

Interveners: One Key to Success

Sally and Mike Prouty

Our son Andy was born 28 years ago with CHARGE Syndrome. At that time we were living in the mountains of Washington State and planning a career move with the U.S. Forest Service to Alaska. Having an infant diagnosed with deafblindness changed everything. A career in the western forests suddenly looked a bit tenuous. We needed a new plan.

After the tears dried, resolve set in. We had heard the story of Helen Keller and Anne Sullivan and knew that Helen Keller was successful largely because Anne Sullivan brought the world and communication to her. We wanted to do the same for Andy, but there weren't enough hours in the day for us to expose him to all of the concepts his older brother learned so easily. We wanted Andy to be as independent as possible, and we knew the early years were vital for educating our son. We were determined to find Andy's own Anne. At that time we had not heard the term *intervener*, but as it turned out, a key to Andy's success was the presence of interveners early on. Here is our story.

An Approach Comes into Focus

Our understanding of interveners became a bit sharper after we read the book *Deaf-Blind Infants and Children: A Developmental Guide* (1982), by John and Jacque McInnes of the W. Ross MacDonald School near Toronto, Canada. The McInneses were early advocates for an education and support model based on *intervenors* (the Canadian spelling for the term), and they stated unequivocally that intervenors dramatically improve the lives of children with deafblindness. We corresponded regularly with John and Jacque and met them two years later when, at our suggestion, they attended a deafblind family weekend event in Oregon where we had moved when Andy was one and a half. We had moved from the forests of central Washington to southern Oregon because our research revealed that there was an excellent preschool there with a teacher trained in deafblindness.

We realized that Andy lived in a bubble. He could only access information as far as he could hear and see. Because he is profoundly deaf and has vision in only one eye, his bubble is quite small. We didn't want Andy to grow up isolated from people and the world. We wanted him to be independent. If he was to be independent, then he needed to learn, and if he was to learn, he needed access to information and communication. It was overwhelming for us to provide all that Andy needed on our own. The only way as with the help of a trained person who could compensate for his hearing and vision losses. An INTERVENER!

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When Necessary, Grow Your Own

Our conversations with the McInneses, as well as our own reading and observations, reinforced our belief that Andy would benefit from an intervener. At that time, there were no formal intervener training programs available, so we adopted a "grow your own" approach. We discovered two college students home for the summer who knew sign language and we trained them as best we could. We received a small grant from the Lady



Andy at age 2 with his first intervener, Donna

Lions Club in our community to pay these interveners to fill in the many hours of the day when we were unable to teach Andy ourselves. These young women, who were short on training but long on commitment and energy, worked on sign language vocabulary and concept development and supported the goals on Andy's individualized education program (IEP).

Working closely with the school district, we were also able to obtain the service of an intervener at Andy's preschool. She was an amazing woman who developed a trusting relationship with Andy, and this led to his making great strides in language, concept development, and independent mobility. This was a good start, but we were driven to provide more for our son. While he was still in preschool, we were thinking 20 years ahead. We realized that anything we did to help him academically as a young child would pay huge dividends in helping him to achieve independence later in life.

A New Chapter

We kept in touch with the McInneses, who told us about a grant-funded project at the SKI-HI Institute at Utah State University to hire community interveners for children with deafblindness. So when Andy was 3 years old we moved to Ogden, Utah, but we stayed there for only 3 years. In an effort to balance Andy's needs, a career in the Forest Service, and our family's quality of life, we made the decision to move again in 1987. Our search took us briefly to Washington D.C., and then finally to St. Paul, Minnesota, where we still live today.

When we came to Minnesota 21 years ago, we were intrigued by a nonprofit agency now called DeafBlind Services Minnesota (DBSM). At that time, DBSM provided supports only to adults with deafblindness. We asked if they would consider serving children and suggested they contact the McInneses in Canada. As a result, DBSM requested funding from the Minnesota Department of Human Services, Deaf/Hard of Hearing and

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DeafBlind Services Division and received a grant to fund community interveners for children.

Thanks to this grant, Andy benefited from interveners until he was 21. These community interveners supported his IEP goals but did it in our home and community. Andy spent hundreds of hours over the years with his interveners practicing shopping, handling money, cooking, learning the layouts of stores and museums, participating in a group for teens with deafblindness, communicating with the public, and having fun in the process. Several of his interveners were members of the deaf community, so his use of American Sign Language also blossomed in the process. Because the role of interveners was not recognized in educational settings at that time, we requested the term *interpreter/intervener* when his IEP was written.

Andy was the first child in Minnesota to have an intervener, but currently at least 30 Minnesota children have interveners at home and/or in school. In 2003, the Minnesota Statewide DeafBlind Specialist at the Minnesota Department of Education established intervener training with a grant from that agency. Training consists of 72 hours of training over six weekends. Both community and school interveners receive training through this program. To date, over 100 community and school interveners have been trained in Minnesota. *[Editor's note: This is a correction to an earlier version of this issue of Deaf-Blind Perspectives which stated that 30 community and school interveners have been trained in Minnesota.]*

A Developing Field

Our family hasn't been alone in recognizing a need for interveners for children who are deafblind. The use of interveners has been a developing practice over the past 20 years throughout the United States. We and many other parents and professionals are convinced that school and community interveners create an excellent foundation for learning by providing:

- ◆ access to information and communication,
- ◆ consistency and repetition to support skill development,
- ◆ experiential learning in natural environments, and
- ◆ opportunities for children to solve problems and make decisions.

Over the years we have heard many arguments from teachers and administrators why the use of interveners for children who are deafblind is not a

good approach. Here are some of those arguments and our replies.

