

VIBRATIONS

NEWSLETTER OF COLORADO SERVICES FOR CHILDREN AND YOUTH WHO ARE DEAFBLIND,
THEIR. FAMILIES, AND SERVICE PROVIDERS.

Winter 2009



Raising Kelsey The Worst, The Better, and The Best

By Lisa Schwartz, Kelsey's Mom

The worst part -

Our five-year-old daughter has an extremely rare genetic disorder. So rare, in fact there is no name, other than 46XX,der(12)+6;12)(p21.1 or p21.3;p13) mat. Not something you can easily explain to people in the medical, therapeutic, and education fields, let alone at a cocktail party. This translates into a pretty good laundry list of medical, physical, and mental issues. I believe we have visited just about every specialty clinic at the Children's Hospital. We lost track of Kelsey's secondary diagnoses somewhere around number 25. Eating remains her biggest physical issue. She is on a continuous feeding pump during the day, and we have to flip her upside down two times an hour to burp her through her tube, or she will throw up. Kelsey has had numerous surgeries on her ears, eyelids, nose, head, stomach, and urinary tract system. This does not include all of the examinations under anesthesia for vision, hearing, dental, and I can't remember what else, or the overnight tests for seizures, reflux, sleep patterns, and the like. Kelsey is severely visually impaired (septo optic nerve dysplasia, retinal dystrophy, fovea malformation, -20 severe myopia, three ptosis repairs, and possible cortical-visual impairment), and hearing impaired (mild loss in her right ear after spending her first three years with a severe to profound bilateral hearing loss due to drainage issues). Kelsey also has severe chest infections in the winter, which often require an overnight visit to the hospital or a few trips to the emergency room.

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The better news-

Now Kelsey visits only four to five doctors on a regular basis, down from a peak of thirty during her first two years of life. We would love Kelsey, no matter how many medical issues she had or how she developed. However, despite all this, Kelsey walks and rides a tricycle with help, crawls on her own, uses on the potty, and chews food by mouth. Lynn Wismann Horther, Colorado Home Intervention Home (CHIP) Coordinator introduced Kelsey to the communication matrix developed by Dr. Charity Rowland and Phil Schweigert over four years ago. It taught our family to observe Kelsey for communication opportunities we would have never noticed. It also allows a multimode communication approach, including verbal, modified signs, object representation, and augmentative speech. This has worked well for a child who



can communicate in one or two ways, but is unable to grow in just one form. Now everyone in the family can communicate with Kelsey! We never would have dared to dream of this, not in a million years. I had no idea what a little personality this girl has, and now she has become a rather opinionated master of communicating her wants, needs, and whims. She says “Ma Ma” and signs “up” to walk and then walks me where she wants to go upstairs, downstairs, inside or outside the house. When we sit down for dinner, she crawls over to the kitchen and signs “eat” with a very loud “eeeeaaaa” grunt. Kelsey giggles and has a little smirk on her face when we walk her over to her chair to join us. She is quite proud of herself as she picks up her crackers and spits them out. (She is unable to swallow). She says “all done” and signs it by slapping her legs when we put her down for nap and she doesn’t want to sleep. Kelsey’s favorite modified signs are “music” and “sing”, whether I sing out of key, her father plays the guitar, or she plays the piano. She gives a “high five” for hello and goodbye, and her latest is signing “chair” and “toy” by directing my hands. There still are days, however, when Kelsey communicates but we cannot understand her. We just hope she doesn’t get too frustrated waiting for us to figure out what she is trying to “say. Because believe me, this girl has an opinion.



The best of all-

We call it “The Kelsey Way.” It began as a term we used to describe how our daughter learns and experiences the world, which is the complete opposite of what people expect. Now “The Kelsey Way” means so much more. It is how my 71-year-old Mom can’t wait to see her granddaughter because she has forgiven herself for the mixed feelings she had as a sibling of a brother with special needs. Or how my Dad and stepmother have learned the amazing joy and a “tragic situation” are not mutually exclusive. All my parents have learned the priceless gift of caring for Kelsey and how it makes them transcend to a level they didn’t know exist. My husband Jeff has a spiritual - musical connection with Kelsey when she puts her head on his guitar and shows him there is more to music than mere sound. “The Kelsey Way” worked through our ten year old son when he befriended a boy, who is severely autistic, at school who had difficulty relating to other kids. Whenever we go outside, our neighbors stop what they are doing and make it a point to say hi to Kelsey. Something I would have never thought of doing before our daughter arrived, and I know that our neighbors are forever changed in ways I can’t describe. One of the biggest positives in Kelsey and our lives has been her dedicated and passionate providers. It goes way beyond making a living for these folks, and I am honored to have met

such amazing people. Kelsey really is an agent for positive and immeasurable change in all of us. She is a reminder that we can’t take all the stuff we think is so important and work so hard for everyday in the end. Kelsey has taught us to transcend daily life. We all just have to take the time to see it, and believe me; some days I completely miss what Kelsey is all about.

Editors’ Note: We would like to thank the Schwartz Family for the glimpse into their lives. THANK YOU!

Thoughts from Kelsey's Grandma

Who knows when life will be re-directed by the advent of a very "special" child? Kelsey blasted her way into my life March of 2003 and has been an ongoing challenge. Granma had to learn new terminology like Mickey button and Nissen. Now at age five, I am so charmed by Kelsey that I cannot imagine life without her. She is loving, has a wonderful "belly-laugh" and has a mind of her own. She loves to hear her Granma sing (off key of course) and will roll a ball. She is happy to be in a swing and her next favorite is water, either a bath or a swimming pool.

While creating wonderful memories, she has "stretched" Granma's skill bank from learning to drive in downtown Denver to responding to a coughing spell in the middle of the night. She lives in a loving environment and Granma especially enjoys her "hugs and kisses." Her latest accomplishment is "high five." It has been difficult to see my daughter and Kelsey's family be in constant attendance of Kelsey's situation, but it has drawn us closer. What a blessing!



“While we try to teach our children about life, our children teach us what life is all about.”

-Anonymous

Online Courses in Communication

Design to Learn and Oregon Health & Science University offer two ongoing courses developed by Charity Rowland and Philip Schweigert.

Pre-symbolic Communication

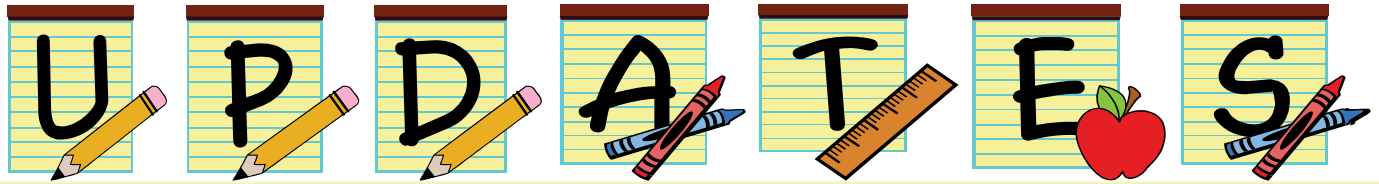
http://www.designtolearn.com/pages/tsonline_pccourse.html

Tangible Symbol Systems

http://www.designtolearn.com/pages/tsonline_tscourse.html

A growing number of online/distance education opportunities pertinent to deaf-blindness are available.

<http://www.nationaldb.org/ppConf-Train.php>



This Newsletter Edition: This edition of VIBRATIONS is focused on the topic of Communication and the use of the Communication Matrix. We have been out to many schools this fall and have seen the Communication Matrix and the learning from the Summer Institute in action. Please keep in touch with your technical assistance needs specific to these tools. We are happy to help with more resources and onsite consultation.

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 forms were mailed out in November and due back to CDE by mid December. Your attention to updating and assuring that we have the most current information on the children and youth is greatly appreciated. If you have any questions about the census process or would like a census form to register any newly identified children, please be in touch with Tanni Anthony at (303) 866-6681 or anthony_t@cde.state.co.us.

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

Technical Assistance (TA): Staff is available to provide free consultative assistance to families and school personnel both in the child's home or 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 the awesome work that you are doing in your classroom

Project Website: We have been adding information to the website! Be sure to check out the new Fact Sheets that have been translated to Spanish! To check out the website, please go to <http://www.cde.state.co.us/cdesped/SD-Deafblind.asp>

Summer Institute: We are currently working on dates and topics for the 2009 Summer Institute on Deafblindness. If you have suggestions on a topic, please be in touch with Tanni Anthony.

