VIBRATIONS

NEWSLETTER OF COLORADO SERVICES FOR CHILDREN WHO ARE DEAFBLIND Serving Children with Combined Vision and Hearing Loss (Deafblindness),

Their Families, and Service Providers

Fall 2005



OUR FAMILY JOURNEY

By Shannon Cannizzaro. Parent Consultant

My husband and I have three wonderful boys. Andrew is eleven, Christopher is 7 (soon to be eight) and Nicholas is two. Christopher our middle son was born September 19, 1997. After a typical pregnancy and a repeat scheduled cesarean section our new sweet baby was finally here. Andy was so proud to be a BIG brother, Todd and I were thrilled, and we of course had many visitors to the hospital grandparents, great- grandma, aunts, uncles, and friends. A few days later we were given a clean bill of health and sent on our way.

I had some concerns that he looked a little bit different, he was always upset and his eyes were spaced very far apart. At his two-week appointment the resident filling in for our doctor asked "if my other son looked like Chris" and my mom and I both said "no" hoping he would offer us an answer, but he said "I'm sure he is fine". So we went home and I continued to be concerned. When he was two months old we were in California for his great grandmother's funeral and took him to a doctor, because he wouldn't stop crying. She seemed concerned about his right eye and wrote a note to our doctor in Colorado to have his eyes checked by an ophthalmologist for Strabismus immediately. We had it checked and started patching his eyes.

As the months went by we took him to the doctor numerous times for ear infections and swollen, bulging, runny eyes. We still couldn't find a doctor to take these concerns seriously. I finally requested a referral to

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pediatric ophthalmologist when he was seven months old and after quite a discussion we were able to go. She found Chris to be extremely farsighted and gave him a prescription for glasses. He looked so cute and for the first time in seven moths he stopped crying and his eyes stopped swelling. What a relief.

Well this short term happiness were off when we continued to watch his development fall behind and we still worried that he wasn't quite "with it." His favorite past time was

watching ceiling fans spin . We met with several more doctors and found out about Child Find, when finally at ten months old a developmental nurse saw us at our clinic. She agreed he didn't seem to be meeting milestones and agreed to make the necessary referrals for him in a month if he didn't start pulling up or rolling over. She also suggested a genetic workup, which our doctor denied, saying "we will wait and see how he does." A month later and still no progress when he was referred to an Occupational Therapist, Physical Therapist, Speech Therapist and scheduled for a hearing test.

One morning during breakfast he appeared to have a seizure in his high chair while eating. After a long debate with the doctor and my husband going back to our doctors office and insisting he have an EEG and MRI. They said "okay" and our developmental nurse again requested the Genetic testing, which they did as well. Waiting for the results was horrible, but fortunately we had a hearing test to go to. We were told to bring him very tired so that he would fall asleep during the ABR test. When we arrived they took him into the booth and did an exam and said he did great! We asked if we could still do the other test too? She said "we could do it for giggles". Let me say no one was laughing when it was discovered that he had a moderate/severe hearing loss. I was actually relieved, it explained why he didn't pay attention to us. He couldn't hear. What a whirlwind getting fit for hearing aids, getting the results back that his MRI showed brain cysts, corpus collosum cysts, enlarged ventricles and white matter problems.

Luckily his chromosome testing came back soon and we were able to meet with the wonderful Genetics department at The Children's Hospital. They explained he had a rare chromosome deletion 6p(25) the tiny piece on the end of one his 6th chromosomes had broken off. Who knew this could even happen? I spent a lot of time at the Medical Library researching this chromosome deletion and found that this particular deletion causes hearing loss, vision loss, glaucoma, bone growth delay, brain abnormalities, motor delay, heart problems and Chris had it all. We spent the next several months visiting many other medical Specialists who helped us sort through his syndrome, it still wasn't easy but at least we had a diagnosis and we weren't nuts.

Christopher had many early intervention professionals who made our lives so much easier. We met many wonderful people at the Deafblind project, Anchor Center, CHIP, The Listen Foundation and Fletcher Miller, who we would have never known if it weren't for this situation.

Despite such a long first year we are okay. Life is crazy but we decided that Christopher wouldn't be treated any differently then his big brother (maybe a little more spoiled). He was going to fish, camp and do everything we did. We are so proud of him he has matured into a delightful, funny, smart, silly and excellent brother. He and his brothers are great and we wouldn't change any of them for the world.

Colorado Services for Children with Combined Vision and Hearing Loss

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WE ARE HERE TO HELP YOU!





This Newsletter Edition: The topic of this edition is LITERACY for all students, but particularly those students who are deafblind (have combined vision and hearing loss) and having significant support needs. *Active Learning: Movement, Exploration, and Early Literacy for Children with Deafblindness. or Significant Support Needs* was the topic of our June 2005 Summer Institute. There are a host of wonderful articles by both parents and professionals. Our hope is that this information will help to improve literacy instruction in Colorado for all our students. We have made a particular focus on writing.

Colorado Census of Children and Youth with Deafblindness: The census forms will be mailed to all agency and administrative unit contact persons in mid November. If you have any questions about the census process, please contact Tanni Anthony at (303) 866-6681 or Anthony_t@cde.state.co.us

Lending Library: Our library continues to grow with **many** new items. The Library Inventory and the Request Form are on the website: http://www.cde.state.co.us/cdesped/SD-Deafblind.asp

Technical Assistance (TA): Staff is available to provide free consultative assistance to families and school personnel both in the child's home and school setting. In addition to actual site visits, information can be provided via email, telephone, and the mail. Please let us know your technical assistance needs. The request form is available on the website.

Project Website: We have been adding information to the website! Be sure to check out the Family Connections section of past articles written by parents! This is a section that we hope to continually expand with more stories from families. Please consider doing an article. Your story may help someone else. Give Gina a call if you are interested in contributing. Her number is (303) 866-6605. To check out the website, please go to: http://www.cde.state.co.us/cdesped/SD-Deafblind.asp

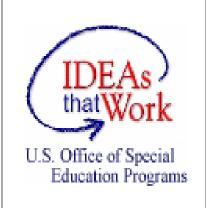
CSAP 2006: The administration window for the CSAP is February 13-24, 2006 for Grade 3 Reading and March 13– April 14, 2006 for Grades 3 (Writing and Math) and Grades 4-10 Reading, Writing and Math and Grades 5, 8, and 10 Science.

CSAPA 2006: The administration window for the CSAPA will be February 8-March 10 for Grade 3. The window for Grades 4-11 will be February 8th—March 31. Administration training for the CSAPA is scheduled for:

Denver Metro Area—January 10-12, 2006 Grand Junction Area—January 18, 2006 Colorado Springs Area—January 24-25, 2006

Please let us know your technical assistance needs specific to literacy.

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by Margaret Cisco, Education Specialist, SESA, from <u>The Reference Shelf</u>, Fall 2004. Reprinted with Permission.

To write is to put symbols or images on paper to communicate thoughts. Written communication is used in to-do lists, day planner, journals, letters, email, completed order forms, hand-drawn maps, or printed reports. A

student does not have to be a novelist to be writer - few are. Yet most students learn to write well enough to function in the world because schools teach them how to compose messages in written format.

Writing instruction begins in kindergarten even though students cannot form letters well and do not know how to read or spell, yet students with cognitive or physical disabilities are frequently excluded from writing instruction throughout grade levels because they cannot speak, cannot read, or cannot use a pencil. This is true even though it is now clear that listening, speaking, reading and writing are interrelated skills and that growth in each of these skill areas is supported by growth in the others. In fact, students with disabilities need writing instruction because engaging in writing will support development of their speaking, reading and listening skills. For example, one student with a disability may begin to either use speech or to use clearer speech as a result of learning to read while another may begin to speak more with a communication device as a result of writing.

In today's classroom, "process writing" means teaching students to be effective writers by having students engage in writing. The teaching focus is the process or stages used to create quality content, not just the final piece of written work. Process writing stages are prewriting, first draft, revision, editing, and publishing. Students are taught to move fluidly back and forth between stages as needed, while they actively develop an effective piece of writing. The emphasis on process means that students of any age or developmental stage can learn to be writers. Students develop ideas that are personally relevant and use many different writing tools from sticky notes and stamps with pictures, to pen and paper to computer. With the new teaching and learning emphasis, students with disabilities can participate in the writing process with writing tools that give them access. Given the right tools, there is no reason to exclude students with cognitive or physical disabilities from classroom writing instruction.

