

# VIBRATIONS

**NEWSLETTER OF COLORADO SERVICES FOR CHILDREN WHO ARE DEAFBLIND**  
Serving Children with Combined Vision and Hearing Loss (Deafblindness),  
Their Families, and Service Providers  
Spring / Summer 2007



## The Passionate Advocate

By Sandy Lyon

We advocate for our children, ourselves and for countless other causes nearly everyday, without even recognizing what we are doing. However, it is when we start thinking of advocating for a child with special needs who has an Individual Educational Program (IEP), medical concerns, legislative changes and so much more, that for many of us, the term advocacy becomes intimidating. It was to me. We hear about how advocacy pertains to laws, environmental issues, politics and countless other subjects. In order to be an effective advocate, do you need to have a law or political science degree or do you need to be a famous Hollywood star? We watch famous people on television advocating for whales, kids in foreign lands and even the spaying of our pets. Does it take extraordinary financial resources or specialized degrees to be a truly effective advocate?

"This advocacy stuff sounds like a huge headache, something I'm too tired and too overwhelmed to deal with!!!" That is what I said on the phone to an old friend last July before heading off to Tampa, Florida. The person I was speaking to at the time was a dear friend of mine from twenty-five years ago. We had been talking about my son, Michael, and specifically about some of his new challenges and the many concerns I have for his education and future. I explained as best I could what it is like to parent a child with so many issues. His words seemed too simple. Could he be right? Was advocacy really about passion?

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With that in mind, I headed for Tampa to attend the National Parent Conference on *Advocacy and Leadership - Achieving the Vision*, conducted by The National Technical Assistance Consortium for Children & Young Adults who are Deafblind (NTAC) and The National Family Association for Deafblind (NFADB). The first thing I learned was to carry a cheat sheet containing the numerous commonly used acronyms and their meanings. These terms are tossed around without anyone blinking an eye. Honestly, that was the toughest part. The rest was easy and so very informative. Not a moment was wasted. For two days they packed fabulous information and resources into our heads.

The first morning we were greeted by an attorney from Chicago, Matt Cohen, who has been working in special education advocacy for twenty-five years. His section was titled *Special Education Under the New Individuals with Disabilities Education Act (IDEA) 2004 and Navigating the Individualized Education Plan (IEP)*.

One of the key concepts Matt emphasized is to remember that Special Education is a political issue and not an educational issue; just one of numerous reasons to link to the many websites containing information on changes to Special Education law. Also, as we see changes in the congressional and legislative branches of government, we need to stay connected and correspond with our state officials. Matt also mentioned "statute shopping" and how parents can endeavor to make the best of each law. In general federal laws prevail, but state law must meet minimum federal requirements or provide benefits beyond those afforded by federal law. Which ever provision gives your child the greater rights, the better education, etc., state or federal, and then pursue that law. He also said "never assume that school officials know more than you know."

Regarding the IEP, use the IEP to set the baseline or minimum for what your child needs. It can be very inclusive; from parent training to what they bring home from school or the assistive technology devices they need. The IEP can include specifics from the time your child gets on the bus until the time they get off the bus. The important part of the IEP is to focus only on what effects the child most significantly; don't focus on the little issues! Use VERY MEASURABLE language and goals in the IEP. Also, focus on the specific services and accommodations your child needs. Services and accommodations, once made a part of the IEP, are legal elements the school must provide, whereas goals are just that. Goals are not as measurable and are highly subjective, especially when lacking specifics. For example, if your child needs one hour of individual, one-on-one therapy, the IEP must state exactly that. Otherwise, your child could be placed in group therapy, with five other children. Such an arrangement could result in a teacher meeting five hours of required work in just one hour. Matt's final comment was one that stuck with me and should serve as a basis for virtually all advocacy decisions. He said "the purpose of all special education and all standard education is to prepare kids to be successful in all aspects of real life...not just academically."

- The law, pending legislation and regulations can be found within many of the websites which I have included in the Resource Guide following this article.

After Matt spoke, we heard from Joseph J. McNulty, Executive Director at the Helen Keller National Center. He spoke about deafblind issues on local, state and national levels. He discussed deafblindness, the current definitions, the proposed changes, the recommended changes and the rationale for the change. This is an area where our children really need our advocacy!!

He said, "approximately 85% of the more than 10,000 children served by the federally funded State and Multi-state Deafblind Projects have, in addition to their hearing and vision loss, additional disabilities including cognitive disabilities and physical/health impairments." Currently the definition in the IDEA states that a child has multiple disabilities if they are more than deafblind. Mr. McNulty is

working to have the definition revised to state: "if a child has both significant hearing and vision loss, whether or not other disabilities are present, that child must be reported under the category deafblindness." He went on to say,

"We need to advocate keeping the codes of Deafblindness. Do not let the school change the label to something else. Deafblindness magnifies other disabilities. If deafblindness is listed as the secondary disability, what else could you have which would be worse as the primary disability? Is your child's teacher qualified to work with a deafblind child? Chances are no. In fact your child may be the first child the teacher has ever worked with, that has combined hearing and vision loss. If the school codes your child as having multiple disabilities, then in some settings, anyone may be deemed capable of working with your child. If deafblind is coded as primary, the teachers may need specialized training."

Of the many things I learned at the conference, the message in the above section was one of the most important. As I sat listening to this presenter, I became passionately aware that to act in my son's best interest, I could not, would not; let the school change Michael's Primary Disability to Multiple Disabilities. We recently had Michael's Triennial. At that meeting, we were able to change his Primary Disability to Deafblind and his Secondary Disability to Speech-Language! It had been Visual Disability as Primary and Deafblind as Secondary; the combination had never made sense to me. Thanks to the things I learned from Mr. McNulty, we came to the meeting prepared and prevailed!

As the time for changing the IDEA definition of deafblindness draws nearer, it will become more and more imperative to advocate for our children in this very important issue. It will be crucial, when the time comes, to contact state senators and congressional representatives. We need to act on our kids' behalf when they look at the change of definitions under IDEA. Stay tuned, I have no intention of letting this slip by without a lot of letter-writing, faxing and anything else I can do. These changes don't come about often, so when we have an opportunity, we need to take full advantage of the situation and effectively work for change. This can help all of our wonderful children.

The afternoon session was spent with Dr. John Reiman, the Director of DB Link. He spoke about *Conflict Resolution Styles and Strategies*. This was an enlightening session, learning about the different ways we can resolve conflict. One of his main points was this: "We as parents cannot get so caught up in the process and in the issues that we forget the child." We need to be well informed, ask questions, questions, questions and listen. Then, we must consider what motivates the other person so we can better plan our strategy. Always keeping in mind... that it's all about our child. It is okay if we understand the other person before they understand us. In other words, listen and do not insist on getting your point expressed first.

Because this session involved so much role playing, I would suggest checking out the many specifics regarding conflict resolution styles and strategies in John's power point presentation, which will be available through the Colorado Project for Students with Combined Vision and Hearing Loss' Lending Library.

The next morning Sheri Stanger, President of the NFADB and Elisa Sanchez Wilkenson, coordinator of Regional Directors for NFADB spoke about *Perspectives on Empowerment, Leadership and Advocacy*. Some of the key points worth sharing include:

- ◆ Know your topic, be prepared, have written notes - they will keep you focused.
- ◆ You don't have time to be unclear; above all do not be emotional.
- ◆ Believe in your capabilities.
- ◆ Stay calm; everyone is working within the same system.

- ◆ Keep organized records; keep everything - even notes sent home from school.
- ◆ Document, document, document! Keep a pad by the phone and make detailed notes including names, dates and times! Save notes where you can find them!
- ◆ When you advocate effectively, you may change an entire system.
- ◆ **Remember who is going to benefit from your efforts!!!**

Sheri and Elisa also went into detail on how to tell your child's story. Often your child's story needs to be effectively told at IEP meetings, to hospitals, insurance companies, teachers, legislators, congressional committees and more. Knowing how to properly tell the story is one more step in becoming a passionate and effective advocate!

After Sheri and Elisa concluded, we attended concurrent sessions on effective communication skills. We acted out various scenarios with regard to:

1. Speaking with schools or public officials.
2. Giving testimony at a public hearing.
3. Writing letters to elected officials.

I have recently written letters which I hope will prove to be effective. Congressman Ed Markey of Massachusetts is spearheading an effort to increase funding for the technical assistance and dissemination program at the Department of Education aimed at helping children who are deafblind. The funding for deafblind programs has not received any increase in twenty years, yet there are more than twice as many children with deafblindness now than there were twenty years ago. Because I am on the NFADB list serve, I received an email alerting me to this important issue. I contacted the congressional representatives in Colorado and asked for their support of this funding increase. At the time of this article, the decision has not been announced, but I am hopeful that my work paid off and someone from Colorado will sign on as a supporter.

