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 2006

ADVOCACY

By Gina Quintana

When I looked up the term *advocacy in education* on one of my favorite search engines, this is what I came up with from Wrightslaw.org:

"This term refers to the role parents or guardians play in developing and monitoring their child's educational program. Advocating for your child means knowing what rights are assured you by the law and actively participating in the decision-making process to ensure that the services are delivered in line with your goals for your child's development and education."

Parents are the biggest advocates for their child in everything from education to medical issues. It is up to parents to speak up for their children who can not speak up for themselves. Whether its attendance at Individual Education Program (IEP) meetings, parent conferences, keeping the lines of communication open whether it's a phone call, email, or back and forth communication notebook.

I have been to IEP meetings that have lasted a long as an hour and to those that are 6-8 hours long—granted on different days, but 8 hours is a long time for a meeting! In this newsletter, I have included articles on *Advocacy* and *Strategies for a Successful IEP Meeting,* as well as several websites, locally and nationally. I hope that you find them valuable resources as you journey through the land of Advocacy!

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Deafblind Advisory

One of the recommendations from the Federal Onsite Visit in August 2005 was to have Deafblind Advisory Committee, as opposed to a Task Force. The charge to this Advisory Committee is to provide specific guidance to the Colorado Services for Children with Combined Vision and Hearing Loss project. It is crucial to have input from all the stakeholders on what the project is doing, what needs to continue, what should be done differently, and what needs to be done in the future.

The Project Advisory Committee on Deafblindness met for the first time on February 6th and will meet again in May. 17th, 2006. Key topics that were discussed were:

1. The August 2005 Site Visit and recommendations which include:
    - A. Name Change from Task Force to the Project Advisory Committee on Deafblindness
    - B. Updates to the Parent Needs Assessment
    - C. Capturing the TA provided by Anchor Center for Blind Children and the Colorado Home Intervention Program (CHIP)

2\. Updates from the Family Specialist and Parent Consultant

2\. Updates on the Summer Institute 2006 (see pages 24-25 for more information)

2\. Membership of Advisory
    - A. We are in need of a high school aged student to serve on this advisory, if you have any suggestions on a candidate, please let us know.
    - B. Currently we have representation from Anchor Center for Blind Children, CHIP, teacher or administrator representatives from metro area Colorado school districts (Brighton, Littleton, Jefferson County), Commission for the Deaf, Colorado Center for the Blind, Colorado School for the Deaf and Blind, Developmental Disabilities, Helen Keller National Center, Colorado Department of Education, Social Security Administration, and two parents.

5\. The next meeting of the Deafblind Advisory will be on Wednesday, May 17th from 2-4 at the Anchor Center. If you would like to join us, please be in touch with Gina Quintana at (303) 866-6605.

Colorado Services for Children with Combined Vision and Hearing Loss

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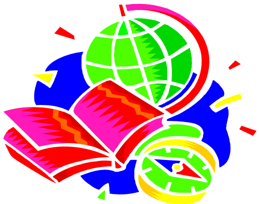
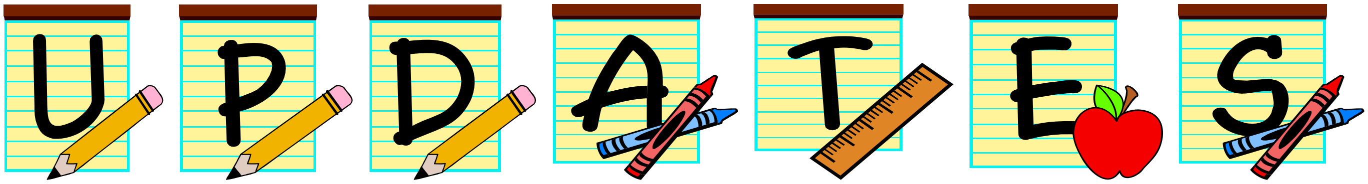
Location: Colorado Department of Education
201 East Colfax
Denver, CO 80203

Fax: (303) 866-6811
TTY: (303) 860-7060
Web Page: http://www.cde.state.co.us/cdesped/SD-Deafblind.asp





This Newsletter Edition: This edition of *VIBRATIONS* is focused on Advocacy. We are all advocates for children, its one of the most important jobs we will ever have. It is up to us to speak for those who can not speak for themselves.

Colorado Census of Children and Youth with Deafblindness: Many thanks to everyone who completed and sent it the census information. This information is reported to the Federal Government and accurate information is vital!

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. We can provide TA over the summer months—so keep in touch with us during this time of the year!

Project Website: We have been adding information to the website! Be watching for new Fact Sheets and the new topical editions of past newsletters. Our goal is to provide you with accessible and easy-to-read resource information. 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 an article. Her number is (303) 866-6605 and email is <Quintana_g@cde.state.co.us>. To check out the website, please go to: http://www.cde.state.co.us/cdesped/SD-Deafblind.asp

VIBRATIONS: We are in need of cover articles for future editions of VIBRATIONS. In the past we have highlighted a different family for each edition. We would like to highlight your family too! Please consider writing an article—and telling YOUR child's story. Families can always benefit from hearing from another's experience. If you are interested, or want more information, please give Gina a call and visit with her about it. She can also put you in touch with other families.

2006 Summer Institute: We are so excited about our presenters and topic for this year's institute. Please consider joining us for this mountain-high training. The flyer and registration form are on pages 24 and 25 of this newsletter.

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 Jennifer Dinges, CDE, 201 East Colfax Avenue, Denver, CO 80203. This newsletter was prepared primarily by Gina Quintana with a little help from Tanni Anthony. Thanks to all of the guest contributors.