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Grants Available for Families Struggling with Child Health-Related Expenses

Deadline: Open

The United Healthcare Children's Foundation (<http://uhccf.org/>) has announced that new grants are available to help children who need critical health care treatment, services, or equipment not covered or not fully covered by their parents' health benefit plans.

UHCCF provides grants to families to help pay for child health care services such as speech therapy, physical therapy, occupational therapy sessions, prescriptions, and medical equipment such as wheelchairs, orthotics, and eyeglasses.

Parents and legal guardians may apply for grants of up to \$5,000 each for child medical services and equipment by completing an online application at the UHCCF Web site.

To be eligible for a grant,
children must be 16 years of age or younger.
Families must meet economic guidelines, reside in the United States,
and be covered by a commercial health benefit plan.



“Let no child be demeaned, nor have his wonder diminished,
because of our ignorance or inactivity.
Let no child be deprived of discovery,
because we lack the resources to discern his problem.
Let no child ever doubt himself or his mind
because we are unsure of our commitment.”

-Allen Martin

We Did It!

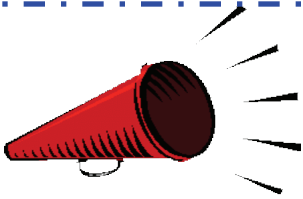
By Gina Quintana, Project Coordinator

Yes, that's right! We did it! *The Colorado Services for Children and Youth with Combined Vision and Hearing Loss* Grant was funded for another 5 years! This is great news, especially with the current state of the nation and funding being cut for many services and grants across the country. The current grant has many of the some aspects of the past grant , as well as a few new activities and personnel. Dr. Tanni Anthony will continue in her role as the Project Director, Gina Quintana will remain as the Project Coordinator and Shannon Cannizzaro will switch from Parent Consultant to Family Specialist.

We would like to introduce and welcome the newest members to our team. First of all, we have 2 new Technical Assistance Specialists (TAS). Ann Gillmeister and Shawn Sweet Barnard will fill these roles and their primary responsibilities will be to provide Technical Assistance to school district teams and / or families who have a child on the Deafblind Registry. Ana Trejo will also be joining us as a Family Specialist with an emphasis on working with our Spanish-speaking families. We are very excited to have each of these ladies join our team!

The new grant's activities include collaborative projects with many state, regional and national entities including the Anchor Center for Blind Children, CO Assistive Technology Project, CO Center for the Blind, CO Council for Exceptional Children, CO School for the Deaf and the Blind, CO Home Intervention Program, CO Instructional Material Center, CO Families for Hands and Voices, Helen Keller National Center-Rocky Mountain Region, Marion Downs Hearing Center, PEAK Parent Center, Rocky Mountain Deaf School. The Regional partners include the Mountain Plains Regional Resource Center and Area 1 Projects for Children with Deafblindness. National Partners are DB-Link Clearinghouse, National Family Association for Deaf-blind, National Center on Severe and Sensory Disabilities and the National Consortium on Deafblindness.

We are very excited about the new grant and look forward to meeting all of your training and support needs. Please do not hesitate to contact us for Technical Assistance. ... we are here for YOU!



Introducing...

Ann Gillmeister received a degree at UNC in teaching students with visual impairments and orientation & mobility. After having taught a diversity of visually impaired learners including students with multiple disabilities and students with combined vision and hearing loss in Colorado schools, Ann retired from her local school district. She currently works with the CDE Project for Students with Combined Hearing and Vision Loss providing technical assistance. We are so grateful to have Ann on board!

Greetings! My name is **Shawn Sweet-Barnard**. I am excited to be a member of such a wonderful community consisting of adults and children who are deaf-blind, their families, and an array of educators and related service providers. Together, I believe we can improve services and the quality of life for children and youth who are deaf-blind, as well as their families. For the past three years, I have been working on my doctorate in special education and low-incidence disabilities. During this time, I received my special education administrator's license and have worked as a Coordinator for the National Center on Severe and Sensory Disabilities (NCSSD). Prior to my doctoral study, I worked as a Technical Assistance Specialist for the National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind (NTAC) now known as the National Consortium on Deaf-Blindness (NCDB). Some of my other related professional roles have included working as job coach, independent living teacher, high school counselor, and signed language interpreter for adults and youth with deafness, visual impairments, and deaf-blindness. It is a great pleasure to join the team at the Colorado Services for Children and Youth with Combined Vision and Hearing (Deafblind) Project! I look forward to meeting many new people across Colorado!

THANKS FOR THE SUPPORT!

The Colorado Services for Children and Youth with Combined Vision and Hearing Loss Project would like to thank the following people for sharing a letter of support / partnership for the April 24th, 2008 grant project submission:

- Barbara Adams, Samantha Hoffman, Judy Mumford, Wendy Stoltman, Nancy Cozart (TVIs from Mountain BOCES, JeffCo, Academy 20, Brighton, and Littleton)
- Linda Alsop (Utah State University)
- Alice Applebaum (Anchor Center for Blind Children)
- Maurice Belote (CA), Robin Greenfield (ID), Mary Ann Demchek (NV), Nancy Hatfield (WA), Patrick Pallai (AK), Joanne Whitson (WY), Lyn Ayre (OR), Darla Fowers (UT), Cindi Robinson (AZ) (Area 1 Deafblind Projects)
- Robin Brewer (SSN), Paula Conroy (BVI), and Lewis Jackson (SSN) (University of Northern Colorado)
- Arlene Brown and Sandra Gabbard (Marion Downs Center)
- Barbara Buswell (PEAK Parent Center)
- Diane Carroll (Metro State College)
- Shannon Cannizzaro, Chris Cannizzaro, Andy Canizzaro (family!)
- Beth Celva (Unit of Student Assessment, CDE)
- Julie Deden (Colorado Center for the Blind)
- Janet Cerny Dickenson (Rocky Mountain School for the Deaf)
- Paddi Davies (National Consortium on Deaf-Blindness)
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- Janet DesGeorge (Hands and Voices)
- Kay Ferrell (National Center on Severe and Sensory Disabilities)
- Jennie Germano and Jon Vigne (Colorado School for the Deaf and the Blind)
- Monika Gyls (Western State University)
- Colleen Head (Part C, Developmental Disabilities)
- Jenn Leitzke (parent)
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- Maureen Melonis (Colorado Assistive Technology Project)
- Cheryl Nelson (parent)
- Karen Roberts (parent)
- Jim Olson (Colorado Instructional Materials Center)
- Julie Richter (Adams 12)
- Karen Riley (University of Denver)
- Cory Robinson (JFK Affiliate Programs)

REFERENCE POINTS: A Parent Toolkit
A Project of PACER Center



REFERENCE POINTS: Special Needs Parent Toolkit

The DOD Special Needs Tool Kit is designed to help military families and others with special needs children navigate the maze of medical and special education services, community support and benefits and entitlements. The Toolkit is broken down into six colorful modules that can be easily downloaded and printed.

The Toolkit can be found at http://www.militaryhomefront.dod.mil/portal/page/mhf/MHF/MHF_DETAIL_1?section_id=20.40.500.570.0.0.0.0.0&content_id=218947

New National Consortium on Deaf-Blindness Website

www.nationaldb.org

- * Comprehensive source of information and resources on deaf-blindness, technical assistance, and personnel training
- * Easy access to full text materials on more than 70 subjects in Selected Topics
- * Announcements of upcoming events and new publications
- * Resources for Families and Teachers

The National Consortium on Deaf-Blindness
Improving Outcomes for Children Who Are Deaf-Blind

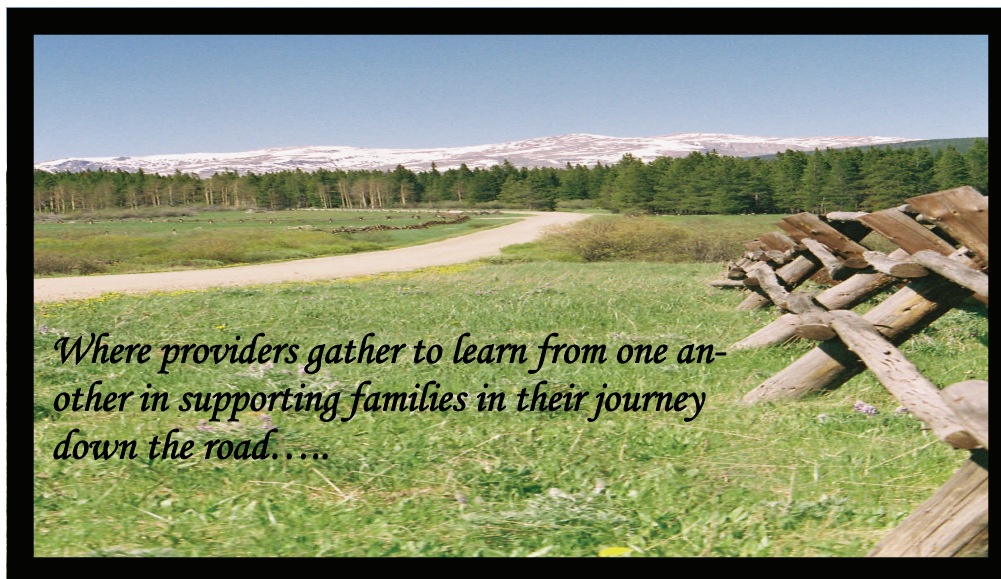
National Center for Family Literacy Invites Entries for
Toyota Family Literacy Teacher of the Year

The [National Center for Family Literacy](http://www.nationalcenterforfamilyliteracy.org) and [Toyota](http://www.toyota.com) are accepting applications for the 2009 Toyota Family Literacy Teacher of the Year.