If your son gets an intervener, all parents of special needs students will want interveners. Their children could benefit from one-on-one learning too! This is true, but Andy is deaf and blind and does not have the same access to information and communication as hearing-sighted peers. An intervener provides access to things and people he cannot hear or see. Children who are deafblind need a way to access information, communication, and the world. Intervenors provide this.

Your son will become too dependent on an intervener. If interveners are trained properly, children should become more independent. Initially, Andy did become dependent on new interveners as part of the process of developing trust and building a positive relationship, but once he felt secure and comfortable, he became increasingly independent.

An intervener will isolate your son from others. Just the opposite is true. Over the years, Andy's interveners provided information to him that enabled him to better interact with others in and out of the classroom. Intervenors must know when to step back to encourage independence and communication among peers. In the 1995 Teaching Research video series, *You and Me*, in which the intervener is called an interpreter-tutor, this person is described as an "Ambassador for Friendships." We love that description! An intervener is a bridge to others, not a barrier.

An intervener does not have the proper licensure to teach your child. That is true, but the intervener works under the direction of licensed teaching staff. Frequent planning meetings with the education team keep everyone abreast of current goals, and the intervener is the team member who can provide much needed consistency for the child.

Andrew's Perspective

Recently when Andy was asked how interveners helped him, he said, "My intervener helped me, for example, in school when the teacher would write on the blackboard. My intervener/interpreter would write or show me what was written on the blackboard. My intervener would also interpret what other kids said (signed). Well, if the kids were close, that was fine, but I couldn't see them farther away and she would interpret that for me. If I didn't have an intervener in my school, my teacher wouldn't be able to pay attention to the other students. The teacher would have to be close to me and sign and couldn't focus on the other students."

Andy continued, "I think an intervener helped me when I was growing up because I am more independent now. I live in my own apartment, I pay my own bills, I do my own shopping, and I travel independently to work. I think it is important for deafblind children to have interveners for a variety of reasons—so they have access to the world and communication, fewer behavior problems, and independence. I think it's important to pay for that." We agree. It is a small investment in a long



Andy at age 28 at work

future.

Conclusion

Looking back over the past three decades, we see how important the influence of interveners on Andy and ourselves has been. We met amazing individuals who were committed, talented, and loving. We experienced life turns that we never anticipated, which opened up a new and exciting, albeit unorthodox, world to us. We were all united in our desire to make the best possible world for Andy. Our dream was realized when Andy moved into an apartment a few years ago. We see him frequently, but on his own terms. He *is* independent.

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Sally Prouty is the project coordinator and family specialist at the Minnesota DeafBlind Project.

Transition Time at NCDB

John Killoran

Director, Teaching Research Institute

On July 11, 2009, after 11 years at the helm, Kat Stremel Thomas stepped down from the directorship of the National Consortium on Deaf-Blindness (NCDB). During Kat's tenure as director of NCDB, and of its predecessor NTAC (National Technical Assistance Consortium on Children and Young Adults Who Are Deaf-Blind), she guided the project with a never-ending blend of passion and energy, while maintaining her, and the project's, focus on increasing the quality of services and supports for children with deaf-blindness and their families. As a result, not only did she affect the lives of the children and service providers with whom she worked, but also of each of us who worked so closely with her.

Among the many exciting things recently occurring in her life, Kat has received funding from the U.S. Department of Education for a proposal through which she continues her research and passion for working with young children who are deaf-blind who have received cochlear implants. We look forward to the results of her new research and the contributions it will make to what we all do. Although no longer serving as its director, Kat will remain involved with NCDB and will assist with a variety of technical assistance and leadership activities.

I am also pleased to announce that Jay Gense is now serving as the director of NCDB. Jay has nearly thirty years of experience in the field of deaf-blindness as a teacher, consultant, and project director, as well as extensive experience in state and regional agency administration. Having had previous experience as a state deaf-blind project director, he is familiar with the workings and activities of the federal technical assistance and dissemination network and with the role of NCDB. Jay has not only "hit the ground running," but he brings new ideas, additional insight, and expertise to the project.

Please join me in congratulating both Kat and Jay as they embark on their new adventures!



New NCDB Director

Jay Gense



As the new director of the National Consortium on Deaf-Blindness (NCDB), I am pleased to take this opportunity to introduce myself and express my heartfelt enthusiasm for the work ahead. Most readers of *Deaf-Blind Perspectives* know that NCDB is a national project funded by the U.S. Department of Education, specifically by the federal Office of Special Education Programs (OSEP). NCDB works collaboratively with families, state deaf-blind projects, and federal, state, and local agencies to provide technical assistance, information, and personnel training. NCDB brings together the resources of three agencies with long histories of expertise in the field of deaf-blindness, the Teaching Research Institute (TRI) at Western Oregon University, the Helen Keller National Center (HKNC), and the Hilton/Perkins Program at the Perkins School for the Blind.

I'm very proud of and cherish my "roots" in working and teaching in the field of deaf-blindness. Upon reflection, I find it amazing that these roots now extend back over 30 years. The adage "time flies when you're having fun" certainly holds true! Although I've spent the last 12 plus years working as an administrator at the Oregon Department of Education, serving as director of low incidence programs and director of special schools, I still consider myself first and foremost to be a teacher.

I began my journey in the field working in a deaf-blind program and classroom during the summer of 1977. This classroom was literally tucked away in a very large institutional environment, serving 13 students who were deaf-blind ranging from 3 years old to 22. After a single day of working in this program I recall being "hooked," completely intrigued, and mesmerized by the complexities of deaf-blindness and driven by a newfound curiosity and subsequent passion for trying to understand its uniqueness. This experience served as the foundation for my journey in

seeking a better understanding of the impact of deaf-blindness on learning and development. My professional goal, from that point forward, was to understand how to teach in a way that allowed children who are deaf-blind to process, manage, and use information *individually*, based on each child's abilities to use sensory information. I've been seeking to enhance that understanding ever since.