IDEAs that Work
U.S. Office of Special Education Programs

Sharing the Journey

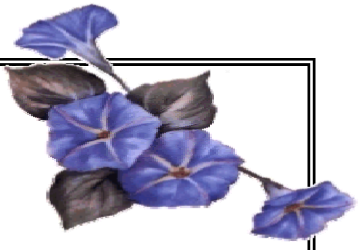
A Parent’s View on Advocacy

By Karen Roberts,
Family Specialist and Advocate for Ben

We begin advocating for our child from the moment he or she is born. Every parent must be a voice for their child but it is essential for those of us parenting a child with a disability. We start a lifetime of advocacy at our child’s birth or diagnosis and oftentimes all we have to rely on is our natural instincts. Instincts raw and numbed by the information we are being asked to process. We are immediately plunged into a world we know little about and are little prepared for. And because our child’s needs are “different,” and often quite extreme, a lot can rest on our skills as an effective advocate. By necessity these skills evolve and as we get to know our child better, and his or her needs, we learn the systems. Some of us find ourselves in very adversarial positions that may be unnatural to us. But when our child and his needs are at stake we are forced to learn a lot quickly—we learn that information is power, that there is strength in numbers, that we need to build alliances and relationships with certain people, that collaboration is powerful and networking with other parents beneficial, that patience can pay off, good communication is essential and building trust with professionals may take time and patience but can be worth it. But there are sleepless nights, tears and heartache along the way. We need to tap into the coping skills we’ve also been forced to learn, lean on our support systems, and remember that for many of us we are dealing with lifelong issues that require the endurance of a marathon runner, not the bursts of energy of a sprinter. So we need to choose our issues, decide what matters most, and surround ourselves with resources of support—here are stories from parents willing to share their experiences and what they have learned about being effective advocates for their child.

Karen shares another family’s story...

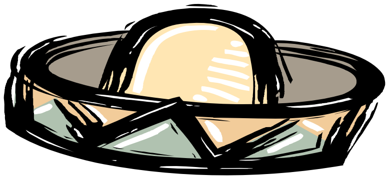
“I have finally accepted the fact that I need to ask for lots of help to raise my child. It is truly impossible to do it alone. Through the years I have gotten to know the people that make the difference—from the name of the scheduler in the audiologist’s office, the maintenance person that can fix the ADA approved swing on the school playground, the voice on the telephone that does outside referrals at our HMO, the advice nurse in pediatrics, the delivery guys for our home healthcare agencies, every person on my child’s IEP team, the school principal, the director of special education…I have a book with many names and numbers in it. I keep track of who I talked to and when—because it often takes more phone calls to get something done. Sometimes it angers me when I don’t get calls back—don’t these people realize they are part of a delicate web of supports necessary to my daughter’s existence? And one of dozens of calls I need to make and resolve…I try to stay calm because it certainly doesn’t help anyone when my stress level escalates. So I remind myself they are all human, occasionally I play the controlled anger card—my child depends on the delivery of her formula for her nutrition and we needed it yesterday… but I only do that when I have to and it really is an emergency. I have found that being polite but forceful pays off—I received a free months worth of formula last year when there were delivery problems. I talk to the people we depend on about their families and their lives. I realize they can also be frustrated by a system that can be slow and cumbersome. When we can’t agree we look for compromise together—I choose my battles and am so patient it used to kill me. But I have found through the years that burning bridges does not help my child. I get lots of information ahead of time — I’ve



found the Parent to Parent (P2P) listserv can be very helpful when I need information and advice from other parents. I have asked about specific professionals and resources on the listserv. But I always form my own opinion about the person or organization. It is hard to need to depend on so many people and their effectiveness at their jobs. I am huge on thank you notes. I try to do things around the school that benefits all children—which can be hard because my child's needs take up 90 percent of my time. But if there is a school book fair or something I can help at where I can show my face—I try to do it. If I'm asked to help I will because I know I'll need the favor returned. I try to focus on the positive, keep my humor, and build as much trust and communication as possible around the needs of my child. I guess this is the most effective way in which I advocate for my child and her needs. I always assume good intentions as well as practice good communication, plenty of humor, patience, gratitude, respect for professionals and knowing the right people to get things done."

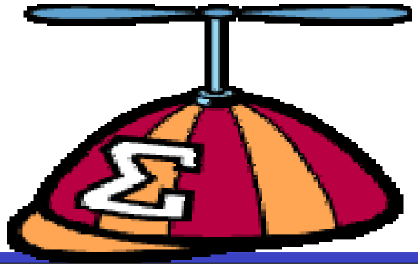
HATS OFF!

We would like to offer a special hats off to the Team from Adams School District 12. A multidisciplinary team from this administrative unit attended the 2005 Summer Institute on Deafblindness. This group then came back and in February 2006 held a training in their district to share the information they had acquired at the Summer Institute. The team, who had implemented strategies they had learned, provided examples—including ***dramatic reenactments*** of classroom situations, showing how they may have handled a situation in the past, and how they handle it now. This team invited Gina from the Colorado Services for Children with Combined Vision and Hearing Loss project to the training, allowed for time for a 'commercial' of sorts and asked her to be present to help answer questions. What a fabulous learning opportunity for all!

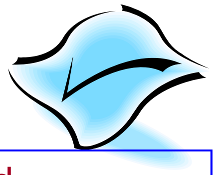


Sue Wiles
Nancy Lyneis
Michelle Soldan
Ann Gillmeister

Sarah Wiberg
Susan Reese
Julie Beard
Illyne Engel



Check it Out!



National Family Association for the Deafblind

Region 8 which compromises Colorado, Wyoming, Montana, North Dakota, Utah and South Dakota is looking for a parent to serve as the Regional Director. If you are interested in applying for this position, or would like more information as to what it entails, please contact Cynthia Jackson-Glenn at cyn98m@fuse.net. She can provide the application packet, complete with requirements and responsibilities.

National Dissemination Center for Children with Disabilities: NICHCY has announced the launching of their new Research Center, designed to connect people with the research evidence on a wide range of educational practices for children with disabilities. The Research Center is located at: http://research.nichcy.org You are encouraged try out the brand-new Research-to-Practice database, where studies are placed in context and practical examples of the research in action are given. If you are looking for information about disabilities in children, special education, early intervention, or materials in Spanish, you are invited to also sign up for NICHCY's eNews service, which is designed to bring the information you need to your door (well, to your email box!). Sign up for eNews at: http://www.nichcy.org/SurveyIntro1.html

Tactile Learning Strategies: Interacting with Children Who Have Visual Impairments and Multiple Disabilities by Deborah Chen and June E. Downing. This new video illustrates strategies to help children who are visually impaired and have multiple disabilities learn through touch. Order at www.afb.org/store or call 1-800-232-3044; International customers, call 412-741-1398. Also—be watching for this video in the Colorado Services for Children with Combined Vision and Hearing Loss lending library—we hope to stock it soon.