Family educators from across the United States are eligible for the award. Nominees must work primarily in children's education, adult/ESL education, parenting education, or other educational services and must be able to demonstrate an impact on intergenerational learning between parents and children. Programs may nominate up to two educators. The online nomination form must be completed by the program director or coordinator. The nomination must include a statement of support for the nominated educator written by an adult student who works with the educator. The winner will receive \$7,500 for his or her family literacy program as well as a free trip to the 2009 National Conference on Family Literacy in Orlando, Florida. In addition, several finalists will be selected to receive a \$500 scholarship. Program guidelines and nomination forms are available at the NCFL Web site.

Contact: <http://www.familit.org/site/c.gtJWJdMQIsE/b.3136491/>

Western Regional Early Intervention Conference



Conference for Providers Working with Children,
Birth to 5 Years Old,
Who are Blind, Visually Impaired,
Deaf-Blind, Deaf, or Hard of Hearing

April 23rd-25th, 2009
Colorado Springs, Colorado

Cheyenne Mountain Conference Center and Resort



For more information:
mbrady@csdb.org
(719) 578-2260

Hosted by:



The registration is now open for this important conference. Please go to the CSDB website at www.csdb.org to find registration materials.

Getting Started with The Communication Matrix

By Tanni Anthony

The theme of the 2008 Summer Institute on Deafblindness was the *Communication Matrix*. This was the second time the project brought Phil Schweigert back to be a lead presenter at our summer institutes. Our goals this time around were to cement our working knowledge of the seven levels of communicative intent, how to use the *Communication Matrix* with families and other team members, and how to use the assessment findings to plan next steps for day-to-day intervention. Thanks to Phil and also to Dinah Beams and Lynn Wismann Horther for their amazing contributions over the two and a half days to accomplish our many goals.

Why are we spending so much time to familiarize people with the *Communication Matrix* and its content? Simply put, the *Communication Matrix* is an invaluable tool. If a team is working with a child who is nonverbal and/or who requires an augmentative communication system, the tool is a must. It is the place to start. When it is used correctly, the *Communication Matrix* helps the team understand what the child can do and is ready to learn to do. It also holds the full team accountable for being responsive to the child at his or her level of communicative need. Parents are full partners with the assessment and next steps of building a communication program.

Communication is the cornerstone of all relationships, classroom membership, learning, literacy, employment, and life success. Every person has a role with a child's communication development. When we work together on behalf of a child, we can see amazing results. Many times children with combined vision and hearing loss have subtle ways of telling us something. We must work together to identify what and how the child is communicating and how to increase these skills across people and different settings.

Time after time as I have been involved with trainings specific to the *Communication Matrix*, I have talked with practitioners about their self-discovery that they have not accurately determined the child's level of communication and have either built a communication system that is too high or too low for the child. Many confess that they moved too quickly to a symbolic system and did not spend enough time building a responsive communication environment to nurture the child's communication intentionality. As they learn about the *Communication Matrix*, their skills grow as evaluators and the people implementing a communication program. Most importantly, children benefit when their parents and service providers plan together based on accurate assessment findings.

The Colorado Services for Children and Youth with Combined Vision and Hearing Loss is committed to ensuring that all parents of and service providers for children and youth with deafblindness have access to the *Communication Matrix* tool and its content. We have ample copies of the following formats of the *Communication Matrix* by Dr. Charity Rowland:

- *Communication Matrix, A Communication Skill Assessment*
- *Communication Matrix: Especially for Parents*
- *Matriz de Comunicacion: Especial para Padres*

Our technical assistance specialists have been trained to use these tools and to train others to use them. If you would like free technical assistance on using the *Communication Matrix* with a child who has combined vision and hearing loss, please call or email Gina at (303) 866-6605 or Quintana_g@cde.state.co.us. She will work to set up a consultation visit with complimentary training materials.

Thanks to everyone who took the time to participate in the 2008 Summer Institute. If we missed you this last time, please know that we will do our best to provide the training information to you over the course of this school year. Please be in touch with your training and consultation needs.

The Communication Matrix as a Map Towards Communicative Exchange: One Child Progressing from Level 2 into Level 3

By Kristen Mylander

Editors' Note: We would like to thank Kristen, Ben, Ben's and Parents Jeff and Karen, for allowing us to take a deeper look into the communication process that has been developed for Ben.

I have known Benjamin for nearly ten of his eleven years. There have been many "firsts" along the way; first day of school, first time sitting up independently, but none have been as exciting to me as when he first began to ask for "more." From February through December of 2005 I had the great fortune to be part of an internship with Philip Schweigert that gave Benjamin and I a whole new way of communicating. Starting with these simple requests, we both began to understand a new communicative contract that was based in dialogue. I also began to see the potential that The *Communication Matrix* had, not just as an assessment tool, but as a guide for developing emerging skills.

From Level 2: intentional behaviors that are interpreted (proactive/volitional behaviors relating to state, environment shaping as consequence) Figure A

Benjamin was always easy to read emotionally. For him, his low vision meant that our facial expressions were either unclear or totally unseen, but for us, his smiles, pouts, quiet attending or mounting frustrations were very clear. There was wiggling and laughing when something was fun. If things were difficult or confusing there was a slumped "checking-out" or worse, angry tears. His likes and loathes were pretty consistent and we became very good interpreters for changing environments or position or demands on his attention. At the time the internship with Phil started Benjamin was communicating with us mostly by these means. He had roughly a dozen tangible symbols he was familiar with that represented the places (home, school, etc) people and activities that were part of his week. Most were being accessed receptively, as in "time for school" and holding on to the school cue. He was inconsistently making choices between two activities such as swinging and computer. The goal most important to his team was to teach him to use an object symbol for "break time" rather than get to fussy emotional indicators that we had to interpret as "break time."

to Level 3: intentionally communicative behaviors (growing self-awareness) Figure B

A) mastering the conceptual framework of communicative exchange

B) becoming motivated by the power of being readably expressive

C) increasing degrees of self-determination: power over topic and ability to gain attention

Phil saw Benjamin's communication as a solid level 2 and emerging level 3. Since a main distinction between the two levels is the directing of an action towards a partner with the intention of communicating, he had us begin with requests for reinstatement (*give me more of that*) within a highly motivating activity. The e-mails we exchanged during this time say it best:

Clarifying the reinstatement routine (April 2005)

Kristen: We have been using the new routine of just once or twice around on the spinner between stops and remaining in contact the whole time. Last Tuesday we had a very nice session with Carol (B's school Sp. Lang.). I was spinning Benjamin at his hip and then when I stopped him I moved my hand to his chest. He grasped my hand at his chest and picked it up and plunked it onto his hip several times. He was quite impressed with himself, cracking all three of us up. It was quite fun in both instances of the swing and the spinner because his level of enjoyment/engagement was obviously so much higher when play was a consistent dialogue.

Phil: Way to go! I bolded a couple of my favorite statements. First that he was impressed with himself. They say that for some the opportunity to have control and the discovery of how to do so can be just as motivating as the reinforcement that follows. The second is the importance of consistency... predictability means he can figure out the "rule" and respond more quickly. Your consistency is what allows him to figure out the communication game.

Benjamin began to really "get it." When spinning, bouncing or swinging he had a reliable way to gain my attention and ask me for more. He had also come to realize that these two things would be expected of him. He was going to have to "speak up for himself". Meanwhile, I had come to realize how much my well intentioned predicting and interpreting for him was actually holding him back from exploring the "voice" we hoped he would find. I had always felt that we had friendship, trust and respect between us, but this was a new way of seeing our responsibilities towards one another as communication partners.

