successfully bridged with effective signed communication. Finally, the interaction might have been quite brief and meaningless, if Mussie had not instinctually given David the time and space to regulate himself and move past his nervousness or uncertainty before approaching and interacting with a new adult in his environment.

It was a short encounter compared to some of the others that occurred at the picnic, but for me it was filled with deep meaning. Certainly, on a concrete level it demonstrated the value and need for effective intervention and supports to create and maintain social connections and relationships. On another, even deeper, level it provided me with a greater understanding of how small the community of deaf-blind individuals really is and the importance of providing opportunities for shared stories, passing of information, and the building of connections for these individuals – across the country, the world, and even across generations. I don’t know if Mussie and David realized how remarkable their conversation appeared to others, but as an educator its impact on me both professionally and personally was incredibly strong.

*For more information about DeafBlind Citizens in Action, please visit:  
[www.dbcitizens.org](http://www.dbcitizens.org) or <https://www.facebook.com/dbcitizens?fref=ts>*