URLs for Your Favorites List

Please 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

Advocacy:

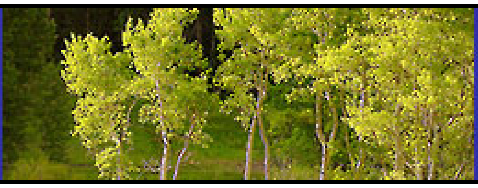
"to speak or write in support of …
another's cause or in support of something."

Advocacy Organizations

Http://www.handsandvoices.org

HANDS & VOICES

"What Works for your Child is what makes the Choice right"



http://www.thelegalcenter.org/index.htm

The Legal Center
for People with Disabilities
and Older People

The Legal Center for People with Disabilities and Older People

Colorado's Protection & Advocacy System

http://www.thearcofco.org/html

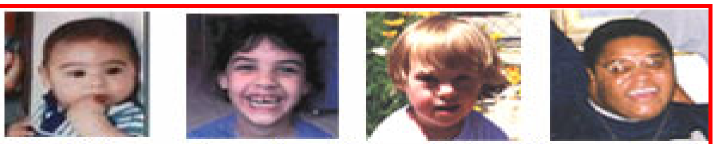
The Arc of Colorado

ABOUT THE Arc

Advocating for people with developmental disabilities for over 50 years.

http://www.familyvoices.org

FAMILY VOICES®



. . . *Speaking on behalf of children and youth with special health care needs*

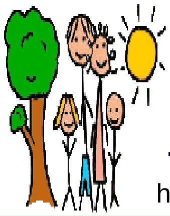
http://wrightslaw.com/

Wrightslaw

Other Informative Sites

Parent to Parent of Colorado

http://www.p2p-co.org/



EMPOWER COLORADO

Education Movement: Parents Offering Wisdom, Encouragement and Resources

http://www.empowercolorado.com/ **1-866-213-4631**

PEAK Parent Center

http://www.peakparent.org/

A Mother's "TO DO" List:

1. **Start Dinner**
2. **Change the World**
3. **Do the Laundry**

By Janet DesGeorges

This article is dedicated to Jane Miller, the first parent who taught me to speak up!

Do you have time for "advocacy" in your schedule? When my child with special needs was born, the journey our family embarked on was a very personal one at first. The identification of hearing loss in our daughter thrust us into a system which we were forced to navigate with no previous life experience. We needed to make choices for our daughters' therapies, education, funding issues, and medical interventions. We needed to learn how to differentiate between professional opinion and facts. We were only concerned with the specific choices we as parents needed to make for OUR daughter, and were not even thinking about the "system" which was in place in our community and state, except how it related to the services our family needed.

As time went on, however, an interesting thing started to happen. I had the opportunity to start talking to other parents of children with special needs. In our conversations, I realized some of the obstacles we had encountered with our daughter in the "system", were exactly the same obstacles which other families were facing. I also realized that other families were able to advocate for their own children and get some services which I didn't think were possible. Advocacy skills began to grow in my life as I watched other parents "push" the system on behalf of their own children. I began to meet advocates in our community who were "pushing" the system, not only on behalf of their own child, but on behalf of all children! What a concept!

A great example of advocates in our community who are "changing the world", are Bruce Goguen and his wife Robin Buldac, who have been recently acknowledged by the Daily Camera's Pacesetter Awards in the quality of life category for their work helping people with disabilities. Bruce and Robin are the directors of Statewide services for United Cerebral Palsy (UCP), in addition to their involvement with other local community organizations which support people with disabilities. Robin, who's journey of advocacy started when she had to fight to get her own daughter, who has Down's Syndrome, into her public school system, has since worked on policy legislation which has changed the lives of thousands of families. Bruce and Robin are shining examples of the influence parents can have in a "system". There are dozens of parents in our community who are working on behalf of not only their own children, but advocating on behalf of other parents and children as well.

We often think of parent-to-parent support fulfilling only one need, a vehicle for emotional support from "one who has been there". While emotional support we as parents give to one another is absolutely essential and life-giving, what happens when a group of parents get together can extend far beyond that. We as parents share some common threads in our experiences: A lifetime commitment to our children, A parent's unconditional love, the ability to see our child as a "child"- not a disability, and the right and responsibility to choose what we feel is best for our child. Coming together as a group builds strength and confidence in our rights to speak out on behalf of our children!

Yes, we all lead very busy lives, and the time constraints of a parent who has a child with special needs can be especially stressful. But advocacy, whether for your own child, or on behalf of the "system" is a fact of life for parents. Get empowered from other parents! When parents get together, good things happen!

* * *

Janet DesGeorges is the mother of three children and lives in Boulder. Janet is a member of Boulder County Spokespeople, a support/advocacy organization for families of children with special needs. Janet is also the current President of Colorado Families for Hands & Voices, a statewide parent organization supporting families of children who are deaf or hard of hearing.

This article was reprinted in its entirety with permission from Hands & Voices ©2005 For more information about Hands & Voices, please go to www.handsandvoices.org.

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. Mar

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

Ian’s Hot Tips for IEP Meetings

By Ian Wattlington

Educational Advocate, Self-Advocate

1. Arrange the table and chairs in a circular formation so all participants can see each other. In addition, sitting in a circle tends to relax the environment and put people on an equal plane.
2. Call a day prior to confirm meeting time and place. This shows you’re down-right serious for this meeting.
3. Come with file folders or binder with your child’s records. The more professional looking the better. For better or worse, the way you present yourself and your materials also sends signals to others in the meeting. Ideally, you want to have a commanding presence in the meeting and professional utensils can certainly help.
4. Organize an outline of what you see as the key issues of the meeting and main points and concerns to plan around. Make enough copies of this outline for all at the meeting. This document gives you and the others a visual and can allow you to bring the meeting back into focus.
5. Bring something visual or tangible that symbolizes a product of your child’s success. For example, art project, photos, read a passage from a book showing growth in reading, a video of a milestone at home. Also, make a brief list of other positive steps or items about your child, and as I said before, make enough copies for all in attendance.

The point of these exercises is to reinforce the notion that the meeting should be focused on the idea of success, what our child can do. Too often the meetings revolve on the child’s deficits, not his/her strengths and abilities; therefore, the visual aid and the list can be used to bring the meeting back to capacity and success.

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! A listserv is an electronic way of having a discussion. Someone can send an email about a thought, need, or concern and the message is sent to others on the listserv. Others can respond so that there is a conversation about that topic. Participation is free—you just need to have access to a computer. 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.

Council for Exceptional Children
The voice and vision of special education

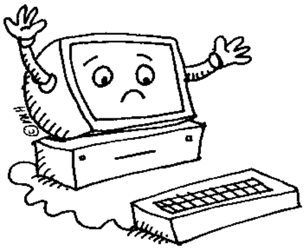
Congratulations and Thanks to Charlie Freeman!

Here is a real life ADVOCATE that we are very proud of … The Council for Exceptional Children's Division on Visual Impairments presented Charlie Freeman with the Exemplary Advocate Award during the CEC International Conference at the Little America Hotel in Salt Lake City on April 6, 2006. This award is presented to those individuals whose efforts promote the quality of life for people who are blind and visually impaired.

We have always known that Charlie is a leader and big supporter of the programs and services for individuals who are blind or visually impaired especially for those individuals with deafblindness. Clearly, the field feels that way as well. This prestigious award has been given to such notables as Nancy Safer (2003), Bill East (2002), and Jimmy Carter (1991).

Our project would like to personally thank Charlie for his tireless efforts on behalf of families and children. He has been our federal project officer since Tanni has been with the grant (14 years!). Charlie will retire this May and we wish him all the best and say "thank you from the bottom of our hearts!"

What is "Technical Assistance"?



When we send out the *Parent Needs Survey* and other documents, as a project, we offer FREE Technical Assistance. Now, if you are like me, I am thinking—I don't need help with my computer! Technical Assistance is a term used by organizations to offer their assistance and services. From the Deafblind Project, technical assistance can be in the form of assistance in setting up an education program, communication plan, or behavior plan in the classroom or in the home. It can come in many forms, such as a school visit, attendance at an IEP meeting, home visit, email or telephone call. We have a couple of people on staff who are ready to assist you with your Technical Assistance Needs! If you have any questions you can contact Gina Quintana at 303-866-6605. I have included a copy of our Request for Technical Assistance form on page 22 of the newsletter, all you have to do is fill it out and either fax or mail it to the address on the bottom.

It is not about the computers!

It is about the kids!

Parent Advocacy:

What You Should Do . . . and Not Do

by Leslie Seid Margolis, Esq.

What Parents Should Do

1. Prepare for Meetings

You should treat the IEP meeting as if it is the first step towards a due process hearing by preparing for the meeting and building a record. If you do this, you make it less likely that you will end up at a due process hearing. If you do end up at a hearing, you will be in a stronger position.

2. Prioritize Your Child's Needs

Everything you want for your child is not equally important. Make a list of what your child really **needs**, what you **want** for your child (but may be willing to compromise on), and what would be nice to have but that you would definitely be willing to give up.

Think about the evidence you have to support each requested item (i.e., reports, assessments, experts, other documents). If you prioritize your issues and have facts and evidence that support what you want, it is more likely that you will be taken seriously.

3. Build Good Relationships

Develop positive relationships with school personnel, to the greatest extent possible. Ask questions. Ask your child's team to explain things you do not understand.

Take the high road. As hard as this may be to do, being polite and courteous is always better than being rude and nasty. If a meeting is deteriorating with nasty comments or behavior from any team member, ask for a break or ask that the meeting be continued to a later date and time.

Good relationships with school personnel and central office staff to the extent possible, will generally ensure that issues you bring up will be taken seriously.

4. Document Issues & Concerns

Ask that items and issues you feel strongly about be documented in the meeting summary or notes. Review the summary before you leave the meeting. Know your rights about amending your child’s records.

5. Use Advocacy Strategies

Use advocacy strategies. Meetings do not have to be drawn out to the point of battle. For example, if the team cannot reach an agreement about the type or amount of service, suggest that the issue be tabled in order to obtain additional information from consultation or conversations between your child’s private therapist (if there is one) and the school therapist.

Rather than immediately asking for an independent assessment, disputes can sometimes be resolved by asking that an assessment be conducted by a school district evaluator who does not know your child.

What Parents Should Not Do

1. Complain Loudly & Often

Parents should not complain about every issue that comes up over the course of their child's school life. This is the equivalent of crying wolf, and ensures that when a serious issue does arise, you will not be taken seriously. This is because you are expending the same amount of complaint energy on the serious issue as you expended on trivial issues.

2. Assume the Worst

Parents should not assume that the school district is out to get their child and deny services. While the reality is that the school district is a bureaucracy with its own interests to protect, most individuals in the district enter the field because they care about children.

While you need to enter the special education process with knowledge to protect your child's rights, you should treat the professionals with whom you deal as if those professionals have your child's best interests at heart.

3. Have a Closed Mind

You need to be have an open mind at IEP meetings. If your child's team proposes a placement with which you disagree, do not dismiss it, or refuse to observe it, or refuse to consider it. This is especially true if you may challenge the appropriateness of the proposed placement.

Again, the IEP meeting is important for record-building purposes. If the case goes to a due process hearing, it is important that you present as a cooperative person who thoughtfully considered the team's program, personally observed the program, and can explain why you believe the program does not meet your child's needs.

4. Stint on Experts

Do not try to save money by stinting on experts. You need to find experts who can provide sound professional opinions and evidence. Experts are critical to successful cases, especially if parents are unrepresented.

If you truly cannot find experts, either through your children's medical service providers or otherwise, you need to think about how to use supportive (or even hostile) school personnel to your advantage.