Being an informed advocate involves staying on top of the current events which affect our children. When you feel like you just cannot deal with anything more... remember the passion; the passion you have for your whole family and how that passion can help you get back on your feet to do what the child with special needs in you life needs. We all have passions and the intimate passion we have for our very unique children is what makes being an advocate so worthwhile and ultimately, so much easier than it sounds.

So, in the end, it truly is all about passion. I know I have unlimited passion for Michael, as you do for your child. Each year when I attend the Family Learning Retreat in Colorado Springs, I see many of your familiar and kind faces; I see it in your eyes and in your hearts... the passionate advocate!

Happy Advocating...Don't Lose the Passion!

Sandy Lyon  
slyon@access4less.net

*(Editors' Note: Thank you, Sandy, for this important article. You are truly a passionate advocate!)*





# Resources



Being informed is one of the best tools to being an effective advocate for your child. Please use the following Internet sites to stay informed. They are excellent resources and pertain to a huge array of subjects relevant to many of our children.

<a href="http://www.cec.sped.org">www.cec.sped.org</a>	Council for Exceptional Children – Policy and Advocacy
<a href="http://www.democracynaction.org">www.democracynaction.org</a>	CT Parent Power – Advocacy 101
<a href="http://www.dblink.org">www.dblink.org</a>	DB Link
<a href="http://idea.ed.gov/">http://idea.ed.gov/</a>	U.S. Dept. of Education – Building the Legacy: IDEA 2004
<a href="http://www.monahan-cohen.com">www.monahan-cohen.com</a>	Matt Cohen, Special Education Attorney
<a href="http://www.dbcoalition.org">www.dbcoalition.org</a>	National Coalition on Deafblindness
<a href="http://www.nfadb.org">www.nfadb.org</a>	National Family Association for Deafblind
<a href="http://www.nclld.org">www.nclld.org</a>	National Center for Learning Disabilities
<a href="http://www.pacer.org">www.pacer.org</a>	Parent Advocacy Coalition for Educational Right
<a href="http://www.taalliance.org">www.taalliance.org</a>	Technical Assistance Alliance for Parent Centers
<a href="http://capwiz.com/thearc/home/">http://capwiz.com/thearc/home/</a>	The Arc Legislative Action Center
<a href="http://www.directionservice.org/cadre/">www.directionservice.org/cadre/</a>	Consortium for Appropriate Dispute Resolution in Special Education
<a href="http://www.fape.org">www.fape.org</a>	Families and Advocates Partnership for Education
<a href="http://www.nichcy.org">www.nichcy.org</a>	National Dissemination Center for Children with Disabilities
<a href="http://www.wrightslaw.com">www.wrightslaw.com</a>	IDEA 2004 made simple; a resource you've seen before but it is well worth mentioning again!

- A notebook containing copies of the power point presentations from this conference will be available in the Colorado Project's Lending Library. They are, however, loaded with acronyms!!! If you check the book out, feel free to email me and I'll look up anything you need from my notes



“Teaching children to be knowledgeable about differences, supportive of others, and active in changing structures that are oppressive to various groups can all begin within inclusive classrooms. It is within a classroom that openly and directly addresses the interests, needs, and possibilities of all its members that students may best experience democratic structures that empower and support all participants.”

(Sapon-Shevin, 1992, p. 21).



# New Fact Sheets!

- \* Coloboma of the Eye —Order Number 063
- \* Promoting the Wearing of Glasses—Order Number 064
- \* Storybook Boxes—Order Number 066
- \* Dandy Walker Syndrome—Order Number 014
- \* Syndromes Associated with Progressive or Degenerative Vision and Hearing Loss Order Number 045
- \* Taking Up Make Up—Order Number 048
- \* Tips for Successful Medical Appointments—Order Number 052
- \* Incorporating Active Learning—Order Number 060
- \* Promoting Literacy Through Emergent Writing—Order Number 061
- \* Focus on Congenital Rubella Syndrome—Order Number 062

The Colorado Project has 66 different Fact Sheets with information about Deafblindness. Many of these Fact Sheets are also available in Spanish. You can either download the Fact Sheets directly from the website, or you can download the Order Form and send it to us and we will mail you the requested Fact Sheets.

<http://www.cde.state.co.us/cdesped/SD-Deafblind.asp>



## Family—2—Family Listserv

**What is Family-2-Family?** An internet listserv designed to connect families living in the western United States who have a child with combined vision and hearing loss.

**What is a listserv?** A listserv provides a way for internet users to participate in discussions or receive information from other members on the list. An e-mail message from one member of the list is automatically distributed to all other members of that list.

**Who can join?** Any family member of a child or youth who is deafblind and living in one of the following state: AK, AZ, CA, CO, HI, ID, MT, NM, NV, OR, Pacific Trust Territories, UT, WA, WY

**Why would you want to join?** To develop a relationship with other families of children who are deafblind; to share ideas, gain support, ask your burning questions, laugh about life's funny calamities and celebrate family successes.

**How do you join?** Send an email to Karen Roberts with a request to join the Family-2-Family listserv. After joining, you will receive a welcome letter with instruction and guidelines for listserv use, as well as a request to submit a family bio to the listserv.

**For more information:** Contact Karen Roberts at [kdot62@comcast.net](mailto:kdot62@comcast.net)



**Paula Kluth**

Toward more inclusive classrooms  
and communities

<http://www.paulakluth.com/index.html>

This website is dedicated to promoting inclusive schooling and exploring positive ways of supporting students with autism and other disabilities.

Links are included to take you to the following topics (and more):

Do You See What I Mean? Creating Visual Literacy Supports for Special Needs Students  
20 Ways to Adapt the Read Aloud  
Honoring and Including Students with Communication Differences  
Making Relationships a Priority

# Deafblind Advisory



The Deafblind Advisory meets 2-3 times a year, in Denver, to discuss issues around the Deafblind Project. The current membership includes Project Personnel, Teachers of the Visually Impaired, Teachers of the Deaf / Hard of Hearing, Agencies, Helen Keller National Center, Commission for the Deaf, Center for the Blind, Social Security, Part C, Vocational Rehabilitation, and Parents. We are currently looking for a Student Representative for this Group.

If you have a High School student who would be eligible to serve of this committee, please give Gina Quintana a call at 303-866-6605. We would love to have a student's input!

## Colorado Services for Children with Combined Vision and Hearing Loss

**Project Director:**  
Tanni Anthony  
(303) 866-6681  
anthony\_t@cde.state.co.us



**Family Specialist:**  
Karen Roberts  
(303) 329-8950  
kdot62@comcast.net



**Project Coordinator:**  
Gina Quintana  
(303) 866-6605  
quintana\_g@cde.state.co.us



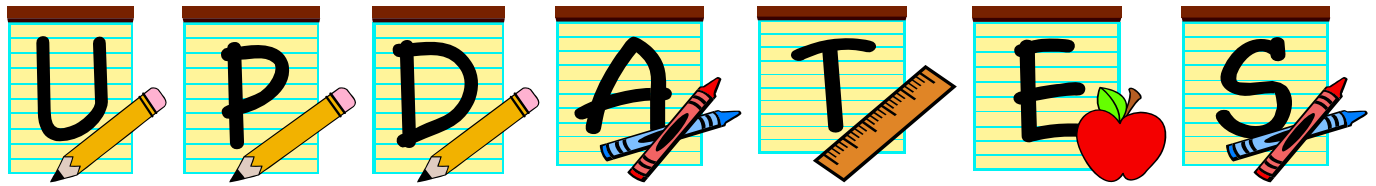
**Parent Consultant:**  
Shannon Cannizzaro  
(303) 424-6077  
stc383@cs.com



**Location:** Exceptional Student Leadership Unit  
Colorado Department of Education  
201 East Colfax  
Denver, CO 80203

**Fax:** (303) 866-6811  
**TTY:** (303) 860-7060





**This Newsletter Edition:** This edition of VIBRATIONS is focused on the topic of inclusion and the general education curriculum. Please be in touch with us on how we can provide assistance to you on these important topics.

**Colorado Census of Children and Youth with Deafblindness:** The census is a CDE-approved data collection process to identify the children ages birth through 21 years who have a combined vision and hearing loss. All identified children, their families, and service providers are eligible for free technical assistance from the project. The census forms were mailed out to each district / agency contact person by last November. Please find the article in this newsletter about the census results. Thanks to all of you who worked with us to ensure an accurate count! If you have any questions, please be in touch with Tanni Anthony at (303) 866-6681 or [anthony\\_t@cde.state.co.us](mailto: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 and in this newsletter edition.