Generalizing the reinstatement routine in new activities (August 2005)

Kristen: Benjamin really seemed to blossom this summer. We had our routines of swinging and spinning that he knows so clearly now. He also had days when he chose to explore one activity after another in short bursts (maybe 10 min or so) but where the format of his request for reinstatement was the constant. For example, he'd chose to play with his star stacker toy, using my hand to make it play one of the recorded songs 6 or 7 times, suddenly drop that and begin playing a game of tugging my hands to sit up for a few minutes, then pull my hand towards a drum or keyboard. I got the impression that he was experimenting not only with different kinds of play, but also his understanding of this communicative agreement between us.

Phil: As to Benjamin wanting to try a bunch of different things sometimes; Yes it is generalization when he exerts the same efforts to control a variety of different things and activities. I also think that as he discovers his ability to do so, he is motivated to look for other such opportunities. The more similar the process for reinstatement is across activities the greater the likelihood that he will anticipate and readily respond because he will know what to do.

As Benjamin began to expand the activities and situations that he could gain attention and request in, the team could keep consistent through the use of Communication Scripts. I found the first one I completed to be very helpful to my own understanding of my role in the dialogue, the clarity of my actions and expectations. The first several scripts were all templates for vestibular types of play, but after roughly 8 months of him gaining mastery around those routines, we experimented in using them for other situations. Assisting with transfers for changing at school, and "page turning" with a light box and "reading" with a Big Mac switch became something that scripts made sense for. This was all slow going, with health complications and setbacks, but Benjamin's arenas for expressive communication and dialogue were growing.

Most daily routines are rich with potential conversation. One needs enough time, predictability, and a consideration of how orientation can promote interaction. Within this framework, what is "listening" from BOTH participants? How does each party cue the other that exchange is sought? Phil suggested that for some, directed attention/listening is shown through a "stilling response." Once these basic parts of the communicative contract are identified the stage is set for mutual attention, experimentation, humor and dialogue. It is experiences of this that evolve a persons expressive capacity for choice and control.

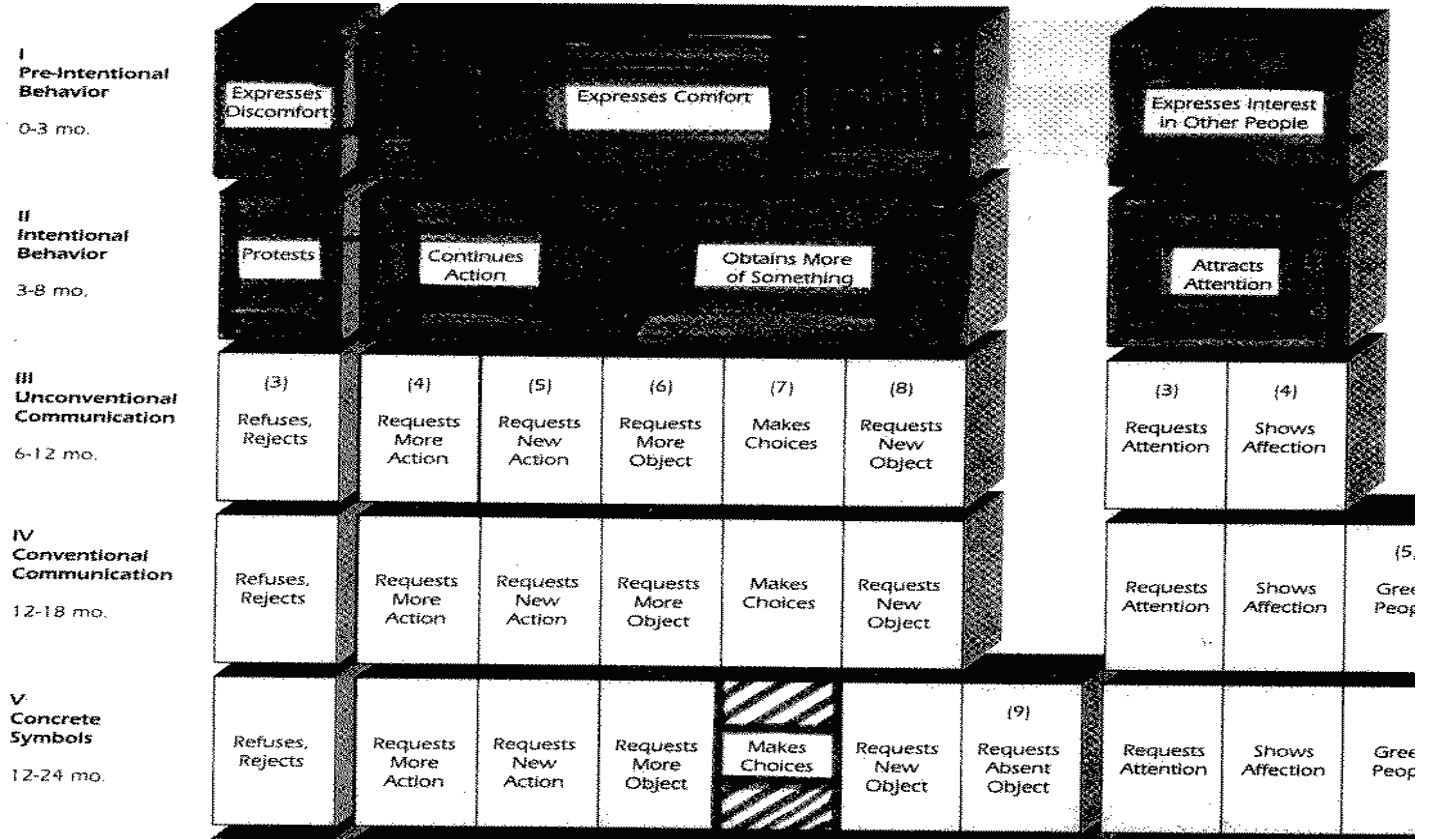
Benjamin and I will continue to expand the situations and activities where he can request reinstatement as a way of refining and reinforcing the dialogue between us. We will also use his emergent areas of the Matrix as a map of what's next, so that his skills and self-determination can continue to grow. Who knew "more" could mean so much. *Figure C*



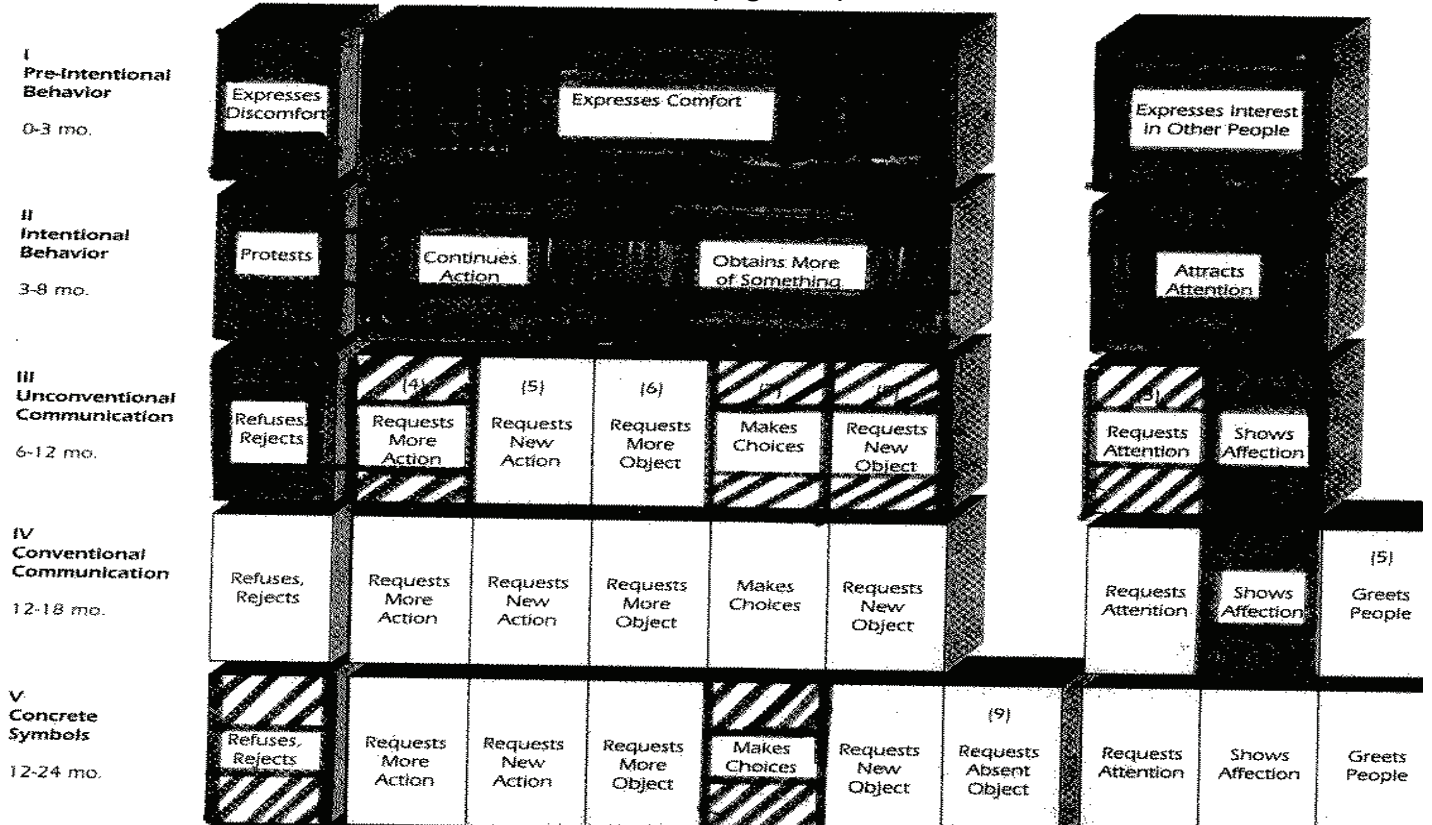
“Education is the most powerful weapon which you can use to change the world.”