About the Author

Leslie Seid Margolis, Esq. is a managing attorney with the Maryland Disability Law Center (MDLC), a private, non-profit organization staffed by attorneys and paralegals. MDLC is the Protection and Advocacy organization for Maryland.

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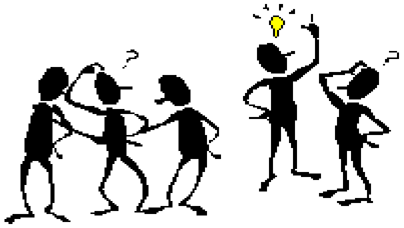
Fax: 410-727-6389
TDD: 410-727-6387



Reprinted with permission from Wrightslaw.com

SUCCESSFUL MEETING PLANNING SHEET

For successful school, medical, and agency meetings – form by *Upward Communications*.

Meeting Name and Agency: ____

Meeting Attendees and Titles: ____

____

____

____

Meeting Date:________________ **Time:**_________ **Location:** _________________

What I need to do *before* the meeting:

____

____

____

What (and whom) I need to *bring* to the meeting:

____

____

____

What I need to *say* at the meeting:

____

____

____

What I need to *learn* at the meeting:

____

____

____

What I need to do *after* the meeting (any "next steps"):

____

____

____

Other Notes and Reminders:

____

____

____

____

Adapted from presentation by Mike Zizzi at Upward Communications

More Advocacy Tips.....

1. Document, document, document. Train yourself to take notes and keep copies of all forms of written communication. According to Pete Wright, of Wrightlaw.com “If it was not written down, it was not said. If it was not written down, it did not happen.”

2. Keep a log of contacts, record pertinent information about each phone call or email including:

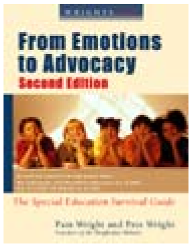
Date of Communication	
Who	
What	
Response	
Other information	

3. Learning to negotiate is part of the process.

4. Ask lots of questions – listen to the answers.

5. Read before you sign.

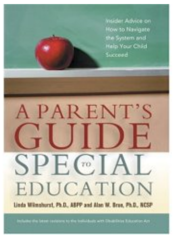
Books on Advocacy



From Emotions to Advocacy ,The Special Education Survival Guide, by Pam and Pete Wright, Sample Letters and Logs

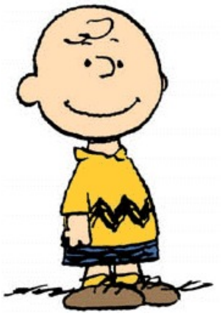
✋ Checklists and Forms

A Parent's Guide to Special Education: Insider Advice on How to Navigate the System and Help Your Child Succeed by Linda Wilmshurst and Alan Brue



"A good education is the next best thing to a pushy mother."

Charles Schulz, cartoonist



And if you have a little more time for advocacy…..

We would not have the statewide services we have--such as family support funding and Medicaid waivers--were it not for the letter writing, phone calling, e-mailing and physical presence of parents and children with disabilities at the state capitol. In recent years this advocacy has been directed towards maintaining the level of services and funding already in place. Of course, the entire history of the disabilities movement has depended on the actions of families--were it not for families thirty years ago most of our children would not even be allowed in school today. It's hard not to take this right for granted and we all must continue to push the system and make it work out of necessity on behalf of not only our child but those that will certainly follow. It isn't easy, even in this day and age. But when I have gone down to the state capitol, sometimes just as a physical presence with my child, other times to testify, the legislators like us. They are interested in our stories and they love to meet out kids. Just a note to your legislators (anytime), thanking them for their time and commitment to us, with a picture of your child--will do wonders. To keep up on big issues subscribe to Parent to Parent at P2P-CO@yahoogroups.com and you'll get alerts during the session which runs January through May. Below are some tips provided by Kelly Stallman of Colorado for Family Voices--a woman and an organization that has been advocating on behalf of our children for years. She can be contacted through Family Voices at **kelly@familyvoicesco.org** For information on calling and writing legislators, check out P2P at http://p2p-co.org/hot-topics/phoneleg.htm. But really, they are very human and just a note of appreciation that you might write a friend can make an incredible difference--especially when an issue comes up that will directly impact your child. And it will, maybe not this year but certainly along the lifetime journey. --Karen Roberts, Family Specialist

Simple Directions

1. Go to www.votesmart.org, enter your 9 digit zip code and find out WHO are your legislators - be sure to write the info in your address book, or somewhere handy.

2. Write down your story. The first time I always write it in DRAFT form, just to get all the issues OUT on the table.

3. Then, if you're willing to share, let's you and I talk. We can see what the message is, find out if we need more information, and then write a final draft.

4. After this, we are set for next steps. Depending on how much you want, or are able, to do - we can send the letter, add a cover letter from Family Voices on policy, GO TO THE CAPITOL and meet your legislators, and if your testimony would be valuable to testimony, you could go to a specific Health Committee and tell your story.

5. Trust me, testimony is intimidating, but it's important to know that legislators REALLY want to hear from you. They CARE about your story. They WANT to do the right thing. They may not always agree on what the right thing is, but they really want to do a good job for families and society.

6. Lastly, USE ME! I'm delighted to help with anything and everything, and if you visit/testify, I'll be right next to you! I'm happy to meet anyone, anytime! Let's make it happen!!!--Kelly Stallman

ACHIEVING THE VISION!

An NTAC/NFADB

National Parent Workshop on Advocacy and Leadership

Tampa Airport Marriott

Tampa, Florida

July 13-15, 2006

NFADB

For more information contact:

NFADB@aol.com

HK
NC

Helen Keller National Center
For Deaf-Blind Youths and Adults

TAKE CONTROL OF YOUR FUTURE!!

Share two weeks of your summer with your peers!
Explore your Vocational goals!
Learn strategies for college planning!

If you are deaf-blind and a junior or senior in high school,
The Helen Keller National Center is offering a 2-week program just for you!

Summer 2006 dates:
JULY 9th-21st, 2006

For more information contact: Mo McGowan at: maureen.mcgowan@hknc.org

Maintaining Your IEP Agenda:
Ten Child-Centered Planning Practices

By Tracy Gershwin Mueller, Ph.D.
Assistant Professor
University of Northern Colorado

Most educators and parents would agree that they come to the IEP table with the intent to discuss and plan practices for the continued improvement for the students' academic, social and behavioral needs. Unfortunately, sometimes, this vision becomes lost. How does this happen? To put it very simply, there are many issues that are formally and informally addressed during IEP meetings. According to the recent IDEA reauthorization of 2004, each IEP must include information and discussion about the following categories of information: 1) a statement of the child's present levels of academic achievement and functional performance, 2) a statement of measurable annual goals including academic and functional goals, 3) a description of how the child's progress toward meeting the annual goals will be measured and when such reports will be provided to the educational team, 4) a statement of the special education, related services and supplementary aides, based on peer-reviewed research to the extent practicable, 5) the child's inclusion/exclusion in educational activities with students who do not have disabilities, 6) the projected dates of service initiation, frequency and duration, 7) state or district-wide assessment modifications, and 8) appropriate post secondary goals and transition plan services, by age 16 (Wright, P.W.D., 2004, pg. 29-31).

Typically, however this is not the only information that is covered during IEP meetings. Oftentimes assessment results are reported and interpreted, along with discussion about any of the student's cognitive and social behaviors at home, during non-instructional times at schools, and any relevant incidents that may have developed at school or home. The aforementioned lengthy list of IEP components is meant to be formally covered before anyone can sign the IEP document, but is it really all addressed collectively as a team with the students needs placed at the center of those decisions? My own experiences at IEP meetings have shed a great deal of light on how IEP teams can lose their focus on child-centered planning. It is important to note that I use the word child and student synonymously to represent students of all ages and abilities. Additionally, my own definition of child-centered planning is the practice of placing the student's needs at the forefront of all team discussions and decisions. Following this framework, student strengths, experiences and the like are placed at the center of team discussions concerning the student's educational, behavioral, and social programming. For example, before a team would discuss the method, frequency or duration of a given intervention, such as speech and language therapy, the team would first chart all of the student's strengths, perceived limitations, student goals, and family goals. Using this information as a guide, the team would then evaluate the methods, frequency and duration *options* that could assist the student with achieving their goals and closing the gap between their strengths and perceived limitations.

Prior to providing any intervention suggestions, I think that it is important for both parents and educators to first gain an understanding of both sides to this dilemma. After all, without knowing how we lose focus at IEP meetings we cannot really understand how to address the problem. Research on deterrents to parent advocacy indicates that one of the major obstacles parents experience at IEP meetings is inflexible scheduling and restricted time limits (Harry, B., Allen, N., & McLaughlin, M., 1995). Studies indicate IEP meeting are not planned or conducted in parent-friendly ways (Harry, B., Allen, N., & McLaughlin, M., 1995; Turnbull & Turnbull, 2001).

Parents are notified of IEP meetings as late as 2-3 days prior to the meetings with inflexible meeting schedules that make it very difficult for parents to attend the meetings. Additionally, IEP meetings are often conducted over a short time limit. Observations also indicate that parents who are allowed more time for the meeting come prepared with questions and concerns about their child's education. Consequently, parents who do not actively participate in the meetings experience abrupt and concise meetings. This finding indicates that those parents who openly challenge and engage in discussion with school officials are more apt to receive a thorough meeting that allows more time for collaboration. Parents also describe IEP meetings as document directed with the focus taking place over receiving information and signing paperwork, rather than student-centered discussions.

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Looking at this dilemma from a special educator's perspective, school personnel are often placed in difficult situations at IEP meetings. Teachers face the obstacle of providing social services to their students (i.e. providing an education), while representing the local policies (i.e. legal mandates) (Weatherly & Lipsky, 1977). In the case of special education, where the IDEA has such a great influence, these teachers are inadvertently wedged into a predicament. The required IEP components, enormous amount of paperwork, large case-load of students, and a lack of educational support place many special educators at odds between the district they work for and the children and parents they serve. Although the IEP components are clearly important to the student's education, the formal requirements can get in the way of the cooperative planning that was originally intended during the construction of IDEA. The recent IDEA reauthorization (2004) has also attempted to address these constraints.

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Knowing that both sides of the table have unique experiences with the IEP process and the special education system at large, there are many strategies each stakeholder can employ to assure that they don't lose the child-centered focus. In this next section, I will present some proactive student-centered strategies both parents and educators can employ. The ideas presented come from special education literature, research, my own professional experiences, as well as parent and professional tips I have received over the years. For the purpose of accessibility and efficiency, I will present the next section by listing the strategies along with a brief description of the procedures and purpose:

1. ***Conduct Pre-IEP Meetings***: Parents and educators can discuss the child's yearly progress, assessment results, upcoming events and the parents emerging goals for the student in the home, school, and community at least one or two weeks prior to the IEP meeting. At this time, the two parties can come together to discuss their own goals for the upcoming meeting and any issues that can be discussed ahead of time.

2. ***Obtain Assessment Results Prior to the IEP Meeting***: Parents can request, in writing, that each member of the IEP team provide them with any assessment results one to two weeks prior to the meeting. Not only does this strategy allow parents time to reflect on the information provided and plan ahead, it also makes room for more active team discussions about *what to do* with the results during the IEP meeting.

3. ***Set Goals for the IEP Meeting***: Prior to the IEP meeting, the educators can call, meet or email all of the stakeholders who will be attending the meeting and ask them to state their goals for the meeting. Upon arriving to the meeting, the goals from all of the participants should be posted throughout the room for the others to view and to maintain focus.

4. ***Display Student Memoirs***: If the student is not present at the meeting, bring a picture of the student and place it at the center of the table, as well as work samples, or any artifacts that represents the student. This strategy includes the student's presence and brings the meeting back to child-centered planning.

5. ***Actively Include the Student***: Students who attend their IEP meetings can become actively involved by working with their teachers to facilitate their own IEP meeting. Because student attendance at IEP meetings can easily result in the student passively attending, specific plans need to be made to promote the students' engagement. One effective example I have seen used with this strategy included students' presenting their IEPs in power point form. With the availability of adaptive equipment and assistive technology, students of all abilities can successfully perform this task. The purpose and goal of this practice is to provide the students with an empowering way to learn self-determinism, autonomy, and to keep the focus on their work.

6. ***Create a Meeting Schedule***: Team members can collectively create a schedule prior to the meeting to assure that all important issues are addressed and to maintain focus.

7. ***Implement an IEP "Parking Lot":*** I first became introduced to this strategy from a school district that implemented facilitated IEPs as a means to resolve conflicts between parents and school personnel. Because the district recognized that often times IEP meetings can result in a loss of focus and a lengthy discussion over an issue unrelated to the task at hand, the district implemented a "parking lot." Quite simply, a large piece of paper, labeled parking lot, is posted in the room and used to document any comments or issues that come up during the meeting and are identified as off topic. Essentially, the parking lot strategy acknowledges the issues presented and promises to return to those concerns at a later date. Simultaneously, the meeting maintains it's focus, all team members' concerns are validated and relationship issues are not constrained.

8. ***Create a Student Needs Chart***: Team members can create a chart with the student's name placed in the center. Surrounding the chart, the team could explicitly discuss and document the student's strengths, perceived limitations, previous goals attained, and present levels of academic achievement and functional performance. Based on this information, the team can discuss where they would like the student to proceed by including both short and long-term goals in the following areas: academics, social, and behavioral in the home, school, and community. Next, the team would actively plan how they could assist the student with attaining the goals. Finally the details surrounding the action plan would be discussed, such as interventions, duration, frequency, etc. This practice is the opposite of the typical meetings that begin with the services the student is receiving. The difference here it that the focus always stays on the student.

9. ***Plan Ahead***: Parents can plan for the IEP ahead of time by creating a list of any goals, questions, and concerns they would like to discuss. The pre-planning not only assists the parents with creating their own mental picture of what they would like to achieve during the meeting, it also gives them an outlet to practice active team participation.

10. ***Always Refer Back to the Student***: Any discussions and decisions should always go right back to the student and their needs. Continuously ask questions, such as, How can this help the student? What does the student really need? Is this really beneficial to the student's optimal growth?

Finally, parents and district members should always try to understand each others' perspectives, visions and experiences.

References

Harry, B., Allen, N., & McLaughlin, M. (1995). Communication versus compliance: African American parents' involvement in special education. *Exceptional Children, 61*(4), 364-377.

Turnbull, A., & R., T. (2001). *Families, Professionals, and Exceptionality: Collaborating for empowerment*. Upper Saddle River, NJ: Prentice-Hall, Inc.

Wright, P.W.D. (2004). The Individuals with Disabilities Education Improvement Act of 2004: Overview, Explanation, and Comparison. Retrieved from http://www.wrightslaw.com/idea.2004.all.pdf

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.

2006 SUMMER INSTITUTE ON DEAFBLINDNESS

Links to School and Life Success: Communication and Literacy: for Children with Deafblindness and Other Significant Support Needs

Institute Dates, Site, Presenter, and Content: The Summer Institute is scheduled for June 19-21, 2006. It will be held at the Great Divide Resort in beautiful Breckenridge, Colorado. The featured speakers are Susan DeCaluwe and Lisa Jacobs who are Educational Consultants for the New England Center Deafblind Project (NEC) at Perkins School for the Blind, serving children who are deafblind throughout New England at home, at school and in their communities. Participants will learn to:

1. Identify and be able to articulate the unique learning needs of learners who are deafblind.
2. Explore a variety of tools and strategies that reflect best practice in the areas of Communication and Literacy for students with significant support needs and deafblindness.
3. Create a person centered communication portfolio.
4. Identify literacy strategies unique to learners with significant support needs and deafblindness.
5. Develop literacy kits.

Target Audience: The hands-on 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. Priority will be given to parents and educational teams working with children with a vision and hearing loss. Participants will be limited to 60 persons.

Sponsors of the Training: The Colorado Services to Children with Combined Vision and Hearing Loss Project and the Colorado Chapter of AER.

Schedule: Start at 9:30 a.m. on Monday, June 19 and end at noon on Wednesday, June 21, 2006.

Cost: The registration fee to attend this seminar is $75 for early registration (**May 31**) and $100 for late registration. Colorado participants will be provided with complimentary lodging for Monday, and Tuesday (June 19 and 20) nights (two participants per room). A continental breakfast will be provided each morning and lunch (with a vegetarian option) will be provided on Monday and Tuesday. Participants will be responsible for their own transportation to Breckenridge, their evening meals, registration fees, and elected tuition costs. Lodging arrangements will be made by Tanni Anthony and confirmed with participants.

University Credit: The class will be offered for one university credit through the University of Northern Colorado at an anticipated cost of $55. Participants will need to write a graduate-level paper for course credit and attend the full training.

Participant Agreement: Participants will be expected to attend the full training. Workshop participants who are working with a child with combined vision and hearing loss must 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 2006-07 school year. The purpose of this free visit will be to address the impact of the summer training on the child's school and/or home program.

???s: If you have any questions, please call Tanni Anthony (303 866-6681) or Anthony_t@cde.state.co.us
Please make your check out to: **CAER** and send it with your registration form. **Please do NOT make your check out to CDE.** The training is open to **60** participants.

2006 SUMMER INSTITUTE ON DEAFBLINDNESS

Links to School and Life Success: Communication and Literacy: for Children with Deafblindness and Other Significant Support Needs

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:____________($75 early bird fee by **May 31, 2006**)
(Please make out checks to CAER)
________($100 late fee after **May 31st, 2006**)

I am interested in university credit.____________

Roommate preference, if known: ____
(All hotel rooms are double rooms with two beds – for two participants

Special Accommodations Needed - MUST BE REQUESTED BY MAY 31st (sign language interpreter, braille):

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: ____

Other team members who would like to join me in this training:

Please return this completed form AND registration check to Jennifer Dinges, CDE, 201 East Colfax, Denver, Colorado 80203. ***The early-bird deadline for applying for this training is May 31, 2006***

Family Learning Retreat

Family Learning Retreat 2006

DREAM:

Develop, Resource, Educate, Access, and Mobilize

Colorado School for the Deaf and the Blind
33 North Institute Street
Colorado Springs, Colorado 80903
June 2-4, 2006

The Family Learning Retreat will be returning to the Colorado School for the Deaf and the Blind on June 3-5, 2006. The weekend retreat is for any family with a child who is deaf/hard of hearing, blind/visually impaired or deafblind. This is an opportunity for families to meet other families while networking, learning and having fun together. This year's theme is **DREAM: Develop Resource, Educate, Access, and Mobilize!**

Parents /adults will attend workshops during the day, while children participate in supervised recreational activities or daycare, depending on their ages. Check-in and dinner begins Friday evening, June 2nd starting at 5:00PM until 7:30 PM followed by an opening session. The retreat ends by noon on Sunday, June 4th. Lodging in the CSDB dorms is provided for both Friday and Saturday nights. All meals are included except for Saturday evening.

The cost of the Family Learning Retreat is only $10.00 per adult and $5.00 per child under the age of 18. Spanish and Sign language interpreters will be provided upon request. Interested or know of someone who is? Call Diane Covington at the Colorado School for the Deaf and the Blind at (719) 578-2225 to call in your registration. For Spanish speaking participants, contact Gloria Romero 719-578-2288. For a reservation to be confirmed, a registration must be called in and payment received by Friday, **May 5, 2006**. Any registration not confirmed with a payment by that date will be released to allow others on the waiting list to take advantage of the opportunity. Please contact Diane Covington in Colorado Springs at (719-578-2225) or Gina Quintana in Denver at (303-866-6605) if you have any questions.

We hope to see you there!

Come and Relax. Make New Friends. Experience a valuable learning opportunity.

Child care will be provided Saturday evening for parents to have time relax!

Registration Deadline: May 5, 2006

Retiro de Aprendizaje de Familia 2006

SOÑAR:

Desarrollar, Recurso, Educar, Acceso, y Movilizar

(En Ingles) **DREAM:**

Develop, Resource, Educate, Access, and Mobilize

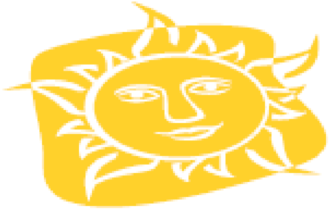
Colorado School for the Deaf and the Blind
33 North Institute Street
Colorado Springs, Colorado 80903
2-4 de Junio de 2006

El Retiro de Aprendizaje de Familia regresará a la Escuela de Colorado para los Sordos y los Ciegos (CSDB) el 2, 3 y 4 de junio de 2006. El retiro de fin de semana es para cualquier familia que tiene un hijo/hija sordo/duro de oído, ciego/discapacidad visual o sordo-ciego. El retiro es una oportunidad para que las familias conozcan a otras familias y establecen contactos, aprenden y se divierten juntos.
Este año el tema es SOÑAR: Desarrollar, Recurso, Educar, Acceso, y Movilizar

Los padres/adultos asistirán seminarios durante el día, mientras que los niños participen en varias actividades o reciban cuido de niños, depende en sus edades.
La facturación y la cena empiezan a las 5:00PM y duran hasta las 7:30 PM en viernes, el 2 de junio. Después reuntaremos para dar la bienvenida.

El retiro concluye al mediodía en domingo el 4 de junio. Habrá habitaciones disponibles en los dormitorios de CSDB para el viernes y el sábado. Todas las comidas menos la cena del sábado por la tarde están incluidas.

El costo para el Retiro de Aprendizaje de Familia es $10.00 por cada adulto y $5.00 por cada niño bajo 18 años de edad. Interpretes de Español y de Señas serán disponibles por solicitud. Si le interesa o conoces a alguien con el interés de asistir, por favor llame a Gloria Romero en la Escuela de Colorado para los Sordos y los Ciegos al (719) 578-2288. Llame ahora para registrarse. Después de recibir su pago, confirmaremos su registración. Envía su dinero antes del viernes, 5 de mayo, 2006 para asegurar su lugar.



¡Esperamos verlos!

*Vengan para relajarse *Conocer nuevos amistades
*Seria una experiencia de aprendizaje inolvidable

¡Padres de Familia - Disfruta, ahora que puedes!
Cuido de niños será disponible el sábado por la tarde

REGÍSTRESE ANTES EL 5 DE MAYO DE 2006

Calendar of Events

2006 2006 2006 2006 2006 2006 2006 2006 2006 2006

June 2-4	**Family Learning Retreat** - CSDB Contact: Gina Quintana—(303) 866-6605 or Quintana_g@cde.state.co.us
June 8-9	**Collaborative Assistive Technology Conference**—Denver Contact: www.uchsc.edu/atp
June 17-23	**American Association of the Deaf-Blind Conference**, Towson, MD Contact: espiers@aadb.org
June 19-21	**2006 Summer Institute on Deafblindness**—Breckenridge Contact: Tanni Anthony—(303) 866-6681 or Anthony_t@cde.state.co.us
July 9-21	**Summer Seminar for High School Students** Helen Keller National Center, Sands Point, NY Contact: Mo McGowan—maureen.mcgowan@hknc.org
July 13-15	**National Family Association for the Deafblind**—Tampa, FL Contact: NFADB@aol.com
July 22-24	**Jan van Dijk Conference—Greensboro, NC** Contact: Chris Jones (919) 807-3991 or cjones@dpi.state.co.us
July 31-August 4 **August 6 –11**	**Lion's Summer Camp**—Colorado Springs, CO Contact: www.lionscampco.org

2007 2007 2007 2007 2007 2007 2007 2007 2007 2007

January 19-20	**Courage to Risk Collaborative Conference**-Colorado Springs Contact: couragetorisk.org

Colorado State Board of Education

William J. Moloney

Commissioner of Education

Colorado Department of Education
Exceptional Student Services Unit
201 E Colfax Ave. #300
Denver, CO   80203-1799

385B 3401