

V I B R A T I O N S

NEWSLETTER OF COLORADO SERVICES FOR CHILDREN WHO ARE DEAFBLIND

**Serving Children with Combined Vision and Hearing Loss,
Their Families, and Service Providers**

Spring 2000 EDITION

This is an edited version of the original newsletter. Only the articles pertinent to parenting have been maintained as resource information. If you copy any of this information, please give credit to its original source.

PARENT RESOURCES IN COLORADO

The Legal Center for People with Disabilities & Older People provides materials about the rights of people with disabilities. Call 800/288-1376.

The Colorado Special Education Advisory Committee (CSEAC) was established for the purpose of providing policy guidance of providing policy guidance with respect to special education and related services for children/youth with disabilities. CSEAC welcomes the public to all meetings. For times and locations, please RSVP to 303/866-6669.

CO Special Olympics Statewide sports training & competition program. Call 800/777-5767.

Colorado Families for Hands & Voices is an information resource for families with children who are deaf or hard-of-hearing. A newsletter is available. Call 866 422-0422 (toll free) or 303 300-9763.

PEAK Parent Center is a Colorado's training and information center for parents and educators of children with disabilities - 800/284-0251.

SPECIAL EDUCATION NEWS

The Colorado Department of Education has published two pamphlets that provide parents of children with special needs important information: *Special Education Law: Dispute Resolution Rights for Students with Disabilities and their Parents and Students with Special Needs* and the *Colorado Student Assessment Program*. The first pamphlet gives a brief description of the ways parents can resolve disagreements with the school when attempts to resolve differences regarding the delivery of services to a child have failed. The second pamphlet discusses standards, accommodations and modifications and how these impact educational testing for children with special needs.

To obtain copies of these pamphlets, contact the Colorado Department of Special Education, Special Education Services Unit at (303) 866-6694.

COMMANDMENTS OF EARLY INTERVENTION FOR PROFESSIONALS WORKING WITH CHILDREN WHO HAVE SENSORY LOSS AND THEIR FAMILIES

By Tanni L. Anthony, June 1997

THOU SHALT:

1. Respect the family's right to raise their child in the manner best suited to their culture, life style, values, and priorities.
2. Hold only the highest and most honorable expectations of the child and his or her family.
3. Believe in a team approach that honors the family as key contributors, as well as the decision-makers of what is important for their child.
4. Understand the importance of the parent-child bond and always work to support the child's sense of security in the world.
5. Value the power of communication in all capacities of the child.
6. Promote the right to learn, belong, and contribute.
7. Honor the challenges inherent in being human ... and the power to achieve with the provision of strong personal and environmental support.
8. Model the value of taking time to observe and learn from the child.
9. Recognize the limitations of professional wisdom.
10. Remember the four tenets of a capable support person:
 - * This is someone's baby ... there is beauty and joy in all children.
 - * This is someone's parent ... this is the most personal of all life's work.
 - * This is someone's childhood ... learning should be fun and rewarding.
 - * This is someone's life ...

... we are but a moment in the life of a child and his or her family ... our time together may be short, but we have a chance to contribute in a loving and meaningful way.



Bonfire of Love

By Ronnie Wells, Parent, Nevada, Texas

Reprinted, with permission from the SEE/HEAR (Winter 2000) Newsletter of the Texas School for the Blind and Visually Impaired and the Texas Commission for the Blind.

This seemed to me to be the greatest news of all. I could not wait to get to the nearest phone and call my husband to tell him, “No more bandanas!”

My son Austin is an adorable thirteen-year-old, who has an unfortunate problem... drooling. Cerebral palsy has a lot to do with his inability to swallow. I can't even begin to express the social bummer this can be.

I could not understand why people just would not look past a little drool. Well...okay, maybe a lot of drool. Maybe even sometimes it hung from his lip like a long spider web. Sometimes it was mixed with food. Often there was a wide wet spot on his shirt just below his chin. During the winter, we had even seen this area freeze! Not a pleasant situation. This has been a difficult obstacle to overcome for Austin.