-Nelson Mandela

**Benjamin's Communication Matrix Data
March 2005 (Figure A)**



**Benjamin's Communication Matrix Data
June 2007 (Figure B)**



**Benjamin's Communication Matrix Data
November 2008 (Figure C)**

I Pre-Intentional Behavior 0-3 mo.	Expresses Discomfort	Expresses Comfort					Expresses Interest in Other People			
II Intentional Behavior 3-8 mo.	Protests	Continues Action		Obtains More of Something			Attracts Attention			
III Unconventional Communication 6-12 mo.	Refuses, Rejects	Requests More Action	Requests New Action	Requests More Object	Makes Choices	Requests New Object	Requests Attention	Shows Affection		
IV Conventional Communication 12-18 mo.	Refuses, Rejects	Requests More Action	Requests New Action	Requests More Object	Makes Choices	Requests New Object	Requests Attention	Shows Affection	(5) Greets People	
V Concrete Symbols 12-24 mo.	Refuses, Rejects	Requests More Action	Requests New Action	Requests More Object	Makes Choices	Requests New Object	(9) Requests Absent Object	Requests Attention	Shows Affection	Greets People

Teaching Children with Visual Impairments [Online video in 2 parts]

www.campabilitiesbrockport.org/Camp-Video.html

Teaching Children with Visual Impairments is a 35-minute-long free online video that was filmed during Camp Abilities, a summer sports camp for children with visual impairments, blindness, and deafblindness. Topics include: 1) types of visual impairments, 2) child-specific considerations, 3) instructional techniques, 4) safety considerations, 5) other specialists in the field of visual impairment or deafblindness, 6) running techniques, 7) equipment and game modifications, and 8) teaching children who are deafblind. The video highlights the experiences of four children with visual impairments and three children with deafblindness. It is available online in 2 parts from: www.campabilitiesbrockport.org/Camp-Video.html. The information on deafblindness is included in the second part. The Camp Abilities web site is www.campabilities.org.

The video was made possible by a grant from the Children's Miracle Network and is a collaborative effort by SUNY Upstate Medical, SUNY Brockport, and SUNY Cortland. The professionals involved in the project were Nienke Dosa, a physician at SUNY Upstate Medical, and physical education specialists Lauren Lieberman, Dan Tindall, and John Foley. Videographer David Smith created the video.



A PARENT'S PERSPECTIVE FROM ONE PARENT TO ANOTHER

One Family's Opinion on the Family Learning Retreat - June 2008

For one weekend in June my family stayed at the Colorado Springs School for the Deaf and the Blind to attend the Family Learning Retreat. We had two large dorm rooms attached to our own private bath for the four of us. We weren't expecting the Hyatt, but the accommodations were carpeted, spacious, comfortable, and clean. The first night my husband Jeff and I attended the Keynote Address by Tom Sullivan, who is a singer, actor, author, writer, etc, etc, and a motivational speaker who happens to be blind. I have to confess, Jeff and I are not easily impressed, but we were. After five years of hearing what our daughter can't do most of the time, it was refreshing to hear from someone who can.

All of the topics at the retreat related to the real world of raising a child who is deafblind. We enjoyed the Mom's and Dad's Break Out Groups the first morning. Jeff, who is not a touchy feely kinda guy, talked with other men who were "normal" as he put it, about the challenges of having a child who has dual sensory issues. My husband also told me he didn't feel "under the spotlight" as he often does in small groups. The Deaf Adult Role Model Panel had a pragmatic Q&A session about their positive and negative experiences with integration in school and beyond. The Sibling Shop Follow Up also had a panel of counselors who provided information on coping with a special needs brother or sister. The Assistive Technology session exposed parents to new accommodations outside of a catalog, the Positive Behavior Support meeting was informative, and the Parents Night Out was Jeff's favorite. On the last day at the last hour we attended the Deafblind Break Out Group, which was by far the most helpful. We both felt we finally met other parents of special needs children who had more than one issue in common with us. Since our daughter is the only child in the country with her rare chromosome arrangement, we correspond with a family in Scotland with the same disorder. However, we often feel like the lone ranger(s) in special needs groups and even more so in our own community.

Our "typical" ten-year-old son Aaron attended the supervised activities with other kids his age while Jeff and I participated in the workshops. Aaron can be a stick in the mud in new situations. According to him, he had an "ok time", which is relatively good. Jeff and I were glad to see our son just get out of his comfort zone. Our five-year-old daughter, who is medically fragile, disabled, deafblind, and an inspiration to all, was very well accommodated. We felt comfortable with her in daycare after meeting with the nurse, and we know she had a super time.

Looking back, we would have liked to do a few things differently. We now know our daughter with special needs would have done well with kids her own age, instead of in the nursery as we requested. I also could have opened up more during the break out sessions and admit that some days stink as a parent instead of agreeing that things are ok all the time. At the request of the conference coordinators, Jeff and I also came up with a few suggestions for next year as follows: 1) Add a Blind Adult Mentor Panel in 09 to complement the Adult Deaf Panel of 08. If possible, we would love to hear from a combined vision and hearing loss role model, or even someone who also has additional issues; 2) Add an additional break out-group for parents of children who are deafblind during the assistive technologies session. Jeff and I were a bit lost during this time and many of the deaf technologies don't work well for a blind child and vice versa; 3) Our ten-year-old son would like to request a sign and a Spanish interpreter so all the kids can communicate with each other. Aaron also mentioned that he would like to have other options during craft time and even more athletic activities next year. Overall, Jeff and I felt we benefited in some way from all the sessions and we plan to attend next year. Thanks to everyone who put the Family Learning Retreat together.

Consortium for National Paraprofessional Training in Deafblindness

Article reprinted from the SKI-HI Institute; April 2008 Newsletter Edition



The logo for Utah State University, featuring the text "Utah State UNIVERSITY" in a white, sans-serif font on a dark blue background.

This Project addresses the national need for competency-based pre-service training for paraprofessionals in deafblindness by developing online coursework in deafblindness. The courses are designed to prepare paraprofessionals to work as interveners with children and youth who are deafblind. The field testing of coursework was done at two community colleges in Utah, Massachusetts, and at one two-year, and at one two-year program of study in Arkansas. The field testing was completed in December of

2007, and the evaluation data is currently being compiled. The introduction to Deafblindness coursework won the Blackboard Greenhouse Exemplary Course Award, which recognizes it as one of the top 10 online courses in the country in 2007.

The deafblind training program has now been institutionalized at Utah State University. The coursework can be taken for undergraduate or graduate credit. Upon completion of the coursework students will receive a certification of completion from USU. Utah State University is also offering an Associate's Degrees in Deafblindness.

The following options are available to interested students:

Option 1: Students can take the training program in deafblindness which consists of two 4-semester credit hour classes to be offered in the fall and spring. From 1 to 6 credits hours of work experience are also available to those who qualify. Tuition is \$188/credit hour with no out-of-state fees. Upon successful completion of the coursework, students will be awarded a certificate of completion from USU. The courses can also be taken for graduate credit at a cost of \$240/credit hour.