**Literacy in Action:** We would love to come to your classroom or home to capture "literacy in action" - we are developing modules of best practices and would love to include your good work!

**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>

**Summer Institute:** Check out the flyer and registration form for our one-day Summer Institute In the City with David Brown located on page. Space is limited, so be sure to register soon!

The Colorado Services for Children with Combined Vision and Hearing Loss Project is part of the Colorado Department of Education. This project is supported by Grant #H326C030022 from the U.S. Department of Education. This newsletter was produced and distributed pursuant to the grant. Points of view do not necessarily represent CDE positions or policies. Mention of trade names, commercial products, or organizations does not imply endorsement by the U.S. Government. The newsletter is published three times a year. Requests to be placed on the mailing list should be mailed to Gina Quintana, CDE, 201 East Colfax Avenue, Denver, CO 80203. This newsletter was prepared by Tanni Anthony and Gina Quintana.





## A PARENT'S PERSPECTIVE FROM ONE PARENT TO ANOTHER

### What Inclusion Means to Us

By Karen Roberts, Family Specialist

As I write this article for *VIBRATIONS*, it's early on a Monday morning and my family is just starting to wake and head out the door for another week of work and school. I think Benjamin may have half an eye open...in a few minutes I'll help him wake up, change him, dress him, move him to my bed where I'll tube feed him, and give him his sandpaper cue which will let him know it's a school day. Since his ears are draining some nasty stuff we'll skip the hearing aids. And the glasses...I'll let him wake up a little more and we'll see if this is a glasses day or not. Into the wheelchair he'll go and down to the van where the noise and routine of going to school has become all very familiar, click goes the seatbelt, grind and slam as the van door closes, on and on goes my voice about going to school as we drive the four short blocks to our neighborhood elementary school, down the van ramp and on to the playground where once he hears all the voices of the kids—a light of recognition and anticipation crosses his face and up his arms go in excitement.

And on some days that is enough for me to know that we are doing the right thing. Benjamin spends the first half of his day in the third grade general education classroom and has math and some “down” time in the special education classroom. Our school is not a center school for children with severe support needs. But I didn't really know that when I was searching for the “perfect” place for him, six years ago. I started looking early, and it was overwhelming. There were almost too many options in our district (Denver). Eventually our family narrowed it down to three priorities—

The most important thing to Benjamin and his family for his elementary school education is that he be included in a general education classroom in a neighborhood within his community—social inclusion is an essential part of every child's education; his family will be involved in the neighborhood school; Benjamin's classmates will motivate him to reach his potential and he will motivate them to achieve theirs. The second most important goal we have for Benjamin is that he be able to communicate his wants and needs in a generally understandable way. The third most important goal we have for Benjamin is that he be allowed the same rights of access as other children to typical school activities such as the playground, art, music, the cafeteria, the auditorium.

These goals were important as we went through the very complicated “placement” process with our district. Different folks said different things. Certainly everyone supported (and legally had to) his going to our home school. BUT, we also needed the structure in place to make the education meaningful for Benjamin. And that has taken an incredible amount of work on my part, as well as on the part of key IEP team members. It has meant great patience when I was told there was not a bathroom to change him in (it always seems to boil down to that!), waiting a long time for books to be adapted and for a paraprofessional to be found and hired. It has taken a few years for the staff to feel completely comfortable with Benjamin and his educational style. And every year is a new teacher and a new working relationship. I feel the key to Benjamin's success is a positive working relationship among his IEP team. We have gone through a few people but all in all he is supported by an incredible team. But it has taken time to reach this level of trust and comfort with one another.

Everyone's story is different and our children's needs change through the years. But the acceptance of Benjamin among his peers, those with disabilities and those without, is a constant. I anticipate that Benjamin will be in a more segregated situation in middle school and beyond, but I am also confident that the community he is a part of, and will continue to always be a part of, is so much stronger and richer due to his inclusion. And I feel that is important for all my children. That they contribute to the world in whatever way they can, make it a better place and make it a good place. That makes for a good life. What more can we ask for?

# When Students Have Severe Disabilities

*Reprinted with permission from the Fall 2006 SESA Newsletter*

*By Margaret Cisco, education specialist, SESA*

Regular and special educators often have limited exposure to individuals with severe disabilities so they assume these students cannot learn. A related problem occurs when educators initially believe the individual can learn, but the instruction provided does not result in learning, so they conclude that the student cannot learn after all. These expectations and conclusions are flawed because they are based on inaccurate assumptions. The fact is that since the middle of the last century, fundamental beliefs about individuals with severe disabilities and the instructional interventions for them have changed. These changes reflect a different set of fundamental beliefs.

During the 1960s, individuals with severe disabilities were placed in institutions for “custodial” care because the belief at the time was that they could not learn. A pioneer special educator named Marc Gold developed a framework for instruction based on a different set of fundamental beliefs. His beliefs were that: (a) students with severe disabilities have a lot more potential than anyone realizes; (b) people with disabilities should have the opportunity to live their lives much like everyone else; and (c) everyone can learn if we can figure out how to teach him or her. Marc Gold’s slogan was: *Try Another Way*. Or in other words, “If at first you don’t succeed, try and try again.”

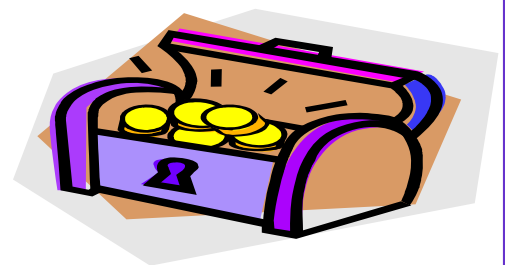


Friend and former SESA specialist, Doyle Burnett, described the educator’s job with an analogy. He said that a student who has a severe disability is like a treasure chest. The educator’s job is to find the key that will open the chest to reveal the treasure within. This analogy can be taken a step further. Consider the treasure seekers’ staying power: They do not stop with the first key if it fails to open the chest. As educators, we need to keep trying new keys until we find the one that works for our student.

Our students with severe disabilities rely on all of us to “try another way” over and over again until we get it right for them. We must focus on changes to the environment, activity adaptations, and instructional strategies that support students who must engage in instruction differently from their peers to be successful learners. Students may experience cognitive challenges, autism, orthopedic impairments, and/or other limiting conditions. The fundamental belief of this author is that even students who most people think cannot learn will be able to do so with appropriate accommodations and positive expectations. Our goal is to provide many potential keys to the treasure chest for you to try if the first one fails. Use the keys to spark new ideas and try the ones that fit best based on your knowledge of the student and change them as you learn more about your student.

For more information about Marc Gold’s work go to:

<http://www.marcgold.com/aboutmarcgold.html>



# Start with Three Key Concepts

*Reprinted with permission from the Fall 2006 SESA Newsletter*

*By Margaret Cisco, education specialist, SESA*

These three key concepts apply across all areas of low incidence disabilities. They are *respect, organization, and expectation*. Set up the learning environment with these three concepts to create a solid foundation for the educational program.



## **FIRST KEY CONCEPT** **Be Respectful of the Student**

Lack of respect is a barrier to learning. The following situations demonstrate a lack of respect for students with severe disabilities and describe the alternative. Use the list to assess the classroom situation and teach others how to show respect for the student with severe disabilities.

1. Many students with severe disabilities have instructional aides with them all day long. Whenever educators or peers look at or talk to the aide but do not include the student, the student is not respected. Everyone in the student's environment needs to interact directly with her. Speak to her and wait for her to respond in her own way and time. Teachers need to be models of good interaction for peers and explain to them how the individual can respond. It would help to ask other students or teachers how they would feel if no one ever addressed them.
2. Some students with severe disabilities cannot speak. When educators or peers talk to each other in front of the student as if the student is not present, then the student is not respected (and it's just plain rude!). To show respect, everyone needs to include the student in the conversation and talk about information that is interesting and relevant to him. Otherwise, save the conversation for another location or time of day.
3. Many students with severe disabilities have a delay between taking in information and reacting to it. When educators or peers do not wait for the student to process and react to information before they proceed, then the student is not respected. To show respect, everyone should wait long enough for the student to understand before expecting him to respond in some way.
4. Some students with severe disabilities may not understand information they see or hear. When educators or peers do not notify the student before a change (e.g., before moving or touching, changing position, giving or taking an item, going to another location, or starting a new activity), then she is not respected. To show respect, everyone must inform the student of what is about to happen, and they need to do it in a way that she can understand. This may not be words. Other ways for giving information are discussed in the visual supports section. Be sure to wait until the student shows that she understands before making the change.
5. Many students with severe disabilities have full time paraprofessionals with them throughout the school day. When educators leave the entire program to para-professionals and do not provide directions, materials, and ongoing program support, then the student is not respected. To show respect, educators need to consistently work with the students who have severe disabilities and the

paraprofessionals who support them.



## **SECOND KEY CONCEPT** **Get Organized**

A second common barrier to instruction and learning is the lack of instructional planning for students with severe disabilities. While other students have classroom schedules, classroom routines, and daily lesson plans, the students with significant needs often go with the flow. This can mean anything from doing something on the whim of the adult or just listening to what is happening around the class.

1. Establish a daily activity schedule (and stick to it!) Typical classrooms have daily schedules, even though the schedule may vary across weekdays. For example, Monday's schedule may be slightly different than Thursday's schedule. Often, the student with a severe disability is moved from place to place without a plan for the day.
2. Even when there is a plan for the day, the student may feel as though events are random because no one informs him. Be sure to inform the student of his schedule in a manner he understands. This will usually require some form of visual support.
3. Use consistent routines for typical daily activities. Everyone functions well with routines. Good teachers know that routines help students to learn, to better manage their behavior, and to become more independent within the established classroom framework. These same benefits of routine also apply to students with severe disabilities. Doing things in the same way with the same cues will increase the student's ability to understand what is about to happen, and thereby better engage in the anticipated event.



## **THIRD KEY CONCEPT** **Enable Active Participation**

In most schools nowadays, the special education placement model involves inclusion. In other words, students with severe disabilities go to general education classes. Whether the student is included or attends class in the special education room, another barrier to learning occurs if the student has no purpose except being present and cared for in that location. Being present and cared for is not enough. When educators do not expect and modify activities to enable participation, learning cannot occur.

SESA multiple disabilities program specialist Kathy Osinski uses a good rule of thumb to evaluate whether the student is actively participating. The original source of the following is unknown:

Ask yourself if a potato could do what the student is being asked to do. If a potato can do it, then the student is not actively participating. For example, a potato can be present in the kindergarten or in the chemistry class so just being there is not active participation. Other articles in this insert address student participation in more detail.

# Access to the General Education Curriculum TWO STRATEGIES

Reprinted with permission from the Fall 2006 SESA Newsletter.

by Margaret Cisco, education specialist, SESA

Definition of appropriate curriculum for students with severe disabilities progressed over time as educators became more experienced with such students and researchers began to assess the benefits of different methods for different curriculum content.

- ◆ Initially, the students with severe disabilities were given the kinds of activities given to typically developing infants and toddlers. Exposure to these activities did not support skill development, which is hardly surprising. After all, if exposure had supported learning in the first place, the students with severe disabilities would not need special education instruction.
- ◆ The next effort was to break the same developmentally sequenced activities into smaller steps. Instruction often meant practicing the same skill over and over with the same toys regardless of student age or interest. Although there were some exceptions, life skills and academic skills were generally ignored because the students never did master the entire range of early developmental toys and activities.
- ◆ Eventually, researchers and educators discovered that adults with severe disabilities were more motivated by functional activities, those with real meaning rather than baby toys. The students could participate partially and still be active in the tasks and learn, even though they were unable to perform the whole task without help. With accommodations and supports, individuals with severe disabilities could become more independent in real-life activities than anticipated. The curriculum emphasis shifted to functional and community-based instruction. Gradually, the school age curricula focused more on developing functional skills in life domains such as self-care, housekeeping, community skills, work, and recreation/leisure. Students were “integrated” or “mainstreamed” with other students. They were able to join other students for generally non-academic periods where they could fit for social interaction or participation only. This was called a Community Based Curriculum (CBI). Academic instruction was limited to the skills that would apply in the curriculum domains. Many adults educated in this era are essentially illiterate because they were not taught reading, writing, or math.
- ◆ The inclusion movement emphasized placement in chronologically age-appropriate classrooms in neighborhood schools. The goal was to facilitate belonging and peer interaction. Unfortunately, in many situations, this only meant that a one-to-one aide was assigned to the student creating a social barrier. Sadly, it often meant that neither the general education teacher nor the special education teacher developed or managed the student program, often leaving it up to the person with the least amount of training or experience.

The current requirement of IDEA 2004 is that all students including those with severe disabilities have access to the *general education curriculum* with learning goals consistent with those of students without disabilities. The implications are: (1) all students, even those with the most severe disabilities need access to the general curriculum, including instruction in reading and math and (2)

students with significant disabilities need instruction that is effective in helping them achieve their state's alternate achievement standards for reading and math (and science beginning in 2007-2008). Realization of these goals presents significant challenges for students who have traditionally been given labels of mental retardation, autism, deaf-blindness, traumatic brain injury, and multiple disabilities. Curriculum access is not the same as physical access to the classroom. Sometimes, the student's specific support needs may require that instruction occur outside the grade level classroom.

In any case, whether the placement is a self-contained classroom or resource room (with integration or mainstreaming for some parts of the day) or whether placement is full time in a grade level classroom with age peers, the student is expected to be an active participant who is engaged with materials and grade level curriculum content, active learning, and communicating with other students and educators.

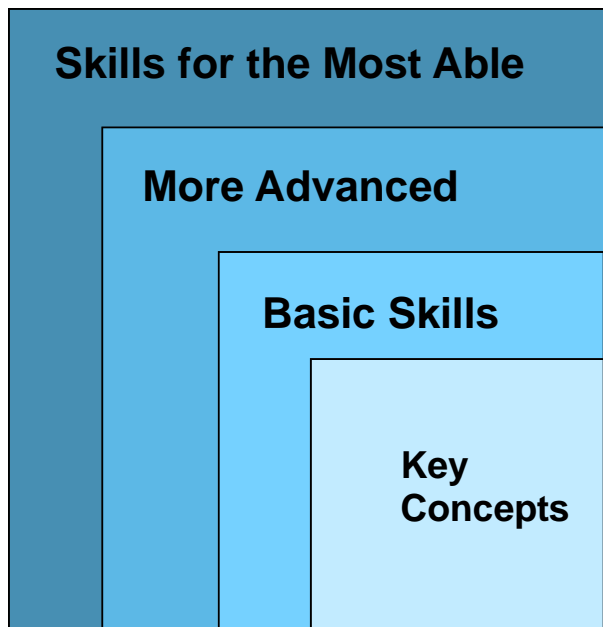
**STRATEGY #1:**

**Selecting Content from the General Education Curriculum**

When choosing the content to address, the curriculum can be viewed as having many levels of information to be learned. The student with severe disabilities may only be expected to learn key concepts.

The general education teacher will be able to assist the team in choosing key content for the class.

The diagram below explains how to select what to teach from the grade level curriculum. The student with severe cognitive challenges might be exposed to all of the information in a chapter, but would be expected to learn or be tested on key concepts.

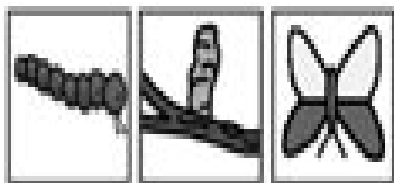


Examples of key concepts:

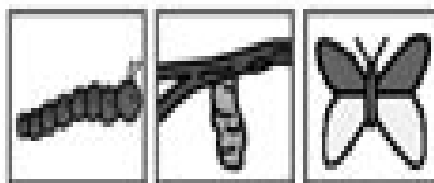
The seventh grade science class is learning about life cycles. The target student is learning to sequence three story pictures. His content is learning about and sequencing pictures of the three stages of the life cycle of the butterfly and the life cycle of the frog.

The sixth grade class is learning about grammar. The target student is a beginning writer. Her target skill is learning to use a capital letter at the beginning and a period at the end of the sentence.

How might a student with severe disabilities participate as an active learner with grade level content? One example is the 7th grade student learning about life cycles. The student's IEP goal relates to learning to sequence three pictures to tell a story: beginning, middle, and end. By blending his IEP goal with the grade level content of the science class, his assessment task is to sequence the stages in the life cycle of butterflies and frogs using three pictures like these:



and



## **STRATEGY #2**

### **When the General Curriculum Seems Like a Pipe Dream**

Sometimes a student with severe disabilities seems to have interests and skills so far from other students in the same grade, that it can be hard to figure out how to provide education related to the general curriculum. This section covers the use of “routines” as a support. Teaching with routines can bridge the gap between lack of participation and participating in typical routines that are different from classmates, and/or from participating in the same routines as peers to access the general curriculum. Teaching with routines is a well-researched support strategy recommended across severe disabilities.



Develop a routine in the following manner: The first example schedule and routine is for a student with deafblindness or multiple disabilities. It is adapted from <http://www.tsbvi.edu/Outreach/seehear/archive/routine.html>

### **CHOOSING THE ACTIVITIES**

Before setting up routines, it is important to decide which daily activities to formalize into routines. The following tips will help in this process:

1. Write the sequence of activities that occurs in a typical school day.
2. Begin by picking obvious activities where routines are likely to already exist, such as eating and toileting. Next, look at the activities that adults must do for the student. Would these activities be made easier if the student could participate partially? For example, it would be helpful if the student could anticipate when the adult needs to slide a diaper under him and participate by raising his bottom rather than requiring the adult to lift him. Finally, look at those activities that could be done as vocational activities.

### **Developing A Routine**

After identifying activities for routines, it will be helpful to write out the routines. List all the steps in the activity in the order in which they occur. The amount of detail in each step will depend on the expectations for the student. Work on specific IEP objectives if they fit into the routine. These objectives would be written into the routine script. One objective might be included in several different routines.

#### **SCHOOL SCHEDULE**

8:30	a.m.	undress
9:00	a.m.	bathroom
9:15	a.m.	morning gathering
9:30	a.m.	table activity
9:45	a.m.	free time
10:00	a.m.	music
10:30	a.m.	medication and snack
11:00	a.m.	physical therapy
11:30	a.m.	music
12:00	p.m.	computer
12:30	p.m.	recess
1:00	p.m.	lunch time
1:30	p.m.	bathroom
1:45	p.m.	wash up, brush teeth
2:00	p.m.	library
2:30	p.m.	dress to go home
3:00	p.m.	go to bus



### **Example:** Mealtime/Snack Routine with IEP targets in parentheses

1. Walk to the table (Trail walk from hall to cafeteria.)
2. Find place and sit down
3. Look for spoon when tapped on table and pick it up (Use vision to explore space and locate objects. Grasp object.)
4. Allow adult to help scoop and carry spoon to mouth (hand-over-hand.)
5. Set down spoon and reach for cup when drink is offered, or set down cup and reach for dessert. (Indicate choice by reaching for preferred item.)
6. Help move plate away when meal is finished
7. Allow adult to wipe off hands and face
8. Drink medication from medicine cup
9. Remove bib (Remove clothing independently.)
10. Get down from chair

Track the student's progress by taking periodic videos of the activity or keeping data.

As seen in the example above, routines provide multiple opportunities to practice a skill in a familiar context. If the routine were developed around classroom participation, such as the free time slot in the schedule, the student would be able to interact with peers without disabilities. Routines provide opportunities to work on functional skills in natural contexts (e.g., dressing for the outdoors, not just to practice shirt-off, shirt-on). Routines also provide predictable events for students who can learn to anticipate and initiate their active role and demonstrate how they are "smart."

The example that follows is for a student with autism or autism characteristics: A typical way of structuring tasks visually might include using baskets or folders for assignments. The student would be taught to get the first basket, complete the task inside, then return that basket and get the next one. Once the student understands the structure and is able to utilize it for independent work, he can use the same routine in the grade level classroom.







Routines can be developed and taught for communication, classroom participation, and academic performance. Each of us uses routines throughout the day. They allow us to be efficient in what we do and enable attending to the content that requires our focus.

### **Conclusion**

In this new millennium, nearly fifty years since Marc Gold advocated "try another way," there continues to be educators who remain uncomfortable in working with and sometimes disrespectful of the type of learners with significant support needs. Without adequate training/knowledge, some educators may even think that their students belong elsewhere, such as a special school or institutional setting. Within Alaska and across the country, it is difficult for teachers and aides to get the information and support they need to use appropriate instructional practice with the challenges presented by working with their students with severe disabilities.

***Editors' Note: We thank Margaret for sharing this article with us. Please be in touch with the Colorado Services for Children with Combined Vision and Hearing Loss Project on how we can work together on educational programs for our learners with deafblindness. Contact Gina Quintana at (303) 866-6605 or Quintana\_g@cde.state.co.us for further assistance.***

Use this chart to “pat yourself on the back” for strategies already in place and to consider what you will add next:

	Already doing this one. Give myself a cheer!	I think I'll start this next
✓ Student is shown respect by peers and adults.		<input type="checkbox"/>
✓ Student has a planned daily schedule.		<input type="checkbox"/>
✓ Student participation supported and expected.		<input type="checkbox"/>
✓ Visual supports make sense to the student.		<input type="checkbox"/>
✓ Student has a meaningful way to demonstrate knowledge of key concepts from grade level standards.		<input type="checkbox"/>
✓ Consistent routines enable student participation		<input type="checkbox"/>

(Chart concept contributed by Brenda Jager, education specialist, SESA)



**WORLD WIDE CONNECTIONS**  
Breaking the Isolation



**14th Deafblind International Conference**  
September 24—30, 2007  
Perth, Australia  
<http://www.dbiconference2007.asn.au/>



# From Here to Activity . . .

*Students that do not write, communicate verbally or comprehend the curriculum at grade level can actively participate, just look and see!*

*In Biology, student receives the same worksheet as others in lab. Student scribbles on the paper as others label the parts of a plant.*



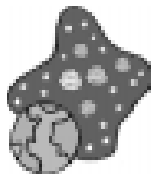
**Active Solution:** Give students Avery labels with simplified terms i.e. stem, roots, leaves etc. Instruct students to use the stickers to independently label the parts of the plant.



*In Health, students create the Food Guide Pyramid. A paraeducator pastes magazine photos onto paper while the student attends therapy.*

**Active Solution:** Mount a switch accessible camera onto the student's wheelchair. Instruct student to photograph foods from each food group during a fieldtrip to the supermarket.

*In Astronomy, students study diagrams of constellations. A paraeducator studies the pictures for the student with low vision.*



**Active Solution:** Photocopy constellation diagrams. Outline each with puffy paint. Let students explore tactile maps with their hands as the teacher lectures.



*In Math, a paraeducator completes long division problems on a worksheet for the student.*

**Active Solution:** Student uses an IntelliKeys keyboard with MathPad software to set up problems and answers independently.

*In History, a paraeducator uses a pencil to fill in the blanks on a test. The student with physical and sensory disabilities sits with a lowered head.*



**Active Solution:** Convert test to multiple-choice format. Create an ABC grid for communication device. Instruct paraeducator to read the questions and choices to student. Student answers A, B or C by pressing a switch.



*In Chemistry, students verbally identify solvents and solutes during a review session. The nonverbal student watches and listens.*

**Active Solution:** Add pictures of food items such as soda pop, water, sugar, etc. to an AAC device. Prompt student to press a key and choose a classmate to identify the food item as a solute, solvent or solution during a review.

*In Computer Class, a paraeducator moves the mouse and student's hand in a preschool program while others create pages for the school web site.*



**Active Solution:** Create a template of the web page. Prompt student to select text and background colors, use a trackball to draw a picture and type their name with a keyboard.



*In Physical Education, the class practices archery outside. A paraeducator shoot hoops in the gym along side a student*

**Active Solution:** Student joins others outside to practice turn-taking, social interaction and learn the names of archery equipment.

# Check it Out!

- ◆ The PAD-CO listserv (Parents of Adults with Disabilities - Colorado) is pleased to announce the Colorado Coalition to End the Wait List for Adults with Developmental Disabilities (CCEWL). According to The Alliance (an association of Community Centered Boards in Colorado) there is currently a waiting list of 3,746 folks for services for adults (those over 21) by the developmental disabilities system. And, it is growing longer daily. Right now there are parents in their 60's and 70's still waiting for services for their adult child with a disability. You may read the Alliance report at: <http://members.aol.com/padcoweb/alliancereportimages.htm>.
- ◆ The CHARGE Syndrome Foundation announced that their manual, "CHARGE Syndrome: A Management Manual for Parents" version 2.1, is available as a free online resource. The manual is broken down into over 30 chapters that can be downloaded separately, or the entire 269 pages can be downloaded as one file. The manual can be found on the internet at [www.chargesyndrome.org/resources-manual.asp](http://www.chargesyndrome.org/resources-manual.asp).
- ◆ The National Family Association for Deaf-Blind (NFADB) is a non-profit, volunteer-based family association. Their philosophy is that individuals who are deaf-blind are valued members of society and are entitled to the same opportunities and choices as other members of the community. NFADB is the largest national network of families focusing on issues surrounding deaf-blindness. NFADB is sponsoring a list serve where you can share ideas, thoughts, questions, successes, etc. To join the list serve, send a blank e-mail to: [NFADB-SUBSCRIBE-REQUEST@TR.WOU.edu](mailto:NFADB-SUBSCRIBE-REQUEST@TR.WOU.edu).

## **Helen Keller National Center National Training Team Seminars Sands Point, New York**

The Helen Keller National Center National Training Team (NTT) was established to increase knowledge and support the development of skills specific to deaf-blindness. The 2007 schedule includes:

- Interpreting Techniques for the Deaf-Blind Population: Touching Lives – August 6–10, 2007.
- Enhancing Services for Older Adults with Vision and Hearing Loss: "The Best is Yet to Come" – September 17–2, 2007.
- Transformation: Person Centered Approach to Habilitation – October 15–19, 2007.
- Technology Seminar: The Magic of Technology - December 3-7, 2007.
- 

### Contact:

Doris Plansker

Phone: 516-944-8900, extension 233

TTY: 516-944-8637

E-mail: [ntthknc@aol.com](mailto:ntthknc@aol.com)

Web: <http://hknc.org/FieldServicesNTT.htm>.

# When a Program is Not Appropriate for Your Child

## What is The Next Step?

We once found our child in this situation and had to begin the process of advocacy. When a program is not appropriate for your child what is the next step? We first found advocates that understood dual sensory loss, other learning differences and the law. Second we gathered as much information as we could about our child and third we researched other school programs in our area.

We had to meet with many school professionals and it took a lot of time and commitment from us as parents and our advocacy team, but we eventually came to an agreement with our school district and our child was finally placed in what we thought was the most appropriate program. Although advocating wasn't easy it was worth the effort. Our child has since excelled in school and is incredibly happy; his support team of teachers, para-educators and therapists are **wonderful**. We are so thankful for them everyday.

I think it is important to remember when you are meeting with the school district, teachers or anyone involved in an IEP or Mediation to always remain polite and respectful. Professionals may not always see things as we do. We are passionate about our children and want things a certain way, but these meetings are going to be much more successful if everyone involved is courteous.

### IMPORTANT TIPS

1. Understand the law, regarding a **Free and Appropriate Public Education**.
2. Find Advocates that understand your child's disabilities, education and the law.
3. Know your child's strengths and areas of need.
4. Always act professional and respectful.
5. If possible have both parents or a supportive person attend all meetings.
6. Keep a paper trail and document all correspondence in writing with letters.
7. Take a break from the stress and take care of yourself so you can be at your best.
8. Remember to stay strong and what really matters in the end, is who benefits the most, your child.

## **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](mailto:kdot62@comcast.net) and your name will be forwarded to the Washington State Family Specialist who maintains the list.

# Become a Braille Textbook Transcriber

*Help Students Who Are Blind or Deafblind Achieve their Dreams through Literacy and Education*

Today, the United States needs at least 380 new Braille Textbook Transcribers. By 2010, that number will rise to an additional 1,020.

Braille Textbook Transcribers meet a critical and growing need. Students who are blind or have vision loss currently wait months for brailled materials, sometimes to never receive them at all, significantly hindering their progress in school.

As a Braille Textbook Transcriber, you can offer these students the opportunity to access an education that is equal to that of their sighted peers by brailleing the books and materials they need in a timely manner.

The Braille Textbook Transcriber curriculum—offered exclusively through Northwest Vista College—will provide graduates the ability to:

- ◆ Read and write braille
- ◆ Transcribe and proofread braille
- ◆ Format textbooks and other educational materials in braille
- ◆ Produce basic tactile graphics
- ◆ Understand braille production
- ◆ Create a Web site and e-portfolio
- ◆ Write a business plan and marketing materials

With a business plan, marketing materials and an electronic portfolio, you can immediately begin work as a transcriber.

Coursework for the Braille Textbook Transcriber curriculum is completed online, so you can pursue this new and exciting opportunity from an location with Internet access

Embark on a rewarding lifelong career and in turn, help the thousands of students who are deaf or have vision loss achieve their dreams through literacy and education.

For more information on this regarding career opportunity, visit <http://www.accd.edu/nvc/areas/braille>.



*One looks back with appreciation to the brilliant teachers, but with gratitude to those who touched our human feelings. The curriculum is so much necessary raw material, but warmth is the vital element for the growing plant and for the soul of the child.*

Carl Jung





# HELEN KELLER NATIONAL CENTER Registry Fact Sheet

The Helen Keller National Center (HKNC) is a national rehabilitation program authorized by the federal government to provide services for youths and adults who are deaf-blind. HKNC's mandate includes maintaining a national registry of persons who are deaf-blind. This registry is separate and distinct from the census information that the state education deaf-blind projects collect on children 0-21 years of age.

## How Will HKNC's Registry Information be Used?

Although all personal information about individuals will be kept confidential, statistical information will be used in several ways. It will be . . .

- ◆ Shared with adult service programs so they will be better prepared for serving these youths/adults
- ◆ Shared with teacher, personnel and interpreter preparation programs to better prepare professionals to work with this population
- ◆ Used for program planning for youth (14-21 years old) as they age out of the educational system
- ◆ Shared with the federal and state governments as they develop priorities for program funding

## How Can You Help?

HKNC serves those who are 14 years of age and older but will include anyone who is deaf-blind, of any age, on the registry. If you would like to register yourself or obtain an application for someone you know, you can request a copy of the registry form from:



Maureen McGowan, Regional Representative  
HKNC  
1880 South Pierce Street #5  
Lakewood, CO 80232  
303-934-9037  
E-mail: [Maureen.mcgowan@hknc.org](mailto:Maureen.mcgowan@hknc.org)

**OR**

Helen Keller National Center  
141 Middle Neck Road  
Sands Point, NY 11050  
Attn: Nancy O'Donnell  
516-944-8900 x326  
E-mail: [hkncod@aol.com](mailto:hkncod@aol.com)

HKNC website: <http://www.hknc.org>  
(The form can be submitted electronically)

## Relationship to the Colorado Deafblind Project:

This registry maintained by HKNC is different from information that the Colorado Services for Children with Combined Vision and Hearing Loss Project is required to maintain. The Colorado project does not share confidential information with the HKNC registry. Families are encouraged to contact HKNC directly using any of the methods above to register their children, especially those children age 14 years or older.



# New Items in the Lending Library!

Welcoming Students with Visual Impairment to Your School: A Guide for training public school personnel and families about the needs of students with vision loss, Perkins School for the Blind, 2006.

**ORDER NUMBER— 1210.135**

Welcoming Students with Visual Impairment to Your School...provides TVI's and certified orientation and mobility specialists (COMS) with the resource tool to train others about the unique aspects of students with visual impairments. We can use parts or all of this tool as need and even expand on sections as needed. As stated in the manual, this resource is not meant to replace direct work or consultation with a certified teacher of the visually impaired or certified orientation and mobility specialist.

More Than A Mom: Living A Full and Balanced Life when Your Child Has Special Needs, Baskin, Amy and Fawcett, Heather, Woodbine House Publishers, 2006. **ORDER NUMBER— 610.066**

More Than A Mom is a lifeline of information and advice for mothers who have children with developmental or physical disabilities, mental health or learning issues, or chronic medical conditions. With the authors' skillful blend of research, personal experience, and feedback from over 500 mothers across the United States and Canada, this book will help you cope, adjust, and find the inspiration to make your daily life easier and more fulfilling.

Promoting Learning Through Active Interaction, Chen, Deborah; Klein, M. Diane; Haney, Michelle; Paul H. Brookes Publishing Co., 1999. 27 minutes

**ORDER NUMBER—520.013**

This training video depicts real interactions between young children with multiple disabilities and their families in natural settings. It demonstrates to students, practicing professionals, and families the techniques and goals described through the PLAI program, such as understanding children's cues, identifying preferences, establishing predictable routines, establishing turn-taking, and encouraging initiation.

Helping Children Who Are Blind: Family and Community Support for Children with Vision Problems, Niemann, Sandy and Jacob, Namita, The Hesperian Foundation, 2000.

**ORDER NUMBER —1210.137**

The transition from high school to college is a significant turning point in any student's life. For a student who is blind or visually impaired, preparing for this transition, developing useful skills, and negotiating for and coordinating appropriate services will help ensure a successful journey into college....this book is intended to provide students who are blind or visually impaired, families, educators and counselors with a comprehensive guide to skills needed by visually impaired students to succeed in applying for an attending college.