New Research Articles about CHARGE Syndrome

The March issue of the *American Journal of Medical Genetics Part A* (Vol. 133A, Issue 3) is devoted to articles about the behavioral aspects of CHARGE Syndrome. A few additional articles about other aspects of CHARGE Syndrome are also included.

Pairing Modeling Writing with Assistive Technology

by Margaret Cisco, Education Specialist, SESA, from The Reference Shelf, Fall 2004. Reprinted with Permission.

Remember that giving assistive technology (AT) to a student will not result in a student being able to write effectively any more than giving a student pen and paper results in a student who can write. To become effective writers, both students will need to participate in the same learning activities about the writing process: selecting a topic, writing a draft, revising, editing, and publishing. The difference is the writing tool they use.

As an example, one teaching procedure is "modeled writing." In modeled writing, the teacher demonstrates the process of writing by thinking aloud as she composes text in front of students. This allows the teacher to demonstrate the thinking that is used in the process of writing. Students can hear the teacher make decisions about selecting a topic, how to start, looking for a better word, and using correct spelling and print conventions such as punctuation.

For a student who uses AT for writing, the teacher needs to model writing using the student's technology. By using the student's technology, the teacher will be supporting the student's use of technology within the writing process. For example: using the technology to find the vocabulary on the device, word choice, and using tool bar items such as <read all, erase, and print>. The teacher will explicitly describe the thinking process used when using the AT and computer to look in a topic bank to choose a topic for writing then write several sentences about the topic modeling how to find words, how to spell, how to erase, and how to have the computer read back the text. When the writing is finished, the teacher will scroll down so the student cannot see what the teacher has written. The student will then use the same technology to compose (not copy) several new sentences. This is a first draft so the teacher will not cue for grammar, punctuation, or syntax. These tasks will come in the later stages of the writing process.



<u>References:</u> Adapted Stories, [Online]. (© 2004 Creative Communicating) Available: www.AdaptedStories.com.

URLs for Your Favorites List

<u>Please</u> add the following web address to your list of favorite websites. Every month, more content is being added and the plan is to continue to build our webpage over the school year. The site will also be scrutinized for its accessibility as we add content. Check each of them out and let Tanni know what you feel is missing. Your input is important!

Deafblindness Webpage: www.cde.state.co.us/cdesped/SD-Deafblind.asp

Check it Out!



Strategies for Teaching Children with CHARGE Syndrome and other Multiple Disabilities (DVD) - *Aapnootmuis Educainment* - In this 30 minute DVD recording of a presentation given at a recent Australian CHARGE Syndrome conference, Dr. Jan van Dijk demonstrates and explains 5 important teaching principles based upon his 40 years of work with children with multiple disabilities and derived from theories on attachment, contingent learning, and neuro-biology. The new Dutch findings related to the generics of CHARGE Syndrome are also explained. Cost: \$15.00. to order, send a check or money order payable to Mr. Joe Franken, 4619 Spyglass Drive, Dallas, TX 75287. For more information, contact Aapnootmuis Educainment. E-mail: info@aapnootmuis.com. Web: http://www.aapnootmuis.com.

HomeTalk: A Family Assessment of Children who are Deafblind (Spanish Version) - Bringing It All Back Home Project, 2003 - A Spanish translation of this assessment tool (HomeTalk: Una evaluación familiar para niños sordos) is now available on the web. HomeTalk is designed to help parents and care providers of children who are deaf-blind nad have other disabilities participate in their children's education by giving them a way to provide a broad picture of a child's skills, special interests, and personality. Available on the DB-LINK web site (http://www.dblink.org) in the Selected Topics section and on the Design to Learn web site (http://www.designtolearn.com) in the Products section. If you don't have access to the web, call DB-LINK at 800-438-9376 or 800-854-7013 (TTY).

Medicaid Reference Desk - The Medicaid Reference Desk is an online resource at http://www.TheDesk.info that explains Medicaid in basic terms, state by state. It gives people with cognitive disabilities, family members and advocates information about what is available through their State Medicaid Plans and waivers. The site also gives information on where to apply for services.

The resource explains each Medicaid service in ordinary language. People can see and hear the information rather than read it. So far, there are about 3,000 recordings on the site.

HEAR NOW - part of Starkey Hearing Foundation, accepts DONATED USED hearing aids which are sold to a repair lab. The money generated funds for the "So the World May Hear" Program which allows persons with low income to purchase a hearing aid for the cost of the application process (\$100 for one and \$200 for two). Compete instructions and application are available on the Starkey website: www.sotheworldmayhear.org Click on 'HEAR NOW' and follow the link to the application. If you have questions or do not have access to the Internet, call 800-648-4327 and a Starkey staff member will return your call. Posted by Shannon Butulla, on the SPARKLE Listserv.



WRITTEN BY ANDY CANNIZZARO

"I liked the sib shop because Kid's could express how they felt about their brother and or sister. It was also nice to see kid's that loved their sibling so much, and felt the same way as I did. All of the kids just wanted the best for their sibling. It also was nice because kids that you never know are now your new friend."

Family Learning Retreat...

By Jillana Holt Reuter, Mom of Caitlin, Michael, and Kenny

This year was a record breaker year for the FLR!! We had many families attend with a range of sensory impairments represented. I was absolutely astounded at the diversity and the amount of people that attended this year. My favorite part is seeing how much the kids have grown in size and accomplishments. My oldest boy is as tall as I am and he turned 14 on Saturday of the FLR!! I felt like I was at the State Fair with the biggest teenager saying "Look how he grew!!!" like I was competing in the "biggest

teenager" category hoping to win the blue ribbon. Nothing is more like the attitude of a mom than showing off their kiddos. The FLR was most definitely one of the nicest weekends I had spent with my family and husband in many months.

I had been in serious IEP meetings that weren't going very well the week of the FLR and I wasn't in the mood to go this year. I knew that I would be grumpy and a little hard due to the situations I had just been dealing with related to my daughter's IEP. It was literally the last minute that I decided to go. My husband, Kevin, reminded me that there would be so many people there I would want to see and if I didn't go, I would regret it. This was so evidently true... Kevin and I have so enjoyed talking to all of the parents we meet every year, but this year was exceptional. I am sure that no one was really aware how much they had or will touch our lives. Kevin found a couple where the husband is someone he has delivered plumbing parts to. This made him feel so connected to other parents this time around. "It's a small world" meant so much more to him. I enjoyed seeing all of the new people and also some of the ones that I have seen for years..... I love admiring them and seeing how they have changed throughout the year.

The FLR theme this year was focused on FAMILIES RELATE! I felt this was an excellent topic and Ian Watlington was exceptional (once again) in his presentation. He gave a sense of

accomplishment; understanding and true caring for all that we parents go through in the education process as well as life in general. When I sat down and read his paper "Danger: Disability & Euphemism Ahead," I was reminded about the interestingly different definition I have for the word 'consumer' now. This definition gives new meaning to my daughter's place in these systems. I also feel that my roles will change in a way with the definition of 'consumer' being attached to my daughter now. It is not me receiving the services here! It is her and the focus I attained from looking at this process has changed my thinking to

being much more of an advocate for her versus the consumer myself. There are some instances where I am the 'consumer' but they aren't near the number for her. We are all consumers of something and having a broaden light placed on the definition, made me have a smile that had a little smirk imbedded in it. When my daughter is identified as being a 'consumer', I silently know this is someone who isn't looking at her with an appropriate mindset. She isn't some pretty sponge soaking up dollars. She is much more than that. My task is set and I begin to make sure this individual has the full-dimensional view of my wonderfully talented daughter.

We all applaud and celebrate when we find parents that aren't going thru some of the muck that can happen in this journey. These parents are the ones we are so glad to see happen. These are the parents that we hope that the hard work we did may have paved them a bit of a smoother ride. After all, they still may be looking for Italy while they are still trying to figure out how they got to Holland. While I was listening to Ian share about his life, he mentioned the trip he and his mother took to Holland (metaphorically) and how they were still a bit miffed that they didn't make it to Italy. One thing I realized is that sometimes parents that are so still in the phase of "How the heck did I end up in Holland? My ticket clearly says

(Continued on page 8)

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Italy!" that they are not taking the time to look and see the various opportunities that being in Holland offers them. They also forget to make sure they have a life outside of being a parent of a child with special needs. There are many things in Holland that can only be experienced there. Windmills are one of them and those uncomfortable looking wooden clogs. I love clogs Don't get me wrong... I have 2 (soon to be 3) pairs of Danskos to prove it. Life in clogs is gooood...... Love 'em.