My professional journey has allowed multiple opportunities to teach in numerous states in a variety of programs. I've taught in classrooms in residential and other specialized schools, in specialized classrooms, in local school-district classrooms, and I've served as an itinerant consultant in a variety of urban and rural settings.

Since moving into educational administration, I've continued to serve programs in these varied environments. While at the Oregon Department of Education, I also served as director of the Oregon Deafblind Project. This experience, as well as direct and indirect work with scores of other state deaf-blind projects, has left me with great respect and admiration for the work of the state projects and of the many partnerships each has established.

So, why did I accept the appointment as director of NCDB? First, I believe that the current state of our field of deaf-blindness and our renewed national focus on the provision of quality education programs for *all* students provide a unique set of opportunities to serve children and families well. Second, I have great admiration and respect for the state deaf-blind projects, and I treasure the opportunity to partner with them through NCDB. Third, I believe that OSEP has established a quality infrastructure for national supports and services through their Technical Assistance and Dissemination (TA&D) network. I look forward to working within this network, through the collective talents and wisdom of NCDB staff, with the state deaf-blind projects and with partner agencies throughout the country to improve the infrastructures for delivery of quality services to some of the most complex children in our schools today. Finally, and most importantly, I have great respect and appreciation for the infants, children, and youth who are deaf-blind and for their families. It is an honor to accept a position in which I will have the opportunity to work on their behalf. I'm committed to bringing my past experiences and perspectives to the table and excited about being open to *new* experiences and perspectives, as we work together to improve and enhance quality programs.

I appreciate this opportunity to join NCDB and its many collaborative partners as we move forward in these opportune times. In future *Deaf-Blind Perspectives* issues, I plan to share some personal thoughts about services and systems, and perhaps to challenge present perspectives. I will always welcome input and feedback about NCDB services and supports, comments of praise and constructive criticisms, and specific ideas and suggestions for improvement. It is clear that the field of deaf-blindness benefits from carefully planned systemic collaborations and partnerships. The needs of the children and families we serve are far too complex to assume that any single approach to service and support will suffice. However, it's also clear that *working together*, our collective passions for quality will help us all to meet our ultimate goal of quality services for children.



An Experience of a Lifetime

Crystal Morales

For one week in June 2009, six other young adults with deafblindness and I participated in an advocacy training program called Deaf-Blind Youth in Action. The one-week course was held at

Gallaudet University, a university for the deaf in Washington D.C. Instructors Amy Parker from Texas Tech University and Suzanne Ressa from the Helen Keller National Center had shared a dream to one day gather a group of young adults to learn to advocate and speak not only for themselves, but for deafblind individuals who may not have the ability to do so. We learned how to present information to senators, congressional representatives, and their staffs. While the program was intense at times, we all enjoyed our stay at Gallaudet and the work we did there. Interpreters, aides, staff members, and volunteers helped coordinate the activities so that we could all learn together. This was the first time many of us met other deafblind people our age, and then to top it off, we met President Obama and brought awareness of deafblindness to the White House and to states all around the country. We have a plan of action that we are continuing to work on today.

As a part of our wonderful journey to Washington, D.C., we had the opportunity to meet many important decision-making persons from the U.S. House of Representatives and the Senate. Being in those buildings and communicating with those people were powerful experiences that changed my mind about how our government and its representatives work together to create change for all of us.



President Obama meets with Deaf-Blind Youth in Action students. Official White House Photo by Pete Souza.

Another part of our journey was a tour of the White House. Walking with my fellow classmates and our interpreters and teachers up to the White House was very moving for me, especially knowing that the last person with deafblindness to meet a United States president was Helen Keller. We walked through the East Reception Room where most people wait to meet the first lady. A secret service agent explained to us that former first ladies' pictures were on the wall. She then described each room we toured and some of the contributions made by those who have lived in the White House. We were allowed to touch items in each room very carefully. We saw the Green Room, the Red Room, the Blue Room, and the State Dining Room in all of their grandeur. We tried to get descriptions that were as detailed as possible from our interpreters and teachers.

We traveled through the Vermeil, China, and Diplomatic rooms before reaching the East Room. When we arrived there, I looked to my left and saw what looked like a harpsichord, which I discovered was actually the White House piano. I looked at my interpreter and we both smiled because I am a composer and musician. The agent told me that I could play a note if I wanted. I told her I couldn't because I was so nervous. She offered again, and I just could not resist. I walked calmly over to the piano, touched the top of it and then the highly polished keys, and played my favorite jazz chord with a small melody above it. I just let the chords hang on and listened to how it sounded in the big room. I stood in shock as the agent told me, "Stevie Wonder played that piano." I just could not believe what I was told! I was in shock all day. Not many musicians have a chance to play the White House piano! What an honor for me. The agent told me that it was a one-of-a-kind Steinway made for the White House. It is supported by three golden eagles and has beautiful red felt inside.

After that wonderful experience, we retreated to a local restaurant while we waited to return to the White House to meet President Obama. While waiting, we were so worried that something would come up and cause our visit to be canceled. But it wasn't, and we were all thankful. We approached the East Gate and went through security, got our passes, and proceeded to walk up the driveway and into the reception office to wait our turn to meet President Obama in the Oval Office. We visited as a group, with our interpreters, staff, and teachers all trying to imagine what it would be like. We were called by the agent to walk in a line down the hallway and towards the Oval Office where President Obama was waiting for us. In

the small hallway, an entry way was visible where one-by-one we walked into the Oval Office to meet him personally.