Going Places: Transition Guidelines for Community-Based Physical Activities for Students who have Visual Impairments, Blindness, or Deafblindness, Lieberman, Lauren J., Modell, Scott J., Ponchillia, Paul, Jackson, I Leah, American Printing House for the Blind, Inc., 2006. Contains CD-ROM

**ORDER NUMBER —810.019**

The six national content standards on physical education established by the National Association for sport and Physical Education (NASPE) have been addressed in this fun to read resource on community-based, independent physical activities for individuals who have visual impairments, blindness, or deafblindness.

Classroom Observation Instrument for Education Environments Serving Students with Deaf-Blindness, Taylor, Ella; Stremmel, Kathleen; Steele, Nancy, NTAC, 2006

**ORDER NUMBER — 410.115**

The Classroom Observation Instrument for Educational Environments for Students with Deaf-Blindness is designed to help identify model classrooms serving students with severe and profound disabilities including those with deaf-blindness. The COI is comprised of three main components: (1) teacher interview; (2) student cumulative folder review; and, (3) observation rubric.



CATS: Collaboration Achieves Travel Success, Indiana Deafblind Project, 2005.

**ORDER NUMBER — 410.116**

This is a multimedia resource to help service providers and families develop and promote travel opportunities for persons who are deafblind and may have additional disabilities. Materials include: worksheets, DVD, and VHS.

Married with Special Needs Children: A Couples' Guide to Keeping Connected, Marshak, Laura E., Prezant, Fran Pollock, Woodbine House. 2007.

**ORDER NUMBER — 610.067**

Married with Special-Needs Children looks at the ways in which having a child with special needs can make it more difficult for a marriage to thrive and how a child's intensive needs can change the structure of a marriage. The authors examine many of the underlying stresses and common pitfalls—a couple's differing coping mechanisms and expectations of a child, communication breakdowns and difficulties resolving conflicts, for example. They then present a wide range of strategies for handling or preventing these problems. Marshak and Prezant also describe what makes a marriage strong, such as continuing to share connections outside of parenting roles, keeping a sense of autonomy, and sharing childcare responsibilities.

Can Do! Growing My Way, Part 1: The Developmental Impacts of Visual Impairment, Visually Impaired Preschool Services, 2006.

**ORDER NUMBER — 1240.03**

A new video series for parents of children who are visually impaired and the professionals who work with them. Follow the five babies and their parents as we track the babies' development at 3-month intervals - beginning at 3 months of age and ending at 18 months of age - an intimate look at them as they progress through their first year and a half of life. The children include a typically developing baby, two babies with low-vision conditions, and two babies who were born very prematurely and are seriously visually impaired. The series highlights what adaptations children and parents make to deal with visual impairments at different ages and developmental stages.

Ophthalmology Made Ridiculously Simple: Interactive Edition, Goldberg M.D., Stephen, Trattler, M.D., William, Med-Master, Inc. 2005.

**ORDER NUMBER — 1210.139**

All the ophthalmology necessary for the non-ophthamologist.

Children with Visual Impairments: A Parents' Guide, 2nd Edition, Ed. Holbrook Ph.D., M. Cay, Woodbine House, 2006.

**ORDER NUMBER — 1210.140**

This thoroughly revised and expanded edition of Children with Visual Impairments is an essential resource for parents of children who are blind, legally blind, or have low vision. Written by an expert team of professionals and parents, it is filled with jargon-free, compassionate information and advice on children from birth through age 7, making it the most useful resource of its kind.

## Change, Change, Change!

The Lending Library is undergoing some changes. Mostly, the cataloguing numbering system is changing. The current Inventory is available on line at: <http://www.cde.state.co.us/cdesped/SD-Deafblind.asp>. The order form has also changed and that is also available at the same website address. We have over 800 items which includes books, videos, CDs, DVDs, and Fact Sheets. You can check out up to 3 items for a period of 1 month. You can email Gina Quintana at [Quintana\\_g@cde.state.co.us](mailto:Quintana_g@cde.state.co.us) and she will mail them off to you and you just need to mail them back. We have really seen an increase in materials being checked out lately and would like to see more.

# Deafblind Registry 2006

Many thanks to all of the service providers and parents who have sent us the most current information of the children and youth on the Colorado Deafblind Registry. This information is a requirement of our grant and is collected and turned into the Federal Government every year.

We wanted to share some interesting findings from all of this data. First of all, there are **141** individuals (ages birth—21) registered in the state.

Ages / Years	Number in CO
Birth—2	27
3-5	29
6-11	41
12-16	24
17-21	12

Male	Female
48	89



The most common syndromes / causes of deafblindness are:



Causes	Number in CO
Other / Unknown	14
Complications of Prematurity	13
CHARGE Syndrome	7
Down Syndrome	7
Hydrocephaly	6
Asphyxia	6
Usher Syndrome	5
Goldenhar Syndrome	5



Numbers of students taking State Assessments\*:

Assessment	Number
CSAP	7
CSAP with Accommodations	1
CSAP Alternate	41

\*Note: There are **83** students who are not taking either assessment because they are at an age or grade that does not require it.

# Technical Assistance Request Form

If you would like to receive **free** technical assistance for your child or a student who is deafblind (has both a vision and hearing loss), please complete and return this form to Gina Quintana. Once this information is received, you will be contacted to determine: (a) the type of technical assistance you need (b) what the specific need is, and (c) when is the best time to schedule the visit.

## Contact Information

Your name: \_\_\_\_\_ Phone Number: \_\_\_\_\_

Your address: \_\_\_\_\_  
\_\_\_\_\_

Name of the child that you would like assistance with: \_\_\_\_\_

Date of birth of the child: \_\_\_\_\_ Your relationship to the child: \_\_\_\_\_

## What Kind Of Technical Assistance Are You Interested In?

\_\_\_\_\_ Inservice      \_\_\_\_\_ Home Visit      \_\_\_\_\_ School Visit      \_\_\_\_\_ Other

## What Topics Are You Interested In (check all the ones you are interested in for this child):

- \_\_\_\_\_ Auditory Training / Listening Skills
- \_\_\_\_\_ Assessment (circle area: vision, hearing, communication, development, or other)
- \_\_\_\_\_ Behavior Management (for problem or disruptive behavior)
- \_\_\_\_\_ Communication System Development (how to encourage a child to communicate)
- \_\_\_\_\_ Daily Living Skills (personal care and self help skills such as toileting, dressing, etc.)
- \_\_\_\_\_ Inclusion into School Program (techniques that support the child's learning in the classroom)
- \_\_\_\_\_ Literacy Mode Determination (use of Braille, large print, etc.)
- \_\_\_\_\_ Medical Issues (gaining more information about a child's diagnosed condition)
- \_\_\_\_\_ Orientation and Mobility Skills (travel independence)
- \_\_\_\_\_ Organizing a Daily Routine (sequence of activities, transition from one activity to another)
- \_\_\_\_\_ Personal Futures Planning (a system of looking ahead and planning for the future)
- \_\_\_\_\_ Sensory Skill Development (vision, hearing, tactile skill use)
- \_\_\_\_\_ Social-Emotional Concerns (relationships with others)
- \_\_\_\_\_ Transition from Program to Program (e.g. preschool program to kindergarten program)
- \_\_\_\_\_ Transition from School into Adult Services (college, rehabilitation, group home)
- \_\_\_\_\_ Vocational Training

Other areas of need: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Please return this form to Gina Quintana, CDE, 201 East Colfax, Denver, Colorado 80203. It can be faxed to Gina at (303) 866-6811. If you have questions, call Gina at (303) 866-6605 or send an email to her at Quintana\_g@cde.state.co.us



# Resources & Materials



- \* **CHARGE Syndrome: A Management Manual for Parents**—this manual is an interactive publication in Adobe PDF Format. Some sections are directed to professionals and others to parents. Sections of the manual address medical aspects of CHARGE, development and education in CHARGE, resources, and more. (A Spanish version can be ordered offline.) More information can be found at <http://www.chargesyndrome.org/resources-manual.asp>.
- \* **Touch of Home. . . Road to Realizing a Vision**—Betsy Hodge & Monika McJannet-Werner. (2006). Liberty Corner Enterprises, Inc. and Helen Keller National Center. Deaf-Blind people with additional and complex challenges are often underserved. This 48-page publication describes a model for the development of a program to successfully support Deaf-Blind individuals in a setting that offers not only a housing option, but vocational choices and opportunities to participate in the dynamics of a community. It is a program that reflects life, rather than life being run on a program. *Touch of Home* was developed through a collaborative process that included local entities and services in the Asheville, North Carolina area and a partnership with Liberty Corner Enterprises, an affiliate program of the Helen Keller National Center (HKNC). The monograph was written in response to many inquiries received regarding the development of the project, and to encourage others to develop similar resources in their own community. Single copies can be obtained free of charge by contacting Rob Ruis at [rruis@libertycornerent.com](mailto:rruis@libertycornerent.com), or Monika.
- \* Two new online courses are available from Oregon Health & Science University. Both are offered as self-paced noncredit learning opportunities. (1) **Pre-symbolic Communication** provides instruction on helping an individual to learn or expand pre-symbolic methods of communication and presents information on related research. (2) **Tangible Symbol Systems** provides instruction on all aspects of teaching an individual to use tangible symbols and also addresses the theoretical basis and research for this approach. Register online at any time. The cost for each course is \$165. For complete information and online registration visit: <http://www.designtolearn.com/pages/tsonline.html>
- \* **Helen Keller Kids Museum Online**—This website includes a lot of information on Helen Keller including: her biography, fun facts, quotes, chronology of her life, and even recommended readings. You can see all of these at: <http://www.afb.org/braillebug/hkbiography.asp>



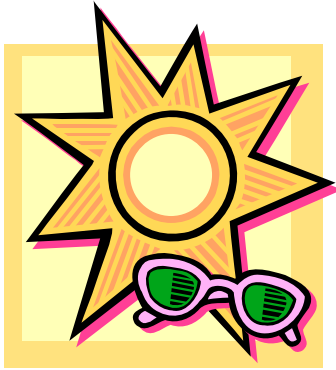
# Calendar of Events

2007 2007 2007 2007 2007 2007 2007 2007 2007 2007

- June 1-3**                      **Family Learning Retreat 2007**—Colorado Springs  
Contact: Gina Quintana <quintana\_g@cde.state.co.us>
- June 21-23**                    **CO Assistive Technology Conference** – Denver  
Contact: [www.AssistiveTechnologyPartners.org](http://www.AssistiveTechnologyPartners.org).
- July 27-29**                    **8th International CHARGE Syndrome Conference 2007**-Costa Mesa, CA  
Contact: <http://www.chargesyndrome.org/conference-2007.asp>
- July 13-15**                    **Families Connecting with Families Conference**—Omaha, NE  
Contact: [www.napvi.org](http://www.napvi.org)
- July 15-17**                    **Early Childhood Summer Institute** – Breckenridge  
Contact: [www.surveymonkey.com/s.asp?u=703393787342](http://www.surveymonkey.com/s.asp?u=703393787342)
- September 25-30**            **14th Deafblind International Conference 2007**, Perth, Australia  
Contact: <http://www.dbiconference2007.asn.au/>
- August 2**                      **2007 Summer Institute on Deafblindness**—Denver  
Contact: Tanni Anthony (303) 866-6681 or Anthony\_t@cde.state.co.us
- September 21**                **Traumatic Brain Injury(TBI) Educators Conference**—Parker, CO  
Contact: [thorfam@rmi.net](mailto:thorfam@rmi.net)
- September 25-30**            **Deafblind 14th International World Conference** - Perth, Australia  
Contact: [www.dblink.org](http://www.dblink.org)
- October 18-20**                **Colorado Fall Conference on Visual Impairment**—Denver  
Contact: Tanni Anthony (303) 866-6681 or Anthony\_t@cde.state.co.us

2008 2008 2008 2008 2008 2008 2008 2008 2008 2008

- April 2-5**                      **CEC Annual Convention & Expo** — Boston, MA  
Contact: CEC —[conteduc@cec.sped.org](mailto:conteduc@cec.sped.org)



## 2007 SUMMER INSTITUTE ON DEAFBLINDNESS

### Sensibility and Movement for Children Who are Deafblind and Have Significant Support Needs

Presented by David Brown

**Institute Dates, Site, and Presenter:** The Summer Institute is scheduled for August 2, 2007. It will be held at the Red Lion Hotel in Denver. The featured speaker will be David Brown who has worked as an Itinerant Teacher for Sense (The National Deafblind Association) in England for 18 years before moving to California in 2000, where he has a similar job with California Deaf-Blind Services. He has special interests in early intervention, in assessment approaches, in multi-sensory issues, and in the collaborative interface between education and therapy. **The day will be divided in to two topical sessions.**

**Morning Session: Title and Description:** *The Forgotten Senses of Balance and Pressure:* The crucial and fundamental importance of the balance (vestibular) and pressure (proprioception), senses for all aspects of child development, and for effective functioning in all skill areas, is rarely understood. Children with developmental difficulties are at increased risk of having problems with these two senses, and within the population of children with deafblindness these difficulties are very common. This presentation will:

- provide simple explanations of the two “forgotten senses” and how they work and what purposes they serve.
- describe ways in which different senses interact to facilitate effective functioning
- examine reasons why there might be difficulties with the working of the balance and pressure senses
- take a brief look at the Sensory Integration Therapy perspective
- consider simple adaptations to positioning, physical support, pacing of activities, and play/teaching materials that can often facilitate greatly improved functioning

**Afternoon Title of session and description:** *Are You Bored With Your Board?:* This session will look at how resonance boards, which are wooden platforms first designed by Dr. Lilli Neilsen that are used to encourage movement, are made, and at some of the many ways in which they can be used with infants and young children, including those with deafblindness or with significant support needs. Using anecdotal examples, and video, we will consider the many skill areas, including academics, which can be addressed using a board, and the ways it can be used both for teaching and for leisure time.

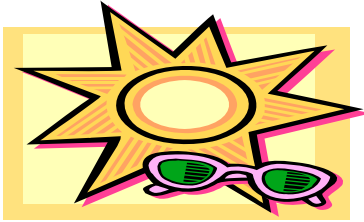
**Target Audience:** This training is designed for parents and educational service providers who work directly with children with combined vision and hearing loss (deafblindness) and/or students with significant support needs and a sensory disability. Participants will be limited to 60 persons.

**Schedule:** Registration will be open from 7:15 to 7:55 a.m. We will start promptly at 8:00 a. m. and dismiss at 4:30 p.m.

**Cost:** \$40 fee for early-bird registration (postmarked by July 1, 2007). \$60 after this date

**Participant Agreement:** Participants will be expected to attend the full training and complete a follow-up survey on how the content was applied. Workshop participants who are working with a child with combined vision and hearing loss will be asked to make a commitment of a follow-up visit by a staff member of the CO Services to Children with Combined Vision and Hearing Loss Project during the 2007-08 school year to address the impact of the summer training on the child’s school and/or home program.

??s - please contact Tanni Anthony at (303) 866-6681 or [anthony\\_t@cde.state.co.us](mailto:anthony_t@cde.state.co.us)



# 2007 SUMMER INSTITUTE ON DEAFBLINDNESS

## Sensibility and Movement for Children Who are Deafblind and Have Significant Support Needs

### Registration Form

Please note that we will need your complete summer address / email address since the final confirmation information may be sent after the school year is over.

Please **PRINT** this information.

Name: \_\_\_\_\_ Home Phone: \_\_\_\_\_

Parent Status / Professional Discipline: \_\_\_\_\_

Summer Address: \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Summer Email Address: \_\_\_\_\_

I have enclosed my registration fee: \_\_\_\_\_ (\$40 early bird fee by July 1, 2007)  
\_\_\_\_\_ (\$60 late fee **after** July 1, 2007)

Need for Special Accommodations: \_\_\_\_\_ Large Print \_\_\_\_\_ Braille  
\_\_\_\_\_ Sign Language Interpreter

Other accommodations: \_\_\_\_\_

Please make your check out to: **CAER** (Colorado Chapter of the Association of the Education and Rehabilitation of the Blind/Visually Impaired) and send it with your registration form. **Do NOT make your check out to CDE.** We cannot take credit cards. No refunds will be made after July 1, 2007.

The training is open to **60** participants – **FIRST COME, FIRST ENROLLED.** Priority will be given to parents of and professionals working with children who are deafblind.

*If you are the parent of or a professional working with a child/student who has combined vision and hearing loss, please complete this section:*

My role with a child who is deafblind (parent / professional): \_\_\_\_\_

Name of child: \_\_\_\_\_

School that the child attends: \_\_\_\_\_

Please return this completed form AND registration check to Tanni Anthony, CDE, 201 East Colfax, Denver, CO by **July 1, 2007.** If you have questions, contact Tanni at (303) 866-6681 or [anthony\\_t@cde.state.co.us](mailto:anthony_t@cde.state.co.us)

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