Option 2: Students can take the two course training program on a no-credit basis for \$110/credit hour with no out-of-state fees. Upon successful completion of the coursework, students will receive a certificate of completion from USU.

Option 3: Students can take the coursework as part of an Associate's Degree program in General Studies with a Focus in Deafblindness. This online program includes 30 semester hours of general education classes and 30 hours of coursework that includes the deafblind classes and other related topics. Tuition is \$188/credit hour with no out-of-state fees.

For additional information contact: Linda Alsop, SKI-HI Institute, Utah State University, Phone: 435-797-5598, email: >Linda.alsop@usu.edu>.

The project is funded by the U.S. Department of Education's Fund for the Improvement of Postsecondary Education (FIPSE).



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?

Please send an email to Gina Quintana (Quintana_g@cde.state.co.us) 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 Gina Quintana (Quintana_g@cde.state.co.us) or 303-866-6605

PARENTS ENCOURAGING PARENTS

February 26-28, 2009—Colorado Springs

PEP Conferences are family centered conferences designed to offer support, information, and education to parents and professionals from Colorado. PEP promotes the partnerships that are essential in supporting and including children with disabilities and their families in all aspects of the school and community.

For more information and to apply for the conference online or download an application go to: <www.cde.state.co.us/cdesped/PEP.asp> or call the PEP hotline at 303-866-6846.

A Very Special Thank you!

Many thanks to the planning committee for the Family Learning Retreat 2008!

Committee members include: **Diane Covington, Gina Quintana, Karla McKechnie, Laura Douglas, Stefanie Morgan, Shannon Cannizzaro and Sandy Fuentes.**



Also, a BIG thank you to **Andy Cannizzaro, Todd Cannizzaro, Mike Morgan, Aaron Taylor, Tani Hurt, Laury Smith and members of SCRID-PPCC** who volunteered their time to help us with setting up the conference and clean up at the end! We couldn't do it without you!

The Family Learning Retreat is a yearly collaborative event co-sponsored by the:

- ◆ **Colorado Services for Children and Youth with Combined Vision and Hearing Loss Project**
- ◆ **Colorado Department of Education (CDE)**
- ◆ **Colorado School for the Deaf and the Blind (CSDB)**
- ◆ **Colorado Families for Hands and Voices**
- ◆ **Colorado AER Chapter**

Save The Date!

Family Learning Retreat



June 5-7, 2009
Colorado Springs,
Colorado



This conference is for families who have a child who is deaf, blind or deafblind. If you have questions, please contact:

Shannon Cannizzaro (deafblind) 303-424-6077

Stefanie Morgan (blind) 719-570-0793

Gina Quintana (CDE) 303-866-6605

Diane Covington (CSDB) 719-578-2225



2009

This retreat is a collaborative effort by:

- Colorado Department of Education
- Colorado School for the Deaf and the Blind
- Colorado Families for Hands and Voices
- Colorado Services for Children and Youth with Combined Vision and Hearing Loss

Colorado Services for Children with Combined Vision and Hearing Loss

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?

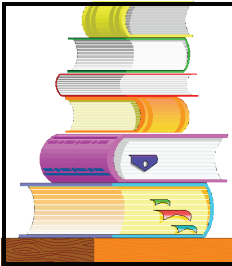
_____ Inservice _____ Home Visit _____ School Visit _____ Other

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

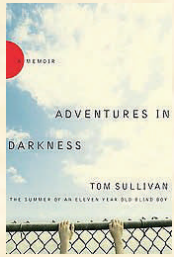
Other areas of need: _____

Please return this form to Gina Quintana, CDE, 1560 Broadway Suite 1175, Denver, CO 80202. It can be faxed to Gina at (303) 866-6767. If you have questions, call Gina at (303) 866-6605.



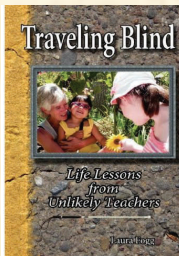
New Items in the Lending Library!

Adventures in Darkness by Tom Sullivan



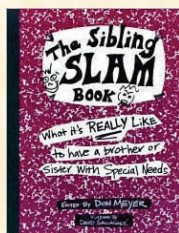
Blind since birth, author and well-known entertainer Tom Sullivan recounts with wicked wit and captivating clarity the hair-raising adventures of his eleventh year in 1950s New England...escaping from his blind school, relief pitching in the neighborhood league, and boxing in a backyard bout with the neighborhood bully. This book is a classic tale of boyhood adventure through a formative season, a summer of hilarity and heart, tears and triumph. Armed with a daring dream,, and the fearlessness and mischief of youth. Tom refused to settle for the conventional confines of his blindness, and set in motion a chain of events that dynamically changed his life forever. (order number 1210.145)

Traveling Blind by Laura Fogg



Traveling Blind will bring you a deeper understanding of the struggles, perils and unexpected wonders of learning to negotiate this world without vision. Laura's students reveal that blindness is a difficult and inconvenient conditions, but one that does not have to rob people of their humanity, their intelligence or their zest for living. Parents, teachers, caregivers, all who love a child with a visual impairment or multiple handicaps, as well as those who have never even thought about blindness, will find stories that resonate in Traveling Blind. (order number 1210.146)

The Sibling Slam Book, edited by Don Meyer



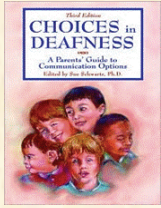
Ever wonder if there are other sibs out there like you--teens know exactly what it's like to have a brother or sister with a disability? Well, here's a chance to hear from some sibs who really know and are willing to give you an honest, non-PC look at their own lives and experiences. Like slam books passed around in schools, this one asks more than 50 different questions. Most, but not all of the questions are about life with your sib with special needs, because being a sib is only part of who you are. (Order number 910.019)

Sensory Secrets: How to "Jump-start" Learning in Children by Catherine Chemin Schneider



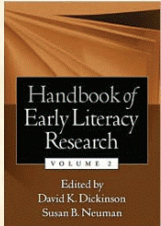
Sensory Secrets: How to "Jump-start" Learning in Children will help you to understand how children learn. Exciting information about the importance of sensory motor processing / sensory integration needs to be tied together and made practical and understandable. This book may be the "missing link" in helping you to understand the foundation skills for all learning. (Order number 610.074)

Choices in Deafness, A Parents' Guide to Communication Options, 2nd edition, edited by Sue Schwartz



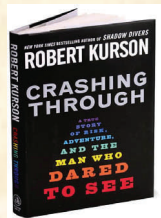
An invaluable guide to the world of deaf education, the second edition of *Choices in Deafness* is expanded to cover two additional communication options, providing an unbiased, thorough overview of the following methods: auditory-verbal approach, bilingual-bicultural approach, cued speech, oral approach, total communication. (order number 710.028)

Handbook of Early Literacy, Volume 2, edited by David K. Dickinson and Susan B. Neuman



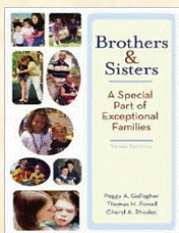
Current research increasingly highlights the role of early literacy in young children's development and facilitates the growth of practices and policies that promote success among all learners. The *Handbook of Early Literacy Research* presents cutting-edge knowledge on all aspects of literacy learning in the preschool years. Volume 2 provides additional perspectives on important topics covered in Volume 1 and addresses critical new topics, making it an essential reference in this rapidly growing field. (Order Number 1410.147)

Crashing Through by Robert Kurson



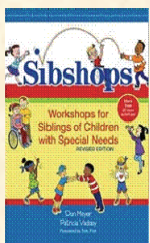
Beautifully written and thrillingly told, *Crashing Through* is a journey of suspense, daring, romance, and insight into the mysteries of vision and the brain. Robert Kurson gives us a fascinating account of one man's choice to explore what it means to see--and to truly live. (Order Number 1410.148)

Brothers and Sisters: A Special Part of Exceptional Families, 3rd Edition, by Peggy Gallagher, Thomas H. Powell, and Cheryl A. Rhodes



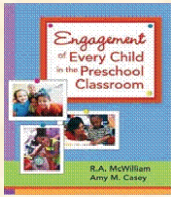
A brother or sister is usually the first close friend a child has--and when that child has a disability, the sibling relationship takes on a new meaning and importance. In the third edition of this classic resource, professionals and families will deepen their understanding of sibling relationships and discover ways to support positive, lifelong bond between brothers and sisters. (Order Number 910.020)