We as parents of children with special needs can get so wrapped up in learning the law, the best way to feed our child, how to help them sleep the night thru, etc, that we are forgetting to look around at the beautiful sights of Holland. They have gorgeous flowers that are nice to take a minute to admire with our senses. Maybe that will be the moment your child learns the correlation between that words you have been speaking/signing/picture symbol to them for the last 2 years and that it means that thing that feels soft and slippery all at the same time. These are the moments that last a lifetime! Life ought to be about making memories you take with you for the rest of your life! These are the moments that help you see this is what all of your hard work has been for.

So as I remembered why my week had been so hard and emotionally draining, I also took time to remember the good things that were there as well. My daughter's teacher was there even though her own son was staffed into Special Education that very morning. I know how hard that is. I have done it 3 times in my life. Her day didn't stop there either. Right after our late afternoon meeting, she was taking him to the hospital for surgery on his broken arm, and her son had never had surgery before. I think being scared was something she was feeling. I have nursed Caitlin through almost 20 surgeries and I get nervous each and every time. She took time for Caitlin and me under great expense to her own personal life. I felt incredibly important all of the sudden and also saddened. I never want to be that much trouble for anyone but it was her choice. I didn't ask her to do this for me. She could have rescheduled, but she didn't and I was so very thankful she made the choice to be there. I also was thankful for lan. He happens to be my daughter's educational advocate and he arrived early to get an agenda put together and was such a source of calming my nerves and feelings of frustration. There is no way in all of Hades that I will ever go to meetings about Caitlin without him.

Then there is the most magnificent Gina Quintana. Even though she couldn't be there for this particular meeting, the time she spent with me on the phone and previous meetings was paramount to this meeting being a success. I felt more secure in my logic regarding my thoughts for my daughter's goals and objectives. That is the hardest thing for me. I know where I want her to go and how to interpret her wishes and desires and how to help her get there is hard for me sometimes.

After remembering, very vividly, I am soooo not in Italy. I remember that there are some really great reasons why I like Holland as well. When I was in the different groups, I was hearing some of the many things I have heard all throughout my years in seminars, workshops and advice in this journey. I got a little bored and then I had wonderful warmth come over me. I had done it!!!! I had accomplished something really monumental! I had finally reached a point that I was very informed and almost saturated in the entire lingo, jargon, subtleties and politics of Sped! I was now maybe able to help others! I was at a point that I could concentrate on making the road less bumpy instead of trying to figure out where the hell I was headed and was I going in the right direction. I had in essence, found my compass rose and was able to determine right where I had been, where I was at that very moment and had a joy about where I needed to be going. This wasn't something I did all by myself.... Many of the parents that attended the FLR were a part of this experience for me. My husband was critical in this as well as other people who have stuck by my side throughout my years in Special Education. Gina Qunitana, Tanni Anthony, Barb Meese, Ian Watlington, Peg Long, Summer Learning Institutes, FLR's, NFADB, people at HKNC that are too numerous to list.

I hope my trials and experiences can help other parents see that even though their dreams for their children are in Italy, if they stop and look at what Holland has to offer, they can revise those dreams and have an even better sense of accomplishment as a parent when their child shows up in that brand new car they just bought for themselves and it has all of the details in it you heard your child speak about having in their car when they were growing up. Then they say to you "Come on, Mom! Let's go to the shopping!" and you are standing there tearing up because this is your child that has made it through incredible obstacles in life to get to this point and happen to be blind. They stand there

with a big proud smile on their face as they have a driver now, waiting to take you two out for a day of shopping. This is Holland... This is the realization that dreams change and can still be accomplished in a manner that is like *all* of the other people that live in Italy. Maybe their kids aren't disabled in any way, but did they have the same sense of accomplishment making it to this milestone? Are their child's accomplishments going to set an example for other kids and adults in their situation? You may never know, but you know how they touched your life and this is something you can share with the world! Like I was telling you at the beginning of this article, you then can be the parent with the State fair mentality of showing them off and saying "See what my child accomplished!" Take the time to look around you. Do it in the next few days. DON'T PUT IT OFF! Look and see what Holland has to offer.... The view is stupendous and I can't wait to see more of this beautiful country. I am sure that I will think about Italy from time to time but I am not so upset I didn't get there. Someone once told me ... "A mistake is something that if you could go back and change it, you would. A surprise is something you didn't even realized you wanted until you had it." I can't go back and change the fact I am in Holland. I just didn't realize Holland had so many wonderful surprises around every corner.

Even though I didn't feel up to going this year, I am so very glad I did. This is a community that even though we find it hard to get in touch with each other throughout the year, we still 'feel' the support

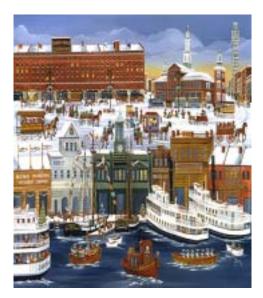
of all of our friends around us. We get this sense of support when we go to different events and realize that we are not so alone in this after all. I renew my strength thru all of you whether you are aware of it or not. Kevin and I had the oldest child with a sensory impairment at the FLR this year. We see how some of you look to us to see how we are doing things. How we handled this difficult situation and we have a great sense of accomplishment that even though are doing this for Caitlin, we helped smooth out the road a bit. I am happy to help people on their path while in Holland and help them see some of the glorious sites. I can be there for you when you are angry you aren't in Italy enjoying your plans and dreams. I know the feeling well and I understand. I can be your personal tour guide if you like.

Pam Elifritz has a great quote that I think all parents of children with special needs should incorporate in their lives "Do not follow where the path may lead – Go instead, where there is no path, and leave a trail" Don't follow my trail... walk with me for a time to learn some of my path to the point where you can then go out on your own and blaze your own trail. We can help each other along this trail and enjoy the view together.

Well wishes and warmth from my heart to all of yours,

Jillana Holt-Reuter, MOM (Master's degree of Motherhood) NREMT-B (and still learning)

American Association of the Deaf-Blind



American Association of the Deaf-Blind (AADB) is pleased to announce the dates and location for the next AADB national conference. The AADB Board of Directors approved a bid to host the conference on the campus of Towson University in Baltimore, Maryland, June 17-23, 2006. Mark your calendar!

More details about the conference will be available through AADB's website (www.aadb.org) and quarterly publication, *The Deaf-Blind American*, which is available to AADB members.

9

GET A LITTLE PEP IN YOUR LIFE!

Parents Encouraging Parents (PEP) Conferences are family-centered conferences designed to offer support, information, and education to parents and professionals. PEP promotes the partnerships that are essential in supporting and including children with disabilities and their families in all aspects of the school and community. The conferences are available to person residing in Colorado who have a child with a disability ages birth to 21 years. Administrators, principals, teachers, medical and other service providers who are interested in parent-professional partnerships are also invited. The two and one-half day PEP Conferences begin Thursday evening at 5:00 p.m. and end Saturday at 3:30 p.m. Child care is not provided. CDE pays for all meals, excluding Friday dinner, and lodging.

Dates for the PEP Conferences for this year are: November 3, 4, and 5, 2005 - in Glenwood Springs February 23, 24, and 25, 2006 in Estes Park April 6, 7, and 8, 2006 in Pueblo.

For more information, go to www.cde.state.co.us/cdesped/PEPapplication.asp or call 303 866-6846.

FOR PARENTS ONLY!

Interested in connecting with other families raising children with combined hearing and vision loss? The western regional Family-2-Family Listserv is up and running and we'd love to have you check us out! Recent topics include communicating effectively with doctors, interpreting your child's difficult behaviors, what computer programs work well for children with dual sensory loss. To be connected to the family-only listserv please e-mail Karen Roberts, Colorado Family Specialist at kdot62@comcast.net and your name will be forwarded to the Washington State Family Specialist who maintains the list.



TA Specialist HIRED!

The project has just hired Bill Muir to be a contract Technical Assistance Specialist for the project. Bill is a certified teacher of students with visual impairments and an orientation and mobility specialist. Bill will be working with Gina to provide TA to families and service providers. Be sure to let us know your TA needs!

Writing Considerations

By Kathryn W. Heller, Ph.D., professor, Georgia State University and Dawn Jones-Swinehart

Some students with physical disabilities will have difficulty using a pencil (or pen) and paper due to their physical disability. Some students will benefit from using a particular writing tool (e.g., a felt tip pen that glides easier than a pencil and that is darker). Sometimes the pen or pencil can be modified, such as using a pencil grip. There are a variety of pencil grips that may help the student hold onto the writing utensil and have more control over it.