My interpreter introduced herself, and then President Obama asked me my name, where I lived, where I went to school, and how I liked Austin. He said that he liked Austin and liked to visit there. He then asked me, "Who is your buddy with you?," meaning my guide dog, Umbro. I told him Umbro's name and that he is almost 6 years old. He then reached down and petted Umbro and said, "Umbro is a good boy!" He also visited with the other dogs in the room, Jerry and Spencer. President Obama said "I wish my dog behaved as well as your dogs; he is still a baby."

It was then time to gather as a group for a professional photo with the president. President Obama then let everyone know that he is proud of our efforts in D.C. and that he supports what the Helen Keller National Center is doing for the deafblind community. We then stood for a group photo, and shortly after, I began to make my way out since the agent told us to start heading out of the office. I didn't realize that the president was still visiting and saying good-bye to the other students. My interpreter and I started to turn away, and President Obama called my name, "Crystal!" He made an effort to call me back into the room to say good-bye and wish me well in the future. I just wish I was able to hear him speak. We shook hands for the last time, and I said, "Thank you very much," and proceeded to walk out of the Oval Office into the hallway where we were all in shock after meeting the president and getting to visit with him.

What an amazing experience for us all, a once-in-a-lifetime event. We are all so proud to be the first deafblind group since Helen Keller to meet the president and to be the first disability group to meet our new president of the United States of America. We are all so honored.

Crystal Morales is from Austin, Texas. She is a recent graduate of East Central University in Oklahoma and has a B.A. in Human Resources with an emphasis in vocational rehabilitation. She is an accomplished musician and composer and an experienced presenter on the topic of deafblindness.



Internet Social Networking Sites: Building Community One Friend at a Time

Mike Fagbemi

National Consortium on Deaf-Blindness

Internet social networking sites have become a part of our culture. They provide opportunities for interpersonal connection that transcend race, religion, and creed, and in many ways, disabilities. Two of the most popular sites, MySpace and Facebook, have more than one hundred million subscribers worldwide. The popularity of these sites has influenced how Americans share information and express their social, political, and economic interests. During the 2008 presidential election, the Obama campaign adeptly used these sites to cultivate the interest and energy of youth who had previously been passive observers of the democratic process.

Social networking sites have also created a more level playing field for people with disabilities. This includes people with deaf-blindness who often lack opportunities to forge meaningful relationships because of the challenges that combined hearing and vision loss create for connecting with other people and accessing information. This article explores the impact, challenges, and usefulness of social networking sites for deaf-blind youth. Many of the young adults who were interviewed are avid Facebook users who are either pursuing academic degrees, looking for employment, or developing life skills.

Facebook was originally created as a free-access social networking website to connect friends within college communities. It allows subscribers to share personal information and photographs about their lifestyles, interests, friends, and communities. Subscribers can invite friends to their Facebook page, join organizations, become founders of organizations, support causes, and engage in online conversations.

The growing popularity of sites like Facebook have made it possible for deaf-blind youth to expand their social networks, cultivate friendships with a broad range of people, and join national organizations that support social causes they care about. Howard, a graduate of the National Technical Institute for the Deaf (NTID) has been a long-time subscriber to Facebook and likes the personal touch it gives him that he feels is missing when e-mailing. "Facebook is appealing to me," he says, "because I choose who I want to share my

life with, and these friends within my network can learn more about me in a more natural way. When I show photographs of me laughing at my cousin's wedding, it tells more about me than an e-mail describing the same wedding." He also likes having the ability to control the stream of information he shares with friends and acquaintances. He says, "I like that for a point in time we are playing on the same field as people without disabilities and we are not seen as disabled, as we are offline, and that is refreshing for me."

Howard uses the program ZoomText to magnify the font size on his computer screen and finds that it works well with Facebook. Kat—a former student at the Helen Keller National Center—uses Jaws 10, a voice output program and likes how it interfaces with Facebook as well. "I can check my mail," she says, "and connect with friends from my childhood. Other than the excessive advertisements and the incompatibility of various applications created by private users, I find Facebook to be easy to navigate."

Facebook encourages users to be a part of a social community and to expand that community to befriend others whom one would otherwise not have met. The usual places where teens gather after school are typically not easily accessible to youth with unique needs and limited resources. Social sites like Facebook appeal to many youth with deaf-blindness because, historically, they have not had the opportunity to forge friendships and often find themselves in the position of being mostly in the company of paid personnel (Petroff, 1999, p. 103). Jason, a recent college graduate, would like to see these social networking sites used to improve the lifestyles of and perceptions about youth with sensory impairments. Jason says, "I use Facebook to gather information about events and to share experiences with my peers and adults who may not know that we are capable of doing great things too. Parents are the hard people to convince that we can be independent and still make mistakes just like other people." He likes to think of Facebook as a resource for youth who might feel more comfortable asking friends within this community for help with issues that they are not comfortable discussing with parents or school personnel.

While in high school, Greg had a passion for art and skill as an artist but often complained about his vision. He thought that buying a good pair of glasses would remedy his situation. He was not aware that he had Usher Syndrome until he graduated and began to consider employment options. He was embarrassed to speak with his family and

was overwhelmed by the prospect of having to research and educate himself about the topic. He learned about an Usher group (Usher Life) on Facebook where he could ask other people about their experiences. This helped reduce some of his anxiety. Greg says, "There are a number of different organizations and forums created by people with disabilities that I feel I can be comfortable joining, and I don't feel alone as much."

Many organizations representing people with disabilities have recognized the importance and popularity of sites like Facebook. The sites allow organizations to publicize events, request donations, maintain a national presence, and expand their membership base. Jason started his own deaf-blind group and was excited to learn that 80 members consisting of consumers, professionals, and family members joined within the first week. He also learned that there were deaf-blind communities in other countries that were excited to connect with like communities of people in the United States. Jason's online community now includes people from Japan, Ireland, Australia, and the UK.

Jason recognizes the value and opportunity of forging relationships with a variety of people. "I decided that I should encourage adults in the American Association of the Deaf-Blind (AADB) to join Facebook." He says, "I shared my members with them so now we are a larger community, which is good for people who want to connect with a big organization and not just me." He continues to encourage people he meets at youth workshops to join these organizations and use them as resources for issues they consider to be important.

Deaf-blindness is a disability of access. This can be literally interpreted as lack of access to environmental features such as ramps, elevators, and accessible transportation, but also as lack of access to information and to people. It adversely impacts social, educational, and personal development. The use of social networking sites bridges some of these gaps, but young adults are often vulnerable and may find the nuances of online social sites difficult to understand. There are communication barriers, misunderstood social overtures, and the danger of befriending a person who may not have one's best interests at heart. Laura, a high school student who likes to search for friends she meets at camp, warns others to be cautious when making new acquaintances online. "I made friends with a man who didn't care that my English was not that good," she says. "He didn't care that I was deaf either. I liked him, but he started to ask me for

money, and when I told him I was broke he stopped chatting with me."

Art Roehrig, the president of AADB, issued a warning in one of the organization's newsletters about scammers who attempt to illegally use the organization's name to solicit money through the instant messaging services of popular Internet service providers. Both of these examples highlight the inherent risk that exists when using the Internet. Youth who are inexperienced may perceive these social sites as safe places and should be taught to exercise caution.

As they increase in popularity and continue to attract new users both young and old, social networking sites may change how people process information. President Obama's inaugural address was reportedly attended by 120,000 Facebook users who were logged on to post and share comments. This included members of the disability community interested in employment, health care, housing, and the stimulus and recovery package. CNN partnered with Facebook to conduct opinion polls on the housing crisis and the future prospects of the economy during their live coverage. One of the young adults, who was not able to watch the address but had been following the updated postings on her Facebook page, wrote on her page the next day, "I missed the speech last night but I voted for him. It was the first time I ever voted and now he is president. How cool is that?"

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CHARGE Syndrome Conference

Pamela Ryan
Perkins School for the Blind

This year's CHARGE Syndrome Conference started on July 23 with a preconference, the first ever CHARGE Syndrome Conference for Professionals. Historically, we have integrated "Professional Day" into the first day of the conference. At previous conferences, this gathering of professionals (medical/scientific, education, and special education), college and university training program faculty, and parents, has been an informal opportunity to discuss interests and research and provide a forum for posing questions and providing

answers. Because of the increasing number of professionals joining the conference and wanting more information, this year Professional Day became a bigger, more formal event. Twelve professional papers and 16 poster sessions were presented. It was very well attended, and we are hoping that new interest in CHARGE Syndrome will be sparked as a result of the attendees' sharing knowledge that will benefit children and adults with CHARGE Syndrome in their own states and countries.

The official start of the 9th International CHARGE Syndrome Conference was July 24, with the largest ever number of participants. Over 757 people converged on Bloomington, Illinois, from most corners of the world. Participants came from several countries including Canada, Australia, Israel, and Chile, and from most of the United States. Families, professionals, and young adults and adults with CHARGE Syndrome came to hear professionals in the fields of education, gene research, hearing loss, and related fields, discuss a wide variety of topics that included cochlear implants and bone-anchored implants, the impact of CHARGE Syndrome on vision, and parenting issues (e.g., the neonatal intensive care unit experience, stress, and planning for future needs). We also had two sessions specifically for those individuals over 18 years of age with CHARGE Syndrome who are getting ready for work and/or planning for college.

In addition to the academic portion of our conference, we also offered entertaining events: the first ever "Conference Idol" talent extravaganza, a visit and show by Rachel Coleman from *Signing Times* (a very popular video series focused on teaching young children sign language), a silent auction, and the ever-popular carnival, complete with a DJ and dancing. It is safe to say that a fun time was had by all during the 3 days of the conference.

As a member of the board of directors of the CHARGE Syndrome Foundation, I would like to invite you to visit our website at www.chargesyndrome.org to learn more about who we are, who we serve, and what our mission is. You will also see several informational packets related to CHARGE Syndrome that are downloadable for free. You may also want to visit www.perkins.org for a new webcast related to CHARGE Syndrome. Perhaps we will see some of you at our next conference in 2011 in Orlando, Florida!



Described and Captioned Media Program

Kelly Gorski
Communications Editor,
DCMP

The Described and Captioned Media Program (DCMP) is funded by the U.S. Department of Education to provide media services and advocacy to support and improve the academic achievement of K-12 students who are blind, visually impaired, deaf, hard of hearing, or deaf-blind.

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All registration, browsing, ordering, and other account-related activities are handled online. There is no need to wait for a catalog in the mail, to pick up a telephone, or to leave your home or classroom in order to enjoy this unique service. If you would like suggestions about videos in our collection, go to www.dcmp.org/recommend. We are constantly adding new titles and looking for ideas from our clients and the public.

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Give your students equal access with DCMP accessible educational media. Browse our articles, use our gateway, and register today!



What Is Maddie Going to Be When She Grows Up?

Debra Garvue

When you learn that your child is deafblind, you become consumed by many concerns. Once I accepted and understood my daughter's diagnosis, I still had many questions: not just questions about her current needs like "What can she see?," "Who is a good therapist?," or "When will her IEP meeting be?," but also questions about her future. The most basic and gut wrenching question I had was this: "What is my child going to be when she grows up?"



I found this question hard. I had watched my older daughter flourish. When she was little and played with a doctor's set, I dreamed of her becoming a doctor. When

she tried to argue her way out of punishments, I thought to myself, "Wow, she would make a great lawyer!" But the basic parenting rules I knew didn't seem to apply to Maddie. I couldn't find her case in any parent book. Dr. Spock had no advice for me.

Maddie was born with Leber's Congenital Amaurosis. Generally this genetic disorder affects eyesight only. However, in addition to her vision loss, Maddie was born with bilateral profound sensorineural hearing loss, severe hypotonic (floppy) muscles, a seizure disorder, and sleep apnea. She only has light perception and can see some hand movements if they are made within one or two inches of her eyes. She is in a wheelchair and, because of her weak muscles, has a feeding tube and requires oxygen at night. At 9 months of age, Maddie received a cochlear implant and loves hearing with it.

Given all of Maddie's disabilities, I still can't help asking myself, "What will she be when she grows up?" It is like a nagging ball of worry in the pit of my stomach. The question haunts me! Will my child grow up to be something, or will she be an eternal companion whom I care for and who never leaves her mark on society?

Recently during a very difficult time, I had an epiphany, one of those rare moments when a light shone down and I knew the answer to that question. Maddie had recently been hospitalized for about ten weeks. She was on a ventilator for eight of those weeks, and for awhile it was touch and

go. I watched her struggle to survive. When she was about a week into her struggle, I developed a website to let friends and family members keep track of her condition, and I was blown away by how many hits it received. It seemed as if everyone was reaching out to Maddie and my family. Friends and family members shared Maddie's site with people they knew, and soon we were receiving hugs and cards from people I had never met. It was inspiring to know how many people were touched by her fight to live.

This led me to wonder, to contemplate deeply, how many lives has Maddie touched? Therapists? Teachers? Doctors? Nurses? Friends? Family? The list is endless. And I realized that I already know what my child will be when she grows up, because she is already it. She has chosen her profession and is practicing it now, and I know that she is already making a mark on society. She is changing the way people think and function in their daily lives. She has inspired me to leave my job as an educator and enter the field of deafblindness with the hope that I can make a difference. What is she? Why, she went into the family business. She is a teacher.

To read Maddie's journal, go to www.caringbridge.org/visit/maddiegarvue.



Honorary Degree for David Brown

David Michael Brown received an honorary Doctor of Science degree from Central Michigan University in May. Brown, an education specialist with California Deaf-Blind Services, has given various lectures and training programs around the world. His published work has been translated into several languages. He serves on several advisory boards including the CHARGE Syndrome Foundation and been awarded many professional honors for his volunteer work.

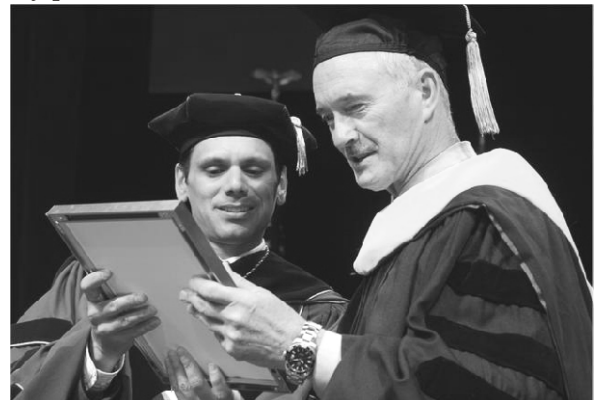


Photo by Robert Barclay, CMU Communications

Research Update

Research Participation Opportunity for Adolescents and Adults with CHARGE Syndrome

If you are 13 years or older and have CHARGE Syndrome, you and/or your parent or guardian are invited to participate in a research study. Little is known about the problems people have as they are growing up with CHARGE Syndrome. To learn more, this study is asking adolescents and adults with CHARGE Syndrome to complete a questionnaire. The questionnaire includes questions about the past and present life experiences of people who have CHARGE Syndrome and takes approximately 30 to 45 minutes to fill out. Some of the questions are about things that are good in life and some are about things that are not so good. This is described as "quality of life."

This research study is being conducted by a medical doctor, Dr. Kim Blake, and a psychologist, Dr. Nancy Salem-Hartshorne, who has an adolescent son with CHARGE Syndrome. If you volunteer to participate, a packet will be sent to you with consent forms and the questionnaire. Please contact the researchers via email or telephone if you would like to be part of this important research.

- ♦ Dr. Nancy Hartshorne: harts1ns@cmich.edu or 989-774-6469 (Eastern Time Zone)
- ♦ Dr. Kim Blake: kblake@dal.ca or 902-470-6499 (Atlantic Standard Time)

New Dissertations

Durando, J. A. (2008). *Home literacy experiences of children with visual impairments and multiple disabilities*. University of Northern Colorado. Available through ProQuest Dissertation Express (www.umi.com/en-US/products/dissertations/disexpres.shtml). Cost: \$36.00 for web download (\$43.00 for unbound paper copy).

Newcomb, S. (2009). *Reliability of the CVI range: A functional vision assessment for children with cortical visual impairment*. University of Maryland, College Park. Available free-of-charge on the web: www.lib.umd.edu/drum/handle/1903/9123.

Parker, A. T. (2009). *Measuring an adapted form of picture exchange communication systems (PECS) for young children with visual impairments and developmental disabilities*. Texas Tech University. Available free-of-charge on the web: etd.lib.ttu.edu/theses/available/etd-06032009-203503.

New Articles

Brady, N. C., & Bashinski, S. M. (2008). Increasing communication in children with concurrent vision and hearing loss. *Research and Practice for Persons with Severe Disabilities*, 33(1-2), 59-70.

Chen, D., Griffin, M. E., & Mackevicius, S. (2009). Home visit practices: Serving families and their young children with vision impairments and multiple disabilities. *Journal of the South Pacific Educators in Vision Impairment*, 4(1), 8-14.

Dalby, D. M., et al. (2009). Development and psychometric properties of a standardized assessment for adults who are deaf-blind. *Journal of Visual Impairment and Blindness*, 103(1), 7-16.

Dalby, D. M., et al. (2009). Characteristics of individuals with congenital and acquired deafblindness. *Journal of Visual Impairment and Blindness*, 103(2), 93-102.

Dammeyer, J. (2009). Congenitally deafblind children and cochlear implants: Effects on communication. *Journal of Deaf Studies and Deaf Education*, 14(2), 278-288.

Hoevenaars-van den Boom, M. A. A., Antonissen, A. C. F. M., Knoors, H., & Vervloed, M. P. J. (2009). Differentiating characteristics of deafblindness and autism in people with congenital deafblindness and profound intellectual disability. *Journal of Intellectual Disability Research*, 53(6), 548-558.

Johnson, C., Kran, B. S., Deng, L., & Mayer, D. L. (2009). Teller II and Cardiff Acuity Testing in a school-age deafblind Population. *Optometry and Vision Science*, 86(3), 188-195.

Sharma, A., Ruscetta, M. N., & Chi, D. H. (2009). Ophthalmologic findings in children with sensorineural hearing loss. *Archives of Otolaryngology Head Neck Surgery*, 135(2) 119-123.

Trief, E., Bruce, S. M., Cascella, P. W., & Ivy, S. (2009). The development of a universal tangible symbol system. *Journal of Visual Impairment and Blindness*, 103(7), 425-430.



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For Your Library

Publications

I Wish I Had . . . Wisdom from Parents of Children Who Are Deaf-Blind

National Consortium on Deaf-Blindness, 2009, 8 pages.

In this publication, 26 parents of children who are deaf-blind respond to the phrase, "I wish I had..." Their brief responses, accompanied by color photos, highlight knowledge that they have gained about the educational and social needs of their children and provide insight into the impact of a child with deafblindness on family life. Available on the web:

www.nationaldb.org/documents/Family/Iwish.pdf

For print copies, contact NCDB at 800-438-9376 (Voice), 800-854-7013 (TTY), or info@nationaldb.org.

Practice Perspectives: Teaching Prelinguistic Communication

National Consortium on Deaf-Blindness, 2009, 4 pages.

This publication describes the findings of a study on the use of prelinguistic milieu teaching (PMT) for children who are deaf-blind. In PMT, an instructor, working one-on-one with a child, uses a variety of strategies to teach and encourage children to use gestures and vocalizations to communicate intentionally. This is the fifth in series of publications called "Practice Perspectives," designed to increase the use of current information resources through the development of easily understandable products in accessible formats.

Available on the web: www.nationaldb.org/NCDBProducts.php?prodID=111. For print copies, contact NCDB at 800-438-9376 (Voice), 800-854-7013 (TTY), or info@nationaldb.org.

AIM: Assessment Intervention Matrix

Enid G. Wolf-Schein & Jerome D. Schein. Three Bridge Publishers, 2009.

The *Assessment Intervention Matrix (AIM)* is a curriculum for teaching individuals with significant communication or sensory impairments (including those with severe auditory and visual problems or autism) how to develop communication and

daily-living skills in realistic, meaningful contexts, at school and at home. It is designed to bridge the gap between assessment and intervention through a process of continuous assessment, structured intensive intervention, and reassessment and can be tailored to the needs of pupils with a wide variety of abilities and challenges. AIM is divided into two parts to address seven skill areas. Part I covers drinking, eating, dressing, and toileting. Part 2 covers personal care, housekeeping, and food preparation. This CD-ROM contains an updated version of AIM (previously released in 1995 and 2002). It includes separate PDF files of the AIM sections and their associated assessment and curriculum forms. The cost of \$34.95 includes priority mailing. Available from Three Bridge Publishers, 1703 Andros Isle, Suite J-2, Coconut Creek, FL 33066. Phone: 954-978-1368. Fax: 954-968-3970. E-mail: scheinej@aol.com.

Early Identification of Infants Who Are Deaf-Blind

National Consortium on Deaf-Blindness, 2009, 20 pages.

This report summarizes the following activities of NCDB's Early Identification Work Group to gather information about early identification and intervention efforts for infants and young children with deaf-blindness in the U.S.: (a) a survey of state deaf-blind project directors; (b) focus group interviews with state deaf-blind project personnel in eight states; and (c) an extensive literature review. Future directions for NCDB, as it forms partnerships to develop and evaluate initiatives to improve early identification of children who are deaf-blind, are outlined. Available on the web: www.nationaldb.org/documents/products/EI-deaf-blind-infants.pdf.

Health, Well-Being and Congenital Rubella Syndrome: A Sense and Sense Scotland Practice Sharing Event

Sense, 2009, 62 pages.