Among other obvious things, we heard, “Your child needs to use a wheelchair to get around.” Well okay, we can deal with that. Then we heard, “Your child is not going to be able to read normal sized print, drive a car, or develop at the same rate as his peers, or eat, sit, walk or talk, and all that other stuff, at the same rate as his peers.” But in time we learned to deal with all of that, too. Austin is fortunate in many ways because the other children seemed to be able to deal with all that stuff also. We've learned to deal with everything but “the drool”.

So, I decided to buy colored bandanas to coordinate with all his clothes. Maybe this would help. My husband and I became very selective when purchasing clothes for Austin. We would give it “the drool test”. We'd hide behind a rack of clothes in the store, and using a spray bottle from my purse, we would add a few drops of moisture to the garment --- a quick check to see how the garment might look after being worn by Austin for a few moments. White and black thin cotton always worked best. Still, Austin was asked a million times a day to swallow. “Wipe your chin Austin!” “Ooh, Austin you're drooling...gross!” His friends at school took it upon themselves to be the drool cops. Some would go as far to wipe his chin for him. Others just exclaimed their disgust at his seeming lack of concern. The color-coordinated bandanas didn't seem to make a difference, even the Nike bandanas, the Tommy Hilfiger or Reebok. None of these sports icons seemed to help matters. I became bitter. The younger children seemed to be more accepting of Austin's problem. I knew that as he got older and moved up in school, this would become more of a social barrier than it had been at a younger age.

So there it began. I was on a mission, a journey, not only in the physical sense but on a spiritual quest as well. I prayed. I read. I took many long walks in the pasture. I attempted to make a deal with God. Some people might say at this point, “She's over the top.” But I soon realized that I had trusted Him with so many other aspects of my life, but not this. I cried “Lord, this is a mountain that I cannot move. Please help!” Soon He did just that.

Our family moved to another city in the summer of '96. Austin was going to attend another school. This was a good thing. This also meant that I would have the opportunity to find a new team of doctors. Also, there was the hope of new horizons and fresh ideas from this change of venue.

We were referred to the Scottish Rite Hospital in Dallas, and we made an appointment with a neurologist. "What can we do about the drooling?" I asked. The doctor seemed to have a lot of experience with preadolescent children with cerebral palsy and to appreciate our concerns. After the usual barrage of questions and answers, we were handed a prescription of Artane. We were assured this may help with the drooling and sent on our way. I was thrilled. Why had I not heard of this before? I was so grateful and gave many thanks to God.

Soon after we started on the Artane, I did notice some improvement. I was very hopeful that this would make a difference for Austin. He started at a new school. The children seemed to love him right away. Even though the Artane helped somewhat, the side effects had us concerned: delayed urination, the feeling of "having to go and not being able to" became a problem. We also noticed that great care had to be taken when our son was exposed to the heat or sun for long periods of a time. He seemed to overheat even on balmy days. His face would become red and blotchy. Ultimately, the side effects continued and so did the drooling.

The summer of '98, I traveled to San Antonio to attend a seminar for doctors, therapists and healthcare providers. One of the topics was prevention and therapy for people who drool. I spoke to a neurologist there about Austin and our family. I shared where we were in our treatment, and what Austin was experiencing. He discussed the importance of oral simulation with different objects and how speech therapy, posture and cognitive awareness played a big part in oral control. He thought we should try another drug therapy called Robinol.

I immediately made an appointment to see our neurologist at Scottish Rite Hospital. With notes in hand and much optimism, I shared what I had learned at the seminar. The doctor was familiar with Robinol and discussed the side effects of this drug. We agreed to try it and see what happened. The new drug seemed to help at first and the drooling did appear to slow down. However, side effects were still a problem: overheating, difficulty urinating, fatigue.

Austin was in middle school by now. The children were less accepting of the drooling and his eating habits. "Yeah, Austin is a pretty cool kid most of the time; but does he drool because he's retarded?" Austin continued to develop a strong self-image despite all this.

It broke my heart to see this happen. Friendships were being strained at best, and in some instances, friendships lost. I continued searching for "the answer". I searched the Internet. I frequented seminars. I grilled other parents in similar situations. Often I heard, "Let me know what you find; keep us informed. Good luck." I was constantly reminded of the desperation shared by numerous parents in similar circumstances. I prayed to God to please have mercy; please either open a door or give me a heart of acceptance.

Late in the fall of 1998, I was talking to a friend about the Scottish Rite Hospital. She asked me if I had been to the Rainbow Clinic there. She had heard about a group of specialists who were preparing to do a clinical study on kids who cannot control saliva flow. I made an appointment.

Initially we were referred to the Scottish Rite dental clinic. Everyone was extremely caring and supportive. They told me that Austin might be a candidate for a new device that could help in controlling the saliva flow. This, I felt, was probably too good to be true. But we would try anything at this point. After a brief

screening process, it was determined that Austin was indeed a candidate for this mouth appliance. We were cautiously optimistic.

An impression was taken of his bite. We learned that the appliance would fit somewhat like upper braces, and that it had a small bead attached to the back to stimulate a swallowing reflex. If it did not cause a gag reflex in Austin, this could be what we had been looking for.

We returned to the clinic weeks later to try out the mouth appliance. The moment of truth! The doctor inserted the tiny plastic and wire device, and to our relief Austin had a minimal gag response. Moments later the doctor and I noticed that he was swallowing. The drooling stopped almost immediately. I had never seen my son swallow without being told to do so. I still find myself staring from time to time in total amazement. The irony of all this is I thought I had looked everywhere for the answer, and here it was in my own backyard.

It has been about a month since Austin received his retainer. I had lunch with him at school a few days ago and was delighted to see some new and curious kids hanging around.

Today the school bus arrived to pick Austin up for school. I was scurrying about gathering all his school stuff. As he was headed out the door in his chair I quickly yelled, "Wait Austin, you forgot your bandanas." With a full grin from ear to ear he said, "Mom, I don't need 'em anymore."

I want to share this story with as many people as I possibly can. The happiness on my son's face when he said, "I don't drool anymore," could absolutely launch a thousand rockets to the moon. No words can express how this has made me feel, but more importantly, what this had done for Austin. God knows...He had his merciful hands all over this, and I am truly thankful.

I am also deeply grateful to the team of specialists at the Scottish Rite Hospital. Because of their countless hours of dedicated service to the children and their parents, this unforgettable opportunity is now available to many people in need.

We are going camping this Thanksgiving, and we are going to have big campfire. Austin and I agreed we should toss those bandanas into the fire. We laughed and laughed. Austin said, "Nah...maybe Ellie the dog will want to wear them."

Never lose sight of what you want.



Where Are the Parents?

By Sue Stuyvesant, Parent

Reprinted with permission from the Forgotten Kids webpage

<<http://www.mindspring.com/~1-mills/writing.html>>

Hey everyone. For those of you who don't know me (I'm only an occasional poster) I am mom to Michelle, 9 years old, microcephalic, athetoid/spastic cerebral palsy, cortical visual impairment, seizure disorder -- and CUTE! OK, now for the reason I'm posting.

To make a long story short, earlier this week a question was asked by some nitwit official as to why there weren't more parents (of special needs kids) involved in the local PTA and other issues that have come up that directly involve our kids. His question, which was passed on to me was, "Where are the parents?" I went home that night, started thinking - and boy was I mad - and banged this "little" essay out the next day on my lunch break. By the way, I took copies of this to the school board meeting that night, gave it to a couple of influential people and it WILL get around ...

Where are the parents?

They are on the phone to doctors and hospitals and fighting with insurance companies, wading through the red tape on order that their child's medical needs can be properly addressed. They are buried under a mountain of paperwork and medical bills, trying to make sense of a system that seems designed to confuse and intimidate all but the very savvy.

Where are the parents?

They are at home, diapering their 15-year-old son, or trying to lift their 100 pound daughter onto the toilet. They are spending an hour at each meal to feed a child who cannot chew, or laboriously and carefully

feeding their child through a g-tube. They are administering medications, changing catheters and switching oxygen tanks.

Where are the parents?

They are sleeping in shifts because their child won't sleep more than 2 or 3 hours a night, and must constantly be watched, lest he do himself, or another member of the family, harm. They are sitting at home with their child because family and friends are either too intimidated or too unwilling to help with child care and the state agencies that are designed to help are suffering cut backs of their own.

Where are the parents?

They are trying to spend time with their non-disabled children, as they try to make up for the extra time and effort that is critical to keeping their disabled child alive. They are struggling to keep a marriage together, because adversity does not always bring you closer. They are working two and sometimes three jobs in order to keep up with the extra expenses. And sometimes they are a single parent struggling to do it all themselves.

Where are the parents?

They are trying to survive in a society that pays lip service to helping those in need, as long as it doesn't cost them anything. They are trying to patch their broken dreams together so that they might have some sort of normal life for their children and their families.

They are busy, trying to survive.

Sue Stuyvesant 10/15/96: Permission to duplicate or distribute this document is granted with the provisions that the document remains intact.

Advocacy Tips and Techniques:
Ideas by and from Parents and Those Supporting Parents and Children
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Information and Consulting on Special Education Issues
<http://members.aol.com/pepofwi>

BRING a BUDDY

A recent PEP-WI survey revealed that only about 18 percent of parents are bringing someone (friend, spouse, neighbor, relative, etc.) with them when they go to IEP meetings. From experience, we know that when the parent brings someone to the meeting who is knowledgeable about the child or who has special expertise, the tenor of the meeting becomes more mutually collaborative, more mutually respectful, and frequently more productive. Children's needs remain the focus; all members of the IEP team are more likely to work together to create solutions. You can improve the quality and effectiveness of your child's IEP Team meetings by bringing a buddy. Here are some ideas to help:

- a. Pair up with another child in your child's special education program. You go to their meetings, they come to your meetings.
- b. Make a friend at a parent support group (like CHADD, ARC, Family2Family, etc.). Agree to buddy-up at meeting. Better yet, attend a PEP-WI (Partners Resource Network) training or two together!
- c. IEP Meetings must be scheduled at mutually agreeable times and locations. Recommend times and locations where you and your spouse or significant other can both attend. You have the right to a meeting at a mutually agreeable time and place.
- d. If your child receives physical or occupational therapy or counseling outside of school, invite that service provider to attend the meeting. Use conference calling if needed.
- e. Ask your child's aunt, uncle, cousin, grandparent or other relative, who has a special understanding of your child, to attend with you.
- f. Consider asking a sibling to attend. He or she "knows" your child in unique ways.
- g. Invite last year's teacher, aide, or therapist to come.
- h. Offer to share YOUR services by going to someone else's meeting with them and have them come with YOU.

IF YOU THINK THE MEETING IS GOING TO BE STRESSFUL

If you think your meeting with the IEP Team is going to be stressful, try these suggestions:

- a. Start by talking about some areas you know you all will agree with. Find common ground. Example: "I know you have found Jon's behavior difficult to control at times. We have had similar experiences at home."
- b. Use AND instead of using the word BUT. "But" acts like an automatic switch inside listeners' minds. It "switches off" the first part of the sentence or message. Example: "We need a plan to get my daughter's behavior under control AND we need to keep in mind that she also needs to experience academic success in the general education classroom."
- c. Avoid using absolutes: "You always...", "We never..."
- d. Use positives to help move the conversation along. Example: "What if we tried...?" "Would you be willing to try this?" "It sounds like it might be better if we..." "Have we thought about this?"
- e. Allow your listeners to correct any possible misunderstandings you may have gotten. "Can you help me understand why you...?" "Tell me again why we are..." "Oh, okay, that clarifies that for me a lot."
- f. Don't take a position. Deal with a need. Example: "My son needs to feel successful at school. How can we make that occur?"