Sibshops; Workshops for Siblings of Children with Special Needs, revised edition by Don Meyer and Patricia Vadasy



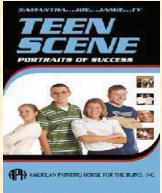
Sibshops is better than ever! With this revised edition of the hugely popular guide used in eight countries, it's never been easier to create effective, engaging support groups for siblings of children with special needs. Fully updated and highly practical, this user-friendly guide helps you develop workshops where 8- to 13-year-old siblings can share their stories, give and receive support, and just have fun with other children who've been there. (order number 910.021)

Engagement of Every Child in the Preschool Classroom by R. A. McWilliam and Amy M. Casey



Educators can increase children's active engagement and prevent behavior problems by making some key adjustments to early learning environments. This practical, accessible book offers an evidence-based approach to promoting engagement in preschoolers with or without special needs. (order number 510.060)

Teen Scene: Portraits of Success (DVD)

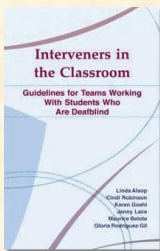


Teen Scene: Portraits of Success follows four Kentucky teens with visual impairments as they experience success as students, athletes, self-advocates, friends and employees. The video inspires student viewers to seek success in their own lives. (Order 1240.004)

Teaching the Braille Slate and Stylus by Philip N. Mangold

This DVD with accompanying textbook guides the reader through learning to use and teach the Braille Slate and Stylus. (Order number 1240.005)

Interveners in the Classroom: Guidelines for Teams Working with Students Who Are Deafblind by Linda Alsop, Cindi Robinson, Karen Goehl, Jenny Lace, Maurice Belote, and Gloria Gil-Rodriguez

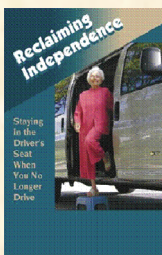


Interveners in the Classroom: Guidelines for Teams Working with Students Who Are Deafblind is designed as a checklist to assist interveners, teachers, administrators, and parents in understanding the roles and responsibilities of interveners in educational settings. As the use of interveners with students who are deafblind continues to increase, so does the need for information and guidelines related to the work of interveners. This booklet provides guidelines, as well as helpful information for teams as the work with interveners in educational settings. (Order number 410.118)

Better Together: Building Relationships with People Who Have Visual Impairment & Autism Spectrum Disorder (or Atypical Social Development) by Linda Hagood

The goal of this manual is to provide practical suggestions for teachers and parents who want to build important foundational relationships and teach social skills to children with visual impairment and autism or other types of atypical social development. (Order number 1210.149)

Reclaiming Independence: Staying in the Driver's Seat When You No Longer Drive, A Resource Guide by American Printing House for the Blind



This resource guide provides information that can help you maintain your independence when you can no longer drive. It is not easy to make the transition from a driver to an independent non-driver. You may have driven for 30, 40, 50 or more years-and now you may be wondering how you can maintain your independence as you lose some of your visual abilities. Though we don't have a magic pill for you to take, we do offer some strategies and resources that can help you adjust to life without a driver's license. Guide comes with DVD and cassette tapes. (Order number 1010.018)

National Center on Severe & Sensory Disabilities (NCSSD)

NCSSD recognizes that over 1 million children in the United States have severe and/or sensory disabilities. The distinction of NCSSD is that we embrace the practice of facilitating and promoting collaboration between the severe and sensory disability fields, hence our motto: "Together WE can do more!"

Why the Name Change? The term low-incidence disabilities is found within federal law and refers to children with: (a) visual impairments, (b) hearing impairments, (c) concomitant visual and hearing impairments or deaf-blindness, (d) significant cognitive impairments, or (e) any impairment for which few personnel have highly specialized skills and knowledge to provide children with the impairment early intervention or a free appropriate public education (Title I (D)(662)(c)(3)). The term *low incidence* emphasizes the small number of children who are blind or visually impaired, deaf or hard of hearing, or deaf-blind, or who have severe or multiple disabilities. Critical to NCSSD is the emphasis on the needs of children with severe and/or sensory disabilities and the strategies to address those needs; to reflect this value, we removed the term *low incidence* from our name.

Visit our Newly Designed Web-Site February 1st! A second goal of NCSSD is to maintain a website that is accessible and user-friendly, modeling our beliefs and values of utilizing current technological innovations. Please visit the NCSSD new website at <www.unco.edu/ncssd>.



New Fact Sheets!

- * **How to Create a Communication Dictionary** —Order Number 1550.070
- * **Interactive Storytelling for Deafblind Children**—Order Number 1550.071
- * **Tips for Using Sign**—Order Number 1550.072
- * **Strategies for Creating Communication-Rich Environments for Children who are Deaf-blind**—Order Number 1550.073

The Colorado Project has 73 different Fact Sheets with information about deafblindness. Most 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>



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>, 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>>.



Resources & Materials

- * **Deaf-Blind Website**—The National Consortium on Deaf-Blindness announces a new website. The new site will include: A comprehensive source of information and resources on deaf-blindness, technical assistance, and personnel training; Easy access to full text materials on more than 70 subjects in selected topics; Announcements of upcoming events and new publications; Resources for families and teachers. Web: <<http://www.nationaldb.org/about.php>>.
- * **Perkins School for the Blind On-Demand Webcasts** - Perkins is a leader in the development of training models for educators who work with students who are visually impaired, with or without additional disabilities. Webcasts from their experts are now available on-demand at www.perkins.org/webcasts. Currently, there are webcasts available on the following topics: creating vocational portfolios, mealtime skills, social skills and Literacy for students with deafblindness and multiple disabilities. For further information, contact Marianne Riggio at 617-972-7264 or Marianne.Riggio@Perkins.org.
- * For the past several years, Kim Conlin, Tish Smith and Lauren Lieberman have been developing a DVD intended to help educators improve the quality of their interactions with students who are deafblind. The DVD entitled, "**You Make the Difference**" is now available through TSBVI Publications: <<http://www.tsbvi.edu/publications/index.htm>>
- * ***The Parent Road Map; Your Guide to Raising a Child with Combined Hearing and Vision Losses*** is the result of several parents getting together through a Family Weekend who discussed ways to share their knowledge and experiences. It is written entirely by parents and the 32 pages are full of photos and parent quotes.



There are seven sections and one pertains particularly to the services offered in Minnesota, the other six sections would be appropriate for a parent living anywhere. It was designed by a professional freelance designer with thirty-three Minnesota families contributing photos and/or pearls of wisdom. This resource is available free through the Minnesota DeafBlind Technical Assistance Project's website: www.dbproject.mn.org.

check it Out




- ◆ The **National Consortium on Deaf-Blindness (NCDB)** has a new project. **The Path to Symbolism**, discusses gesture and intentional communication in children who are deaf-blind and their role in the development of symbolic communication. This new publication highlights research done by Dr. Susan Bruce of Boston College. This document is available on line at: <http://www.nationaldb.org/documents/products/Symbolism.pdf>
- ◆ **Early Childhood Transition Worksheet** The Early Childhood Transition Worksheet lists the IDEA transition requirements and key infrastructure components in chart format. It can be used as a planning tool and discussion guide for identifying factors contributing to non-compliance and effective practices. It is a companion to the Designing and Implementing Effective Early Childhood Transition Processes framework document. This document can be found at: http://www.nectac.org/~docs/topics/transition/transition_worksheet.doc
- ◆ The National Task Force on Deaf-Blind Interpreting (NTFDBI) in conjunction with DB-LINK at the National Consortium on Deaf-Blindness is pleased to announce the completion of a new resource - **an Annotated Bibliography on Deaf-Blind Interpreting**. This document is intended for interpreters, interpreter educators and deaf-blind people who are looking for books, articles and videos about deaf-blind interpreting, communication, advocacy and rights, culture and community, Support Service Providers (SSPs) and more. The bibliography is available on the web at <<http://www.nationaldb.org/ISSelectedTopics.php?topicCatID=767>>. This site also has a downloadable PDF version of the document in both regular and large print and a plain text document. If you have any resources that are not included in this listing, please send the article or information to <NTFDBI@gmail.com>.
- ◆ **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 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 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 listserv, send a blank e-mail to: <NFADB-SUBSCRIBE-REQUEST@TR.WOU.edu>.

Where Do I Start? Who Do I Call?