This is a report of a conference on Congenital Rubella Syndrome (CRS) that took place in Crewe, England, March 6–7, 2009. The seminar was attended by 50 delegates who discussed the topic of aging with Congenital Rubella Syndrome and what practitioners can do to better support people with CRS. Available on the web:

www.sense.org.uk/what_is_deafblindness/rubella_mmr/rubella_conference.htm.

Guide to Designing Tactile Illustrations for Children's Books

American Printing House for the Blind, 2008, 35 pages.

This manual provides the following information about tactile illustrations: challenges and limitations, principles of good tactile design, types of tactile illustrations (e.g., objects, parts of objects, raised lines, and shapes), and a list of tools and materials needed to create tactile illustrations.

Available on the web:

www.apb.org/edresearch/illustration.htm.

**Online Audio, Video,
and Image Resources****Video Topics (about instructional practices in deaf-blindness)**

Washington Sensory Disabilities Services.

This website has video clip examples of instructional practices used with children who are deaf-blind. Current topics include hand under hand interactions, use of a resonance board, using a child's likes/dislikes to promote learning, and routines. In addition to the video clips each topic includes background information and additional resources. Additional topics will be added throughout the year. Web:

www.wsdsonline.org/deafblind/videotopics.html.

Pre-Symbolic Communication Fact Sheets

Robin Greenfield. Idaho Training Clearinghouse.

This online resource contains four fact sheets that parents and caregivers can use to help young children with significant disabilities, including deaf-blindness, to learn the use of pre-symbolic behaviors (e.g., eye gaze, body movement, vocalizations) to communicate. The fact sheets include links to video clips illustrating key concepts. The topics of the fact sheets are assessing communication skills, asking for "more," making choices, and getting attention. Web:

<http://itcnew.idahotc.com/dnn/IdahoTrainingInitiatives/VideoFactSheetIntro/tabid/919/default.aspx>.

Communication Matrix for Parents and Professionals

Charity Rowland, Design to Learn Projects, Oregon Health & Science University.

This recently updated online version of the Communication Matrix is free and available to anyone. The Communication Matrix (first published in print in 1990), is an assessment tool designed to pinpoint exactly how an individual is communi-

cating and to provide a framework for determining logical communication goals. Web:

www.communicationmatrix.org.

CHARGE Syndrome: An Overview

Perkins School for the Blind.

In this webcast, School Psychologist Pamela Ryan offers an overview of the characteristic features of CHARGE Syndrome and discusses the very diverse ways they may manifest themselves in children. This site contains additional webcasts on a variety of topics. Web:

www.perkins.org/webcasts.

Tactile Graphic Image Library

American Printing House for the Blind.

APH has launched an image library database that is accessible from their website. The free images in the database are templates that can be used to create custom tactile graphics. Web:

www.apb.org/tgil.

Family Connect: For Parents of Children with Visual Impairments

American Foundation for the Blind.

This site has information on a variety of topics including audio presentations by experts in deaf-blindness on subjects such as communication, sensory efficiency skills, and self-determination. The easiest way to find information about deaf-blindness on the site is to enter "deaf-blind" in the search box. Web:

www.familyconnect.org/parentsitetime.asp.

Senior Site: Hearing and Vision Loss Videos

American Foundation for the Blind.

This site contains videos of assistive technology devices used by individuals with combined vision and hearing loss (e.g., alerting devices, assistive listening devices). Web:

www.afb.org/seniorsite.asp?SectionID=63&TopicID=388&SubTopicID=154.



Conferences and Events

HKNC National Training Team Seminars

Sands Point, New York

The Helen Keller National Center Training Team has the following two upcoming seminars scheduled:

- ◆ The Magic of Technology: Adaptive Technology Training for Teaching Deaf-Blind Individuals, November 16–20, 2009.
- ◆ Touching Lives: Interpreting Techniques for the Deaf-Blind Population, January 11–15, 2010.

For more information go to www.hknc.org/FieldServicesNTTSchedule.htm or contact Doris Markham (516-944-8900, ext. 233/239; doris.markham@hknc.org).

Australian National Deafblind Conference

April 28–30, 2010
Melbourne

The theme of the conference is "Deafblindness in Australia: New Ideas, Directions, and Solutions." Presentations will cover news, research, and developments relating to deaf-blindness, from Australia and overseas sources. For more information go to www.ableaustralia.org.au or contact Patricia Karagiorgos (patricia.karagiorgos@ableaustralia.org.au).

8th Conference of the Acquired Deafblindness Network

29 September–3 October 2010
Aalborg, Denmark

Using the theme of "Building Bridges," the conference will explore the development of relationships between deafblind people, families, friends, and professionals. The conference coordinating committee is inviting people interested in giving a presentation at the conference to submit abstracts for consideration (deadline February 26, 2010). For more information visit www.adbn.org.

See the NCDB web site for information about other upcoming events.
nationaldb.org
(click on "Conferences & Trainings")

Announcement

NFB promotes Braille literacy

There is a Braille literacy crisis facing the blind in the United States, according to the National Federation of the Blind (NFB). Braille is vital to all blind individuals, yet today in America only 10 percent of blind children are learning to read Braille in school. This continues despite the fact that studies have shown that 85 percent of all employed blind people read and write Braille fluently. These studies reinforce what the NFB has been advocating for years: Braille literacy is the key to employment and full participation in society.

NFB seeks to raise awareness of this issue and support for action through a Braille literacy campaign and through the sale of a commemorative 2009 Louis Braille Bicentennial Silver Dollar. To learn more, visit www.braille.org.

Do you need information about deaf-blindness or to help a child or youth who is deaf-blind?

Contact DB-LINK Info Services at the National Consortium on Deaf-Blindness

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800-438-9376
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