Some students will benefit from an adapted writing tool. Pens and pencils are made with larger grip surfaces, different configurations, or added weight. Some students may wear a brace that helps hold the pen or pencil in place.

Some students may also need to hold the pen or pencil in a modified fashion. This may consist of holding the pen with a different grip. In some instances, the student may hold the pen with a different body part as seen in writing with a mouthstick and slant board.

Writing with a Mouthstick and Slant Board



This student is using a mouth stick in conjunction with a slant-board to writ a paper. These devices are used for students with limited or no movement or control in the arms. The slant board is adjustable to different heights to prevent the slant board from moving, it is sitting on a piece of non-slip material, known as Dycem. Sometimes adapted paper may be used that has wider (or darker) lines.

Another modification is adapted paper. Some students will benefit from darker lined paper or raised line paper. Sometimes the spaces need to be larger to help accommodate the student's needs. Students who have poor handwriting often benefit from additional handwriting instruction. Student's current handwriting should be closely observed for size, proportion, slant, alignment, spacing, and joining of cursive letters. There are several different handwriting programs available that may be used (e.g., Handwriting without Tears; www.hwtears.com). Some software programs are also available to provide custom made worksheets with dotted lines (or arrows showing which way to trace) to provide additional instruction (e.g., School Fonts by Mayer Johnson; www.mayer-johnson.com).

Some students may not be able to use pen and paper or their handwriting may be poor. Teaching keyboarding skills early will then be important. However, due to these students' physical disabilities, modifications may be needed to make the computer accessible.

Computer Access

Some students will have difficulty using a standard keyboard and mouse. When that is the case, there are many different types of modifications:

1. Typing on the computer/letterboard using a different body part

Some students may be able to type on a keyboard, but not with their hands. They may use

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a mouthstick or other device.

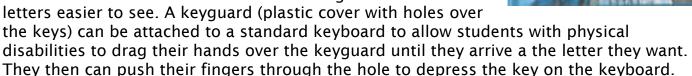
2. Accessibility Options on Computers

Operating systems on computers come with various accessibility options that can aid individuals with physical or sensory impairments to more easily access the computer. In

Windows, the Accessibility Options are found under the Control Panel. One example found the Accessibility Options file in Filter Keys. (Filter Keys allow Windows to ignore brief or repeated keystrokes or slow the repeat rate).

3. Keyboard Modifications

The typical keyboard that comes standard with computers can be modified. For example, labels can be placed over the keys that have dark bold letters on a white background to make the letters easier to see. A keyquard (plastic cover with holes over



4. Alternative Keyboards



There are many different types of alternate keyboards. Some appear similar to standard keyboards, but come in different shapes and sizes. Other keyboards may not be recognizable as a keyboard and require specialized training. The following pictures show examples of large and small alternative keyboards.

Large Alternative Keyboards

Some students with physical disabilities can access a computer best by using a large alternative keyboard. Some keyboards, such as an Intellikeys, can be programmed to use different keyboard arrangements and symbol configurations. Others can only be used

as a keyboard. In the picture, a student is using Big Keys, a large alternative keyboard that enables her to access a computer word processing program. It has large letters and highly contrasting keys making it good for younger students or those with vision or perceptual difficulties.

Small Alternative Keyboards

Students with limited range of motion are able to access a computer by using a small alternative keyboard. In this picture, a student is using a TASH MiniWin keyboard. A key guard is attached to assist with accuracy, reducing unintended key activation.

5. On Screen Keyboards & Alternative Input Devices Reach: An On Screen Keyboard

This student is using an onscreen keyboard in conjunction with a joystick to access a word processing program. An on-screen keyboard allows users with limited motor control to move a cursor across the screen via

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alternative access and click on the appropriate key to create words and sentences. This

particular program includes a letter prediction feature. After typing a letter, the keyboard will display only the letters that can reasonably follow. This feature enhances speed and accuracy of the typist.

Touch Monitor and On Screen Keyboards

This student is using a touch monitor to access computer software. The touch monitor allows the user to directly touch the screen in place of using a mouse. This may be combined with an on screen

keyboard or software program that uses a mouse.



Using One's Own Eyebrow to type with an On Screen Keyboard

This student is typing a message using her eyebrow! The on-screen keyboard (EZ Keys by Words+ www.words-plus.com) highlights blocks, rows, and individual letters depending upon what the student selects. Selection of the block, row, or individual letter is made by the student moving her eyebrow, which has a small switch that detects motor

movement mounted under a headband. The program includes word prediction that displays words starting wit the first letter(s) so that the word can be selected without having to type it out completely.

6. Voice Recognition Software

Voice recognition software allows the user to speak into a headset or microphone instead of typing by hand. The software converts the voice to text. It provides students with limited motor skills and/or processing problems an alternative means of computer access and control.



7. Screen Readers

Students with visual impairments may require software programs that read what is on the computer monitor. Several such programs are available.

IAWS (www.freedomscientific.com) is one example.

8. Output Modifications

While most students will produce hard copies of their work in a typical format (e.g., on letter-sized paper in 12 point font), some student will need to print their work with enlarged print in order to red their own work. Other students may need to produce a Braille copy of their work for themselves. Both enlarged print and Braille formats can be printed in the typical method so that the teacher has a regular print copy of the student's work. A Braille embosser and Braille translation software are needed to print Braille copies of student work.

Auditory output is also available for student who have visual impairments or for students who need auditory feedback. Several programs exist that allow the reader to hear letters, words, or sentences entered into a word processing program (e.g., WriteOutLoud by Don Johnston) or hear the text as it is presented on a web page (e.g., JAWS from Freedom Scientific).

Keyboarding Skills & Tools

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Keyboarding is an essential skill for any student. However, for students with physical impairments who may not be able to handwrite, keyboarding is crucial for the development of literacy skills. When possible, students should be taught to use the standard QWERTY keyboard (so named for the first six letters of the top row) to reduce generalization problems when using a different keyboard. However, alphabetical and Dvorak (a frequency-based layout) keyboards are available. Software is available to assist students with keyboarding speed and accuracy. Three common types of software are described below.

1. Word Prediction Software

Word prediction software, such as Co: Writer, Reach, and EZ Keys, provides possible word choices as the person types. For example, if the person was writing the word "definitely" on the computer. After typing the "d" the computer may display possible word choices such as "date," "dear," "decide," and "dare". Upon typing "de" the choices will change to reflect the second letter and may display "dear," "depend," "definite," and definitely". The student can then select the displayed word instead of typing out the entire word. This is helpful for students with physical disabilities who type very slowly or for students with learning disabilities who use the word prediction to assist with sentence construction.

2. Talking Word Processors

Talking Word Processors, such as Write Out Loud, can speak letters, words, sentences, and paragraphs. It can also be set to highlight each word as it reads. It can be used to read while the student types and to read the entire document when the student is finished.

3. One-Handed Typing Programs

There are several programs designed for individuals who only have one hand. The Half-Qwerty program by Matias Corporation, for example, allows the person to keep one hand on one side of the keyboard. Upon holding the space bar, the other half of the letters are transposed on the opposite side of the keyboard. For example, if a person only had a left hand, he would keep his left hand in the traditional position. To type an "f" it would be accessed by depressing the "f" with the left index finger. To type a "j", the person would depress the space bar and press the "f" which is no a "j". Another program, called "Five Finger Typist" teaches the user how to type by placing his hand in the middle of the home row.

Spelling

In order to be truly literate, students who are unable to communicate verbally need to have the ability to spell. Even students who are highly proficient with their augmentative communication device may not have their device available to them at all times (e.g., due to hospitalizations or equipments malfunctions). Additionally, even the most capable augmentative communication device is limited in the amount of words it is able to store in memory. Therefore, a student who is able to spell using traditional or phonetic spelling has the ability to communicate words and ideas not located on the device. Spelling will be an important skill to teach, especially for students with AAC devices that need to spell out what they want to say.

Written Expression

As students gain literacy skills, they begin to formulate more complex sentences when

reading or writing. Students who are nonverbal often have difficulty learning to create proper sentences because they are accustomed to being asked simple yes/no questions or questions that require one word responses. However, through direct teaching of the necessary components of a sentence (subject/verb) as well as adjectives and adverbs, students can learn to create more complex sentences. Some tools for teaching sentence writing are provided below.

Strategies for Beginning Sentence Writing

Beginning writing depends upon learning how to construct a sentence, then a paragraph, and then a paper. Many students who use augmentative communication lack experience constructing sentences, especially when single symbols are programmed to mean complete sentences. There are several strategies that can be used to help promote beginning sentence writing.

1. Provide a sample card of sentence

Many students will benefit from having a model of sentence construction in front of them for reference and for the teacher to use as a teaching aid. Teachers will often have an index card with an example for easy reference that is placed where the student can see it as sentence construction is being taught. An example of a sample card with very simple sentence construction is as follows:

SUBJECT (Who/What)	VERB (Action)	PREDICATE (Object) (What its about)			
I	like	Candy.			
Tom	ran	home.			

This beginning card is very simple and uses action verbs and simple nouns in the predicate. More complex cards can be made as the student progresses in sentence writing. These cards are often used along with one of the following strategies.

2. Arrange the words strategy

In this strategy, the student is given several words he must arrange in order to make a sentence. For example, the student may be given the words, "I" "music" "like". If the student is unable to physically arrange the words, he could point (indicate) which word to start the sentence and a partner could move the word to a beginning sentence line and continue until the student has selected all of the words. Another strategy is to pair words with numbers over them. The student selects the number and a partner arranges the words in order. Typing out the words is also an option, but the emphasis is sentence construction, and typing may take a long time, depending upon the student's physical abilities and means of access.

3. Complete the sentence strategy

In this strategy, the student is given an incomplete sentence to complete. The student may first be told a very short story to help her complete the sentence, or the student may make up his or her own response. Often the teacher will first have the subject missing for the student to complete (e.g., "_____ ate a hamburger"). The teacher then stresses what a

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subject is and possible words that could go in the subject. Often a sample card is on display as a reference. As the student learns about completing simple subjects, sentencsare give with the verb missing (e.g., "Tom ____ home"). Discussions about verbs then occur and possible verbs are given. Finally the sentence is given with the subject and verb and the predicate is missing (e.g., "Jerome likes ____"). Usually simple nouns are first introduced into the predicate. (Other orders of doing this can be equally effective. Some student do best with first being given the subject and verb and they complete the end of the sentence.) Over time, less and less of the sentence may be provided to encourage more independent writing skills (i.e., "___saw a ____"). Eventually, the student may be only provided with a topic or may need to develop one independently.

4. Expand the sentence game

Once a student is able to produce correct syntax and write simple comprehensible sentences, the complexity of the sentence should be examined. Some students have very few adjectives or adverbs in their sentences. One way to encourage more complex sentences is to first write out the student's sentence. Next, the teacher provides a card that lists the words, "size, shape, kind, color, how many, when, where, how, and how much." the student examines the sentence to see if it can be expanded to include any of these. The sentence is rewritten as more information is added to it. This can be done as a game in which the student makes a check by the descriptors on the card that he was able to use in the sentence and he receives points for each added word.

Student's sentence	Size	Shape	Kind	Color	How Many	When	Where	How	How Much	<u>Points</u>
(Write student's 1st sentence draft here). (Write student's next attempt here, check the columns the student used to expand his sentence & give points for each column that is checked.)										

Strategies for Beginning Paragraph Writing

Software is available to assist students with the process of writing paragraphs and papers. Two common software programs are Inspiration (or Kispiration for younger students) and DraftBuilder by Don Johnston. These programs help students with the prewriting and organization of their thought through the use of concept mapping, or webs. The actual writing of the paragraph or story is supported with outlines based upon the web created.

Reprinted with permission from Heller, K.W. & Swinehart-Jones, D. (2004). Strategies for Promoting Literacy with Students who have Orthopedic Impairments. Atlanta, Georgia: Bureau for Students with Physical and Health Impairments.

September, 2005



IT'S NOT JUST SCHOOL SUPPLIES!

Connecting families with combined vision and hearing loss in Colorado

Pencils, paper, book covers, backpacks, note cards, markers, two boxes of crayons, tissues, hand wipes, rulers, folders, watercolors...Wow, it's that back to school time of year again—when I think of everything I have to do to prepare my boys it seems guite overwhelming. And for my second grader it isn't just school supplies he needs to get off to a good start. Chris is our middle son and he has a combined hearing and vision loss. We have spent a month getting him ready for school—we've gone to the ENT to get his ears cleaned out, the glaucoma specialist to have his pressure and vision checked, two audiology appointments for hearing test and hearing aid maintenance as well as new ear molds, new glasses and a dental exam. Well, I'd say that's enough to wear a family out, but we did it and he is off to his first day as a second grader. I am looking forward to his school bus arriving home and hearing about his day. Even though it is never simple having a child with special needs I wouldn't change it for the world. I think all of our children are unique and even though I'm a little nervous I am also extremely proud as they all begin another school year filled with education and new friendships.

---Shannon

To Shannon's very comprehensive list of school supplies I can add a new intervener (paraprofessional), AFO's and a new feeding tube since Benjamin decided to pull his old one out. At the beginning of each new school year I don't sleep. I wake up at four or five every morning. Benjamin seems to adjust fine, some days he is too fussy to go and we stay home. Last night he was up most the night but seemed awake enough this morning to go to his second grade. The new intervener (who doesn't yet know that's what he is), is learning about object cues and communicating with a deafblind child. I am learning not be too nervous and to give them both time. It'll be a long year and as usual I am sure we will all learn a ton on this unique journey.

---Karen

We recently attended a conference put on by the National Family Association for Deaf-Blind (NFADB). They are a wonderful organization and we encourage you to check out their website at http://www.nfadb.org/ and consider joining. The national conference was entitled "Keeping It All Together—Strategies for Managing Family and Life." We wish we could give you the magic answer but as with everything else it's complicated and for some of us, keeping it all together may simply be a day without a feeding pump breakdown

or a child meltdown. It's a relative term—keeping it all together. But one key strategy agreed on by everyone at the conference was that talking with other parents and sharing the joys and challenges, the laughter and tears is an invaluable help in keeping it all together. As your parent representatives on the Colorado Services for Children with Combined Hearing and Vision Loss project, we hope to connect with you sometime soon. Another great way to connect with families in the western region is by the Family-2-Family Listserv. There are parents of children of all ages with a variety of diagnosis but all united with a vision and hearing loss. The listserv is still new and as we get going will become a great resource for sharing resources as well as stories about our kids—with folks who are there. To connect please send an e-mail to Karen at kdot62@comcast.net. Watch for discussion about the recent NFADB conference and what families think works and doesn't work on the listserv.

We're always looking for ways to connect with other families in the more remote areas of the state---we are just a phone call or an e-mail away. As the school year gets underway, and for the many younger children who may still be at that housebound stage (so recent for us!), please don't hesitate to call us or Gina at the project (303/866-6605). A few years ago we each took the initiative and called the project and have used the technical expertise we've received from Gina, the Lending Library, the Vibrations newsletter and workshops in every aspect of our children's lives. We've shared the information we've learned with the many therapists and educators that aren't familiar with deafblindness (or combined hearing and vision loss). It took the energy to make a phone call but it reaped great rewards. E-mail or call either of us to talk it over. We hope to connect with the rest of you throughout the year. The beginning of the school year is stressful but it is also filled with promise—may the year bring you and your family all good things! And when it doesn't, remember that you are not alone and give us a call.

Sincerely,

Shannon Cannizzaro 6151 Robb Street Arvada, CO 80007 303-424-6077 stc383@cs.com Karen Roberts 720 Hudson Street Denver, CO 80220 303-329-8950 kdot62@comcast.net

Writing and AAC

by Janet M. Sturm

http://www.asha.org/about/publications/leader-online/archives/2003/g3/030909g.htm

Literacy skills can enable quality of life for all members of society—especially those who use AAC. Although reading garners the most attention, for persons who use AAC the power of orthography takes on heightened importance, opening up opportunities for sophisticated communication across home, school, community, and employment settings. Reading allows individuals to learn about the world; writing provides access to the outside world.

The complexity of learning to compose text is particularly challenging for persons who use AAC because of cognitive, language, sensory, and motor needs. Despite these challenges, evidence is mounting that active participation in context-rich instructional opportunities can result in the development of reading and writing skills. Unfortunately, access to these opportunities has been limited. There are several erroneous assumptions regarding literacy instruction for children who use AAC that may be inhibiting this access. These assumptions include:

- Evidence of prerequisite literacy skills is needed before providing literacy learning opportunities.
- Writing skills are best taught in isolated tasks such as handwriting practice, worksheets, or grammar lessons.
- Conventional writing is not possible.
- Products of beginning writers should reflect conventional spelling.
- Spoken communication is not needed during writing.
- Symbol-writing activities provide a natural transition into conventional writing.

It is important that speech-language pathologists challenge these assumptions as they work together with school teams to provide meaningful literacy learning opportunities. In our work with students who use AAC, we use best practices of writing instruction with typically developing students as our point of departure. These practices employ an emergent literacy model of development where reading and writing are integrated with speaking and listening early in life. Best practices of instruction indicate that writing skills are optimally developed in daily, meaningful writing opportunities where children are encouraged to choose their own writing topics, drawings, and writing forms (e.g., sharing opinions or retelling a story) and publish products of their choice. Children also are allowed to choose their own letter combinations and engage in invented spelling.

Best practices also indicate that there is an extensive amount of spoken communication between teachers and students, and among peers, throughout the writing process. This communication involves a range of topics, some of which might include sharing a new idea, discussing a new angle, or providing suggestions for improvement. Finally, evidence does not exist indicating the need for symbol writing as a first step in the writing development of children who use AAC. Whenever possible, it is important that these students be provided with access to orthography when engaged in the writing process.

Language, Communication, and Writing

While language is recognized as central to literacy learning, children who use AAC often struggle to acquire basic language and communication skills. Across language domains they frequently demonstrate significant needs, including vocabulary delays, morphological difficulties, a predominance of 1–2 word utterances, poor syntax, impaired pragmatic skills, and restricted speech acts. Given what we know about the inseparable links between speaking, listening, reading, and writing, a solid foundation in language and communication is essential to full participation in classroom writing opportunities. Development of conventional writing skills will be enhanced when children who use AAC have rich background knowledge, access to a broad range of vocabulary to express that knowledge, and the communication competence to convey their background

knowledge using a range of AAC systems.

When setting up writing experiences for students who use AAC, we can use observations of skilled writers as a point of reference. Skilled writers set goals for writing, have a sense of audience, and approach writing tasks with strategies. They spend an extensive amount of time planning, generate ideas easily, and have an understanding of a variety of text structures. The act of writing involves the juggling of multiple factors, including audience, word choice, sentence development, and text organization. Skilled writers are able to manage these multiple constraints by quickly moving among these factors while in the writing process. From their earliest writing experiences, it is critical that students who use AAC have access to instruction and technology tools that allow them to move recursively among all writing processes.

Supporting Beginning Writers

Beginning writers are persons who are in the emergent to early conventional stage. They are in the process of learning that text makes meaning. In our research at the University of North Carolina at Chapel Hill, we learned that typically developing children in kindergarten and first-grade classrooms received an average of 85 opportunities during the school year to learn how to make meaning through writing. These same students created more than 100 drawings. Most students in general education classrooms achieve more conventional writing forms by the end of first grade.

Beginning writers focus their energy on generating ideas and producing text. They use images in their head to decide what to share through pictures and words. Central to idea generation is having knowledge of the topic at hand. Beginning writers typically use drawings to plan their topic before they begin to write. They chat with each other and their teacher about what they are writing. When this beginning text is created using invented spelling, the drawing and the oral language communicated during the writing process support joint reference between the creator and the receiver.

Our research also shows that beginning writers don't focus exclusively on narratives. They choose to compose a variety of forms of emergent text structures, including text labels, opinions, and story retellings. Students who use AAC can learn about text structures through frequent readings of a variety of types of books and through teacher models that illustrate multiple purposes for writing. Revising and editing are not core components of the writing process for beginning writers. Until second grade, revision during writing involves "saying more" by adding to already-composed text. Therefore, it is not essential that children who use AAC have their writing products edited for errors by teachers at this stage of writing development.

It is important that beginning writers focus on fluent expression of ideas in text. The goal is for students to write and then write more. Students who use AAC need rich life experiences and a solid language base that enables them to share through writing. Persons who use AAC can be beginning writers across the age-span. Understanding the key aspects of early writing experiences and the qualities involved in exemplary writing instruction will allow SLPs to offer appropriate writing support for students of every age.

Colin

Colin, a first-grade student with cerebral palsy, provides insight into the development of writing supports for a student who uses AAC. Colin uses a Dynavox as his dedicated communication system and actively

communicates through gestures and facial expressions. Academically, he knows his numbers, colors, and letters of the alphabet and can identify rhyme in words.

Colin is fully integrated in a general education first-grade classroom. His teacher uses a "writers' workshop" model of instruction where students choose their own topics; share and discuss with teachers and peers before, during, and after writing; and publish writing projects of their choice. Colin's teacher provides writing instruction through a series of short mini-lessons that help students pay attention to different aspects of the writing process. During a typical large group lesson, his teacher provides a model for writing by thinking aloud about her own

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writing process. For example, she may talk aloud about how she generates and chooses a writing topic. Following this lesson, students might be asked to create a folder that contains a list of possible topics for their daily writing. Mini-lesson topics take on a variety of forms, ranging from use of writing conventions to development of sophisticated text structure to selection of vocabulary.

In order for Colin to successfully participate in writing, it is important that he have access to writing tools as well as vocabulary on his AAC system. Because of physical difficulties that result in a slow writing rate, Colin will not be able to compose as many writing products as the other children in his class. It is essential that his writing tasks be carefully chosen to reflect appropriate writing development and high-quality instruction. When Colin plans his writing, he works with his parents to take and choose photographs that reflect important events in his life. These photographs will be used as his "drawings" and allow him to choose topics that reflect his knowledge and that are important to him. The photographs parallel the drawings created by his peers and fit nicely with a mini-lesson on generating and choosing topics.

To be successful during classroom writing sessions, Colin also has access to vocabulary on his AAC system that allows him to communicate with his peers and teacher. For example, he may ask a peer, "Hey, let me see what you picked," to ask about a writing topic. Composing means that Colin's "pencil" includes several AAC tools—an eye gaze frame, a Dynavox, an alternate keyboard, and an alternate mouse system.

While composing, Colin can engage in "writing" through a variety of forms. He can use a Qwerty keyboard array, either on his Dynavox or on an alternate keyboard, to compose text. Like his peers, composing using standard orthography will allow Colin to use invented spelling when writing. Also like his peers, the photograph selected as Colin's "drawing" will support his teacher and his peers in understanding Colin's invented text. Colin also may use word banks located on the eye gaze frame, alternate keyboard, or word-processing program that support him in composing text at a faster rate. When using the word banks, Colin chooses among words that set him up for different types of emergent text forms. For example, he can choose "I like..." to compose a text reflecting his opinions. He also may have vocabulary choices that represent his writing topic.

In this classroom the teacher uses "author's chair," a writers' workshop activity that features individual student sharing of writing products and includes a follow-up large-group peer discussion. When it is Colin's day to share his writing, he is able to introduce himself to the group using his Dynavox and tell the class his writing topic. He then releases his writing product line-by-line using the Dynavox or a talking word processor. Students in the class also choose what writing products they would like published and shared with others. Colin has access to publishing software that allows him to print and share his work.



For students who have greater cognitive or language needs, the tasks above can be adapted to reflect their individual learning needs. For example, a student who is not yet able to compose text using orthography can choose a photograph as her "writing." The adult supporting this student can generate a simple label that can be written below the photograph, read aloud using synthesized speech, and published for others to read. For each writing event there are multiple ways in which the task can be adapted to offer meaningful opportunities that foster the writing development of individual students42

The Role of SLPs

SLPs can play a strong role in fostering solid foundations for communication and language that lead to the development of conventional writing skills. A broad range of authentic and meaningful reading and writing should be integrated into the daily curricular experiences of students who use AAC. It is important that these children are afforded rich literacy learning environments that support them attaining their optimal writing performance. SLPs can support the writing development of children who use AAC by:

- understanding the student's individual learning needs. Assessing the capabilities of students who use AAC will assist
 in knowing where to start with instruction.
- using knowledge of the development of all language domains to support them in building a solid language foundation. Access to rich natural language learning contexts at home and school is essential.
- learning about writing development and best practices of writing instruction. Exemplary writing instructional
 approaches used in general education classrooms can be used as a point of departure for children who use AAC.

- identifying the mode(s) and strategies through which the student will compose text. Children who use AAC will be most successful when supported in being multimodal communicators (e.g., use of a combination of no-tech and high-tech systems).
- ensuring that AAC systems support the range of communication during all writing activities and that these systems
 reflect students' individual profiles. Students who use AAC need access to vocabulary during each writing event in
 the day. The amount and sophistication of their messages will depend on the student's language and communication
 skills.
- selecting systems that will support ease of movement between communication and writing and in the writing
 process. Ideally, students who use AAC will have their communication and writing tools readily accessible at all
 times. They should be able to move back and forth between talk with others and text production.
- assisting with home-to-school transfer of personal experiences that can be used to stimulate topic and idea generation for writing. The transfer of information between home and school can be fostered through a variety of formats, including activity logs, journals, remnants, photographs, and recorded messages.
- building background knowledge that supports topic and idea generation for writing.
- working together with the school team to generate and organize photos that can serve as "drawings" to support students' writing. Photographs shared by the family will only be used in the classroom if they are set up in a userfriendly format that allows teachers to access them easily. Students who use AAC can assist with prioritizing and organizing photos as potential writing topics. When they begin planning, students will be familiar with what is available and their selection will be made easier.
- identifying classroom discourse patterns (e.g., peer conferences or author's chair) of the writing curricula. Eventspecific communication overlays can be created together with the school team that reflect the classroom communication patterns of the writing curricula.
- fostering classroom-based communication opportunities during writing events. SLPs can role-play together with children who use AAC to develop communication competence across the writing process. For example, these roleplaying activities may involve learning how to use communication overlays, communication tools, or word banks. These activities also may foster the student's knowledge of the form, function, and timing of messages essential to successful classroom participation.
- being available in the classroom during writing events to facilitate the student's success in communicating orally or in text. As students work to build communication competence, it is important that they have adult or peer supports available that scaffold them during writing experiences.

Looking Toward the Future

In the future, it is critical that we move greater numbers of students who use AAC from emergent to conventional writing. From infancy, critical connections between language and literacy learning must be made. We must look together to find out which writing activities are most appropriate for students at varying levels of language and literacy development. We should examine which writing activities at varying grade levels provide core foundational experiences across literacy levels. We also must determine which writing tools are best for different writing tasks. Together with educational teams, SLPs have the opportunity to play a core role in the integration of communication, language, reading, and writing. The SLPs' knowledge of language learning applied in the development of writing skills can enable greater access to the world for persons who use AAC.



Janet M. Sturm is an associate professor in the department of communication disorders at Central Michigan University. Her research and clinical interests relate to computer-supported literacy, tying together literacy assessment and instructional strategies, classroom communication, and educational integration of AAC users.

Resources on Writing

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Calendar of Events

2005	2005	2005	2005	2005	2005	2005	2005	2005	2005	
October 7	7				lind Parer agi at 303			r		
October 2	21-23	Colorado Symposium on Deafness - Breckenridge Contact: Diane Covington (719) 578-2226								
November	· 3-5		Parents Encouraging Parents Conference - Glenwood Springs Contact: PEP Hotline (303) 866-6846							
November	· 8-11	AT and Accessible Media in Higher Educatio Contact: National Training Team - 516-944-89 ntthknc@aol.com; web site: www.hknc.org								
November	• 9-12		2005 TASH Annual Conference - Milwaukee, WI <u>Contact</u> : www.tash.org							
December	1-3	Getting in Touch with Literacy Conference - Denver Contact: www.gettingintouchwithliteracy.org								

2006	2006	2006	2006	2006	2006	2006	2006	2006	2006		
January 16	•		Affective Needs Conference—Denver Contact: lthoenne@jeffco.k12.co.us								
January 19)-21		Conference on Inclusive Education—Denver Contact: www.peakparent.org								
February 1	0-11		Courage to Risk Conference— Colorado Springs Contact: www.couragetorisk.org								
February 2	3-25			• •	Parents - (303) 86	- Estes Pa 6-6846	rk				
April 6-8				• •	Parents - (303) 86						
June 2-4		<u>Cont</u>	tact: Gind	•	•)B 866-660	5 or				

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A Federal Review of our Deafblind Project

Colorado was one of 10 states selected for a federal review called the Site Verification Visit The review was designed to evaluate the project's Self Assessment Report, which was turned into the federal government in April of 2005. The Self Assessment Report covered 20 domains of grant activity.

The site review team, consisted of three reviewers, came to Colorado on August 29-30 for this purpose. They reviewed a host of documents and interviewed staff and project recipients over the two day period. The result: he Colorado Services for Children with Combined Vision and Hearing Loss received the highest review possible of our Self Assessment Report! The team had to rate fields specific to the proposed project strategies, their timeliness in implementation, whether they were adequately addressed, whether there was evidence of effort and effect data, and whether there was evidence of expected results. Over 100 fields were rated at the highest rating. So the Self Assessment essentially received an A+ or a 100% What is means in layperson's terms is that the grant proposal said what we would do, the Self Assessment reported what and how we did, there was evidence that we did what we said we would do, and that we had data to support that what we did was effective. YAY, Colorado!

In addition to the verification of the Self Assessment, the team summarized project strengths and need areas. See below for their exact narrative. One of the project reviewers, Bruce Dalke said, "This project is gold!" That was music to our ears. And, of course, they had some constructive feedback. First, lets start with their listed project strengths:

Project Strengths

The project's very committed and experienced staff are most appropriately credentialed and exceptionally skilled. A very clear vision of mission and priorities are evident in their broad array of activities. Project personnel have established and maintain a true team approach to development and delivery of services with all relevant CDE departments and personnel, to the benefit of deafblind learners, their families, and service providers.

- Despite the limited TA-dedicated FTE (.6), the project has been extremely effective in extending its services and impact through contracts with individuals (e.g., parent consultant, family specialist, other technical assistance providers as available) and early childhood agencies (e.g., Anchor and CHIP).
- The project is to be commended for its substantial collaborative relationships with numerous projects and agencies.
- The project's location within the CDE, in combination with the collaborative skills and reputations of project staff, afford the program a particular advantage in its ability to influence systems change within the state. Most notable have been the involvement of project staff in (a) the design and adaptations of the state achievement tests, ensuring that children at all functional levels can be included; (b) the embedding of some deafblind-specific content into course content and state licensure requirements for preservice programs of sensory disability teachers and O&M instructors; (c) the issuance of a state mandate for inclusion of a highly qualified sensory professional in the assessment of and IFSP development for infants and toddlers with dual sensory impairment; and (d) the addition of deafblind-specific criteria to the state monitoring protocol.
- The project's evaluation goals and activities are well-articulated in a series of seven levels. The project targets the most critical components of the program, and acts on findings from data analysis.
- The project is to be commended for the thoroughness of its census procedures. To the best knowledge of
 this review team, Colorado is the only state to have aligned its census count with their state December 1
 student count. Most outstanding is the project's development of functional vision and hearing
 assessments (in collaboration with the state's DHH consultant), for appropriate documentation on the
 census.
- The project's dissemination efforts are extensive and very effective. The project accesses the CDE's
 discipline-specific mailing lists and listservs to disseminate information that is most relevant for particular
 audiences. In particular, the project's newsletter and fact sheets are highly valued by both local and
 national consumers.

Additional comment:

This review team found the project's self-assessment to be highly accurate. It was evident that project staff had a clear understanding of how to report effect and effort data.

(Continued on page 24)

(Continued from page 23)

Area of Project Need

One: To fully credit more of the project's impact by further data collection from other agencies who serve children with combined vision and hearing loss AND who receive some funding from the project. Meaning, we are actually providing services to more children than the project is currently reporting. That is easily fixed and our thanks to the good folks with Colorado Home Intervention Program and Anchor Center for Blind Children for helping us collect additional information.

Two: Modify the Deafblind Force and turn it into a true Advisory Committee. Gina is already working on this recommendation. If you are interested in serving on an advisory committee for the project, please be in touch with Gina.

Three: Increase efforts in gaining information from parents are their training and support needs. With the help of Family Specialist Karen Roberts and Parent Consultant Shannon Cannizzaro, we have lots of ideas to improve our communications with families of children who have both a vision and hearing loss.

In summary, it was a wonderful validation of all of our individual and statewide work with students, families, service providers, and other agencies. Our thanks to all of those who contributed to the Self Assessment Report process and the Site Verification Visit! Thank you also for everyone who has supported the project and the important work of educating and supporting students with combined vision and hearing loss.



What is a Story Box?

It is simply a collection of items in a box or bag that corresponds to the items mentioned in a story. A Story Box is a way for young children with visual

impairments to experience a story. It is an early literacy event that can easily fit into your daily routines as well as a tool to enhance the learning of concepts. In short, it is a fun, interactive learning experience for children and adults alike.

REMEMBER:

- It takes more time to figure out what an object or shape is through tactual exploration than through vision. A tactual learner needs to examine parts of an item separately then put the information they have gathered together to gain full understanding of the item.
- Words are just symbols representing ideas and concepts. Without meaning, words are a series of disconnected sounds and letters. Hands-on experiences help to provide meaning to words.
- You need not present all the items in a box with each reading. Determine your child's interests

and attention so as not to over whelm her with *stuff*.

Share your story boxes with young sighted children. They are very popular.

Why Story Boxes?

The purpose of a story box is to create hands-on literacy experiences for your child. Educators have long emphasized the importance of tactual exploration, i.e. hands-on learning, for young children with Visual Impairments. This is important not just for future Braille readers who will be using their finely tuned sense of touch to discriminate letters and to decode words, but also for all young children so that they can take in information, build concepts and further understand their world. Purposeful exploration involves thinking, and concept building. Children gather information through the experiences that they have. This is how they develop an understanding of how things relate. These experiences give meaning to their lives through the development of concepts. Literacy for any child emerges from hands-on experiences. Sighted children's experiences are rich with opportunities for learning that occur by chance, however, children with Visual Impairments seldom, if ever, take in information incidentally. Yet

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teachers often expect that the youngster with blindness comes to school with the same information that sighted children have picked up on TV, through pictures, etc. Hence, the importance of hands-on experiences such as Story Boxes for young learners with blindness.

Step 1: Books, Books Everywhere: Choosing a Story

- ⇒ When selecting a story for your child, choose one that is simple and tells about familiar objects and concepts. Story Boxes can range from very concrete hands-on to the more complex and abstract.
- ⇒ Initially a box might contain items that your child uses during daily routines. You can make up a story about the routine or family activity. Your child may be the main character of your story. It can be about a trip to Grandparents, bath time, mealtime or a playtime with Dad. No book is really needed.
- ⇒ Choose books about familiar activities. Those stories will be meaningful for your child
- ⇒ Variety is fun. Expose your child to different types of books. Adaptations may make the book more accessible and interesting. Simple board books can be enhanced with Braille Dymo tape. Twin Vision books provide enrichment for siblings as well. Sound books can be made accessibly by affixing a little texture to the spon one must depress to activate.

CHOOSE:

- Books that have characters and items that are readily available. Remember the complexity of the story and the number of items presented should be suited to your child. Often, simple is better.
- ② A story to match your child's attention span. Short and sweet works well for young children.
- A book that does not rely on visual experiences or pictures to provide meaning to the story.
- Books that are predictable and that have rhythm and rhyme.

Step 2: Getting It All Together: How to Actually Construct the Story Box

Choose an appropriate book

<u>Select</u> corresponding items. You may choose to go on a shopping spree but often collecting familiar objects from your household will do just fine.

Place the book and items in a storage container.

Although many folks us Zip-Lock bags or shoe boxes, sweater-sized plastic containers are preferable as they are stackable and durable, thereby affording you an opportunity to establish a story box "library".

NOTE: prying these boxes open is a beneficial activity which develops the hand strength needed to read Braille.

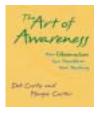
Label the exterior of the container. A tactile marker will enable you and your child to "read" the title; e.g. three pieces of fake fur might be a good label for the story of *Goldilocks and the Three Bears*.

Step 3: Reading the Story

- Handle the objects in the box one at a time giving your child lots of time to explore. Comment on the item's size, its shape, and texture then name the item. If it's a spoon, pretend to eat. if it's a shoe, try it on. Allow the child to explore freely. Compare items.
- After tactually exploring the items, place them aside. Read the story and once again present the items as they are mentioned in the story. Avoid clutter. Too many items at once can be very confusing for young children with blindness.
- Have fun when reading. Use sound affects and dramatic intonation to peak your child's interest.
- When you finish with the story box, put clear closure on the activity by having your child help place the objects back in the box. This provides another opportunity to handle the objects.
 - Children can experience the same story box at many levels over time. Some children will want to touch the Braille on the page. Others will enjoy anticipating and their favorite items, while still others will memorize the book and tell the story to the adult.



What is NEW in the Lending Library?



The Art of Awareness by Deb Curtis and Margie Carter

Featuring nine Observation Study Sessions, *The Art of Awareness* offers ideas, activities, and experiences, as opposed to just a set of checklists and facts to learn. Chapters cover observing seven different aspects of children's lives as well as tips for gathering and preparing documentation. A full-color insert provides examples of documentation. **Order: G70**

<u>Perkins Activity and Resource Guide</u> by K. Heydt, M.J. Clark, C. Cushman, S. Edwards, & M. Allon - The second edition of the *Perkins Activity and Resource Guide* provides a wealth of practical information for those who teach and care for children with visual and multiple disabilities. This book promotes a functional, child-centered approach to learning by addressing the basic principles of teaching children with multiple disabilities, educational guidelines and resources. In addition, it provides sequential checklists and a variety of lesson plans in major areas of instruction. **Order: V 115**





<u>Learning Through Touch: Supporting Children with Visual Impairment and Additional Difficulties</u> - Supporting Children with Visual Impairment and additional difficulties. This text examines the role of touch in teaching and learning. The book is divided into four parts, with each part incorporating a series of activities designed to draw out key issues from relevant chapters and invite the reader to explore the implications for his or her practice. **Order: V 116**

Reflecting Children's Lives by Deb Curtis and Margie Carter

Deb Curtis and Margie Carter present practical ideas in this thoughtful and beautiful hand-book which makes the complex task of planning a child-centered curriculum easier. Learn how to make theme plans, establish times for observation and play, set up schedules, materials, space, and more. Each chapter contains an insightful and touching story by teachers as well as charts, assessment tools, resource lists, and practice sheets. You'll discover activities for both you and the children, and at the same time, chart your own thinking as you consider new possibilities for your curriculum planning. **Order: G 69**

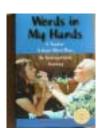


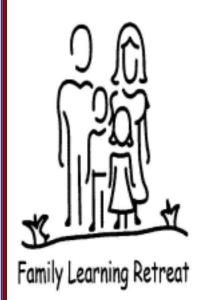


Autism Spectrum Disorders and Visual Impairment by Marilyn Gense and D. Jay Gense - Amid the current controversy around autism, this timely book focuses on the complex and varied effects on learning and behavior that result when a child with an autism spectrum disorder is also visually impaired. In this comprehensive look at how autism spectrum disorders interact with visual impairments, two exceptional educators condense their years of personal and professional experience into a one-of-a-kind handbook of effective ways to work with students. **Order V 117**

Words in My Hands by Diane Chambers

Beautifully and eloquently written, Chambers' story takes the reader through the intricacies and complexities of not only deafness and blindness, but the language itself. This impactful memoir is a must-read for professionals in education, social services, healthcare and rehabilitation. It is an inspiration to the general public as well. **Order: D 100**





The Family Learning Retreat 2005 was held in Colorado Springs this past June at the Colorado School for the Deaf and the Blind. There were <u>27</u> families who attended this wonderful event. We would like to take this opportunity to thank the following people, who helped make the weekend such a tremendous success.

Presenters and Facilitators: Ian Wattlington, Jane Rock, Laura Douglas, Hal Goldstein, Melissa Waggoner, Katherine and Robert Baldwin, Kevin Utter, and Sharon Smith.

Planning Committee: Marybeth Herens, Jon Vigne, Melissa Shular, Shannon Cannizzaro, Jeannene Evenstad, Stefanie Morgan, Gina Quintana and Sandy Radice.

Donations Committee: Jillana and Kevin Reuter and Stefanie and Mike Morgan



We would also like to extend a special thank you to the following businesses who sponsored door prizes that were given out during the weekend:

Jose Muldoon's
Starbucks Coffee Company
Jamba Juice
Creative Memories
Southern Living at Home
Chipotle

North Jeffco Parks & Recreation Department APEX Center
Highland Hills Park & Recreation Department - Water
World
Path Walker Body Work
Kroenke - Colorado Rapids



The Family Learning Retreat 2006 is Already Being Planned!

It will be held at the Colorado School for the Deaf and the Blind in Colorado Springs on June 2-4, 2006. Save those dates and watch VIBRATIONS for more information. If you have any questions or a particular speaker that you would like to see present at this retreat, please give Gina Quintana a call at 303-866-6605.

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