Resources for Parents of Children and Adults with Disabilities or Special Health Care Needs



Between the alphabet soup of disability labels, laws and regulations--CP, DS, IEP, ADA, IDEA, 504--and all the different agencies that serve families with sons and daughters with disabilities--P2P, PEAK, PEP, CDE, ARC, CCB--well, it can get a little confusing! Here is a quick guide to some major resources and what they provide.

<p>P2P: Parent to Parent of Colorado</p> <ul style="list-style-type: none"> • One to one parent matching • Up-to-date information and referral • Listserv linking parents throughout the state • Quarterly newsletter • Resource packed website including support groups throughout the state and Parent Wisdom files 	 <p>1-877-472-7201 p2p-co.org</p>
<p>The Advocacy Coalition: EMPOWER Colorado</p> <ul style="list-style-type: none"> • Support, education and advocacy for families of children and youth with mental health issues • Support groups throughout the state; statewide listserv connecting families • Educational classes for families and professionals <p>Family Voices</p> <ul style="list-style-type: none"> • Advocacy for children with special health care needs • Assists families in navigating health systems including Medicaid, Medicaid waivers and private insurance • Training, information, referral, policy, parent friendly website resources <p>Federation of Families for Children's Mental Health</p> <ul style="list-style-type: none"> • Promotes mental health for all children, youth and families 	<p>1-800-881-8272 empowercolorado.com</p> <p>familyvoicesco.org</p> <p>coloradofederation.org</p>
<p>The Arcs in Colorado</p> <ul style="list-style-type: none"> • If you are looking for an advocate, start with your local Arc • The Arc of Colorado has a list of statewide Arcs on their website 	<p>1-800-333-7690 thearcofco.org</p>
<p>Assistive Technology Project</p> <ul style="list-style-type: none"> • Assistive technology device exchange program • Database of potential funding resources for AT devices, equipment, programs • Make and Take directions on various low-cost AT adaptations and devices • Community based demonstrations • Annual Collaborative Assistive Technology Conference of the Rockies 	<p>1-800-255-3477 uchsc.edu/atp</p>
<p>CCDC: Colorado Cross-Disability Coalition</p> <ul style="list-style-type: none"> • Information and assistance on disability rights issues for youth and adults • Advances legislation and public policy impacting the disability community 	<p>303-839-1775 ccdconline.org</p>
<p>CDE - ESLU: Colorado Department of Education - Exceptional Student Leadership Unit</p> <ul style="list-style-type: none"> • Website resources on special education law, school/district programs, etc. • FAST FACTS on a variety of topics • Information on educational specialists, parent-professional partnerships 	<p>303-866-6694 cde.state.co.us/ cdesped/index.asp</p>

<p>DDD: Division for Developmental Disabilities and CCBs: Community Centered Boards</p> <ul style="list-style-type: none"> • Provides various services to individuals with developmental disabilities • Administers children and family programs, adult programs • Information on CCBs (designated as the single entry point into long-term service and support for persons with developmental disabilities) 	<p>303-866-7450 www.cdhs.state.co.us/ddd</p>
<p>ECC: Early Childhood Connections</p> <ul style="list-style-type: none"> • If you have a child under three needing services, this number will connect you with your local ECC 	<p>1-888-777-4041 earlychildhoodconnections.org</p>
<p>El Grupo VIDA</p> <ul style="list-style-type: none"> • Information, referrals and support groups for Spanish speaking parents • Free annual fall conference in Denver 	<p>303-904-6073 elgrupovida.org</p>
<p>HCP: Health Care Program for Children with Special Needs</p> <ul style="list-style-type: none"> • Information and referral to services and supports including Medical Home, screening, clinics, financial assistance • Regional offices throughout Colorado 	<p>303-692-2370 hccolorado.org</p>
<p>PEAK: Colorado's Parent Training and Information Center</p> <ul style="list-style-type: none"> • Parent advisors who provide information about special education process and parent's rights • Trainings on a variety of topics including Understanding IEP's • Inclusion resources and annual conference for parents and school personnel • Online calendar of events throughout the state; SPEAKout newsletter 	<p>1-800-284-0251 peakparent.org</p>
<p>PEP: Parents Encouraging Parents</p> <ul style="list-style-type: none"> • Free conference, lodging and meals included, held twice per year at various statewide locations (apply early as waiting lists occur frequently) • Brings together parents and professionals for education on supporting your child in school and community 	<p>303-866-6846 cde.state.co.us/cdesped/PEP.asp</p>
<p>The Legal Center for People with Disabilities & Older People</p> <ul style="list-style-type: none"> • Advice on the legal rights of people with disabilities • Publishes <u>Everyday Guide to Special Education Law</u> 	<p>1-800-288-1376 thelegalcenter.org</p>
<p>Wrightslaw</p> <ul style="list-style-type: none"> • Information for parents about special education process and law, advocacy • P2P recommends their book, <u>From Emotions to Advocacy: The Special Education Survival Guide</u> 	<p>wrightslaw.com</p>

Included here are a sampling of several disability specific organizations. Call or visit our website for additional resources.

Autism Society of Colorado: 720-214-0794 (Denver) or 1-866-733-0794, autismcolorado.org

Brain Injury Association: 303-355-9969, biacolorado.org

Hands and Voices: 303-492-6283, handsandvoices.org/chapters/colo.htm

Infantile Scoliosis Outreach Program (ISOP): 1-866-417-4873, infantilescoliosis.org

International Dyslexia Association/Rocky Mountain Branch: 303-721-9425

Mile High Down Syndrome Association: 303-797-1699, mhdsa.org

So where do you start, who do you call?

Still confused? First of all, don't give up. Let us help you get pointed in the right direction. Give us a call. We are all in this together.



Brought to you by
Parent to Parent of Colorado
 1-877-472-7201
p2p-co.org
 08/07



Calendar of Events



2009 2009 2009 2009 2009 2009 2009 2009 2009 2009

- January 23-24** **Courage to Risk Conference**, Colorado Springs, Colorado
Contact: www.couragetorisk.org
- January 30** **Affective Needs Conference**, Denver, CO
Contact: arthomas@jeffco.k12.co.us
- February 4-27** **CSAPA Grade 3 Reading, Writing, and Mathematics Administration**
- February 4 - March 27** **CSAPA Grades 4—10 Administration**
- February 12-14** **23rd Annual Conference on Inclusive Education**, Colorado Springs, CO
Contact: www.peakparent.org
- February 12-14** **2009 Texas Symposium on Deafblindness**, Austin, TX
Contact: Brian Sobeck <BrianSobeck@tsbvi.edu>
- February 26-28** **Parents Encouraging Parents (PEP) Conference**, Colorado Springs, CO
Contact: www.cde.state.co.us/cdesped/PEP.asp
- April 1-4** **Council for Exceptional Children (CEC) National Conference**, Seattle, WA
Contact: www.cec.sped.org
- April 23-25** **Western Regional Early Intervention Conference**, Colorado Springs, C
Contact: mbrady@cldb.org or (719) 578-2260
- June 5-7** **Family Learning Retreat 2009**, Colorado Springs, Colorado
Contact: Gina Quintana at Quintana_g@cde.state.co.us
- July 23** **1st International CHARGE Syndrome Conference**—Bloomington, IL
Contact: <http://www.chargesyndrome.org/conference-2009.asp>
- July 24-26** **The 9th International CHARGE Syndrome Conference**, Bloomington, IL
Contact: <http://www.chargesyndrome.org/conference-2009.asp>



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



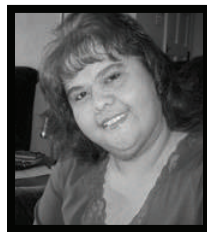
Family Specialist

Shannon Cannizzaro
(303) 424-6077
stc383@cs.com



Project Coordinator:

Gina Quintana
(303) 866-6605
quintana_g@cde.state.co.us



Family Specialist

Ana Trejo
anamt@comcast.net

Please note our new address!

Location:

Colorado Department of Education
Exceptional Student Leadership Unit
1560 Broadway, Suite 1175
Denver, CO 80202

Fax:

(303) 866-6767

TTY:

(303) 860-7060



State of Colorado Department of Education

Colorado State Board of Education

Macia Neal
3rd Congressional District

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6th Congressional District

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Peggy Littleton
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1st Congressional District

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7th Congressional District

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4th Congressional District

Dwight D. Jones
Commissioner of Education



COLORADO DEPARTMENT OF EDUCATION
Exceptional Student Leadership Unit
Colorado Services for Children and Youth with
Combined Vision and Hearing Loss Project
1560 Broadway, Suite 1175
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Mail to: