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April 2011



Hands & Voices of Oregon

is dedicated to supporting families with deaf/hard of hearing children without a bias toward communication modes or methodology. We're a parent driven, non-profit organization providing families with resources, networks and information they need to improve communication access and educational outcomes for their children. Our outreach activities, parent/professional collaboration and advocacy efforts are focused on enabling the deaf/hard of hearing child reach their highest potential.

Dear Hands & Voices Family,

"Mommy, I love you so much!" These words are a dream to hear for any parent, no matter what language is used.



I remember when my oldest was identified with her hearing loss at 18 months I thought, "she hasn't heard me say I love you this whole time?" I was devastated, confused and wondering how she could be deaf. There was no family history. Immediately after the diagnosis my husband and I went out for lunch to process the information. There we were with Ashlin on our laps; our entire world had changed, but Ashlin was the same tender, happy, sweet little girl who's world was the same.

A couple of years later we met a family from Canada. The mom spoke about how during her second pregnancy she hoped that baby would have a hearing loss, like her oldest. I thought that was an interesting thought process. When I became pregnant with our youngest, I began to wonder. Part of me wondered what it would be like have a hearing child and part of me wanted Ashlin to have a deaf sibling so she wouldn't feel alone; so she could have someone to go to when needed. I had visions of them in bed, under the covers talking about

Quick Links

www.handsandvoicesor.org

www.artzcenter.org

www.ndepnow.org

**Run for Hands & Voices
May 14th; 8:30am
Champoeg Park
1 mile family walk/run
5k chipped
10k chipped
register at:**

<http://reasontorun.com/summerRaces.html>

All proceeds benefit H&V. Come out and have some fun!

NPR looks at Newborn Screening Tests Miss Some Babies
Hearing Problems

<http://www.npr.org/blogs/health/2011/03/22/134766739/newborn-screening-tests>

Are you Ready to **Volunteer**?!

H&V could use volunteers in the following areas:

Events - help put together family events

Marketing - creativity needed!

H&V Conference

Membership

Fundraising -help put together events through restaurants, etc

Remember, volunteers receive a priority when requesting scholarships!!!

A huge THANK YOU to Anne Cornelly (Columbia Regional) and Pam Fortier (Tucker Maxon) for providing invaluable information at the GBYS training in March!

how they feel about being deaf. So when we received the news of Mikaylin's hearing loss, my husband and I went out for breakfast (what else would we do?!) to process the information. Part of me was disappointed, but mostly I was relieved. We had a team in place; we knew Mikaylin would be more than okay. She was the same 3 month old baby she'd been. We were slightly changed, but not too much. Ashlin wasn't going to be the only one different on our family and that made me happy. And on the morning of Mikaylin's first implant surgery when Ashlin climbed in bed with her sister to support and love her, I was grateful. They are going to look out for for each other in a way my husband and I cannot.
Helen Cotton Leiser
Executive Director

Five Stages of Reading Development



Learning to read doesn't just happen. It has to be taught through systematic, organized instruction. Reading is a skill which is built upon through stages and is an ongoing process. If a stage of reading development has not been learned, students will flounder in their reading ability, which also affects their writing skills. It is imperative that teachers make certain students fully understand each stage of the reading/writing process before they move on to the next level. Jean Chall, world renowned reading expert and psychologist for fifty years, and past professor emeritus at Harvard University cites her five stages of reading development below:

Stage 0:

Pre-reading Stage: Unsystematic accumulation of understandings about reading between pre-school and kindergarten.

Stage 1:

Initial Reading or Decoding Stage (grades 1-2; Ages 6-7) Students central task is learning arbitrary letters and associating them with corresponding parts of spoken words. Learner acquires knowledge about reading. Phonics.

Stage 2:

Confirmation, Fluency, Ungluing from Print, Automaticity Stage (grades 2-3; Ages 7-8) Consolidation of what was learned in Stage 1. Requires reading many easy and familiar books for developmental reading. Gradual increase in functional and recreational reading. Common use of the basal readers. Functional reading important - content area texts - here's where we fail in our attempts to prepare our students. Range of possible recreational reading increases.

Stage 3:

Reading for Learning the New Stage: A First Step (Grades 4-8; ages 9-13) Readers need to bring prior knowledge to their reading. Children acquire facts.

Stage 4:

Multiple Viewpoints Stage: (High School; Ages 14-18) Should include instruction in reading/study skills, and reading strategies for success.

Stage 5:

Construction & Reconstruction Stage: College ; Ages 18 & up) Adult literacy should stress acquisition of skills useful to the participants and the ability to apply those skills. These are the stair steps of reading development. They are built upon and climbed, as students grow in their literacy development. Sometimes students get stuck in one of the stages. It's my job as a literacy specialist to "unstuck" them so they can move on to the next phase and beyond, empowering them to become enthusiastic readers and writers.

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IDEA Update

<http://www.copaa.org/uncategorized/idea-fairness-restoration-act-introduced-in-house-and-senate>: IDEA Fairness Restoration Act Introduced in House and Senate , on March 17, 2011, federal legislation was introduced to allow parents to recover expert witness fees in due process hearings and litigation under the Individuals with Disabilities Education Act. The IDEA Fairness Restoration Act was introduced in the Senate (S.613) by Senator Tom Harkin (D-IA), Chair of the Senate Health Education Labor and Pensions Committee; Senator Barbara Mikulski (D-MD), and Senator Bernie Sanders (I-VT); and introduced in the House of Representatives (H.R. 1208) by Congressman Chris Van Hollen (D-MD) and Congressman Pete Sessions (R-TX).As COPAA members are likely aware, in its <http://www.copaa.org/public-policy/copaas-major-legislative-priorities/rein-state-parents-right-to-expert-witness-fees/> Arlington Central School District v. Murphy (2006) decision the Supreme Court decided that parents who win/prevail in their IDEA cases cannot get expert witness fees under the provision in the law that allows parents who win/prevail to get attorneys' fees.

Although the legislative history to the IDEA fees provision clearly states that expert fees are covered the Supreme Court refused to consider that history.COPAA has worked hard since that damaging decision was announced to obtain a legislative fix. Congressmen Van Hollen and Sessions have championed this issue for us in previous legislative sessions. This is the first time a bill was introduced in the Senate. COPAA is grateful to all of the members of Congress who are taking the lead on this important legislation. The bipartisan IDEA Fairness Restoration Act will restore Congress' original intent and make due process hearings more equitable and affordable for parents of children with disabilities.Without the ability to recover their expert witness fees, few parents could afford to exercise their constitutional and IDEA rights to challenge denial of FAPE to their children by school districts.This is because parents, who increasingly have the <http://www.copaa.org/public-policy/copaas-major-legislative-priorities/make-burden-of-proof-fair-equitable> after the Supreme Court decision in Schaffer v. Weast, must present admissible evidence about educational methodology, complex behavioral supports, medical issues, and other technical subjects. Only qualified expert witnesses can present this technical testimony and such testimony can easily cost many thousands of dollars, money that few parents have.

There can be no equal opportunity and access to a public education that is both free and appropriate unless all families of children with disabilities-rich, poor and those in the vast middle-can obtain an education on the same terms. Without the ability to recover expert costs, the due process playing field ceases to be level or fair.

COPAA strongly supports this legislation and urges every elected official to Co-sponsor today!!!If you agree, please write your legislator a note today!

11 Questions to Ask About Your Child's Reading Program - Wrightslaw Newsletter

Here are some questions you need to ask about your child's reading program:

1. What is the name of my child's reading program?

2. Is the reading program researched-based? Does the program include the five essential elements identified by the National Reading Panel and required by No Child Left Behind?
3. How many children will be in my child's reading group?
4. How have the children in this group been selected?
5. Has the teacher been trained in direct, systematic, multisensory reading instruction?
6. Is the teacher certified in this particular program?
7. Has the teacher completed a supervised practicum in this program?
8. How many hours of instruction per week will my child receive?
9. How will the pace of the instruction be determined?
10. What criteria will be used to determine mastery?
11. How will I be informed about my child's progress?

Source: The Reading Foundation

GPOD Releases Position Statement

The Global Coalition of Parents of Children who are Deaf or Hard of Hearing (GPOD) is an international collaboration of parent groups dedicated to promoting improved systemic protocols and practices which encourage informed choice and the empowerment of families of deaf/hard of hearing children. Below are parts of the position statement for family support and development of newborn hearing screening systems/EHDI that was first introduced at NHS 2010 in Lake Como.

"...family support should come from a variety of places: professionals, other parents of deaf/hard of hearing children, deaf/hard of hearing adults, information and resources, and existing communities surrounding a child and family prior to the child's diagnosis.

Fact: children who are early identified and receive intervention prior to six months of age have significantly better receptive language, expressive language, personal-social skills, receptive vocabulary, expressive vocabulary and speech production. (Yoshinago-Itano, C. Seedy, A. Coulter, D. & Mehl, 1998)

Fact: On reflection of the early intervention years, a majority of families cite contact with other parents of children with a hearing loss as the most helpful support they received. Direct parent-to-parent support ranks as one of the strongest measures of family support. (Jackson, C.W. 2009)

Fact: Social networks with other parents of children who are deaf were associated with less isolation, acceptance of their child, and improved interactional responsivity. (Hintermaier, M. 2000)

...The impact of a child's hearing loss affects not only the child, but the parents, siblings, extended family and community as well... Because of the low incidence of hearing loss, families of children who are deaf or hard of hearing often feel isolated within their own extended family. And most do not know about support opportunities... No one understands this dynamic as well as another family who also has a child who is deaf or hard of hearing.

Information empowers parents and provides them with a sense of self-esteem and confidence in their ability to raise a deaf child (Bemrose, 2003; Young 2003)

How important is the source of information to parents? On a scale of 1 to 7 with 1 being "most important": 80% of parents ranked face-to-face interaction with professionals as 1,2,3 in importance, and 70% ranked discussions with other parents as 1,2,3 in importance.

...EHDI and UNHS systems must accommodate the child's access to early intervention and education emphasizing fluent language and communication training, and EHDI and UNHS systems must ultimately deliver hope for a brighter future for children with hearing loss and their families.

The complexity of the process for families leads to an understanding that there must be multiple layers of support that envelop a family in their path to success. A respectful and collaborative approach from all stakeholders in the system and an understanding of the important role that each one plays contributes to the degree a family may feel supported as they begin the long and demanding, yet rewarding journey of raising a child who is deaf or hard of hearing.

10 Mistakes Parents of Deaf /HH Kids Make in Preparing for their I.E.P -H&V National

1. Didn't insist on a member of the IEP team who has specific expertise on deafness or hearing loss - allow the meeting to progress even if all required IEP team members aren't there.
2. Didn't ask for assessments/draft IEP's in advance of meeting - you don't understand how to

- read an audiogram, language assessments etc.
3. Let your emotions rule the day
 4. Didn't give school advanced notice of special or new requests, or if you're pulling kid out of placement. You didn't give school 10-day advance notice.
 5. Lose focus on what this process is really about - your child (not you, not the program, not the budget)
 6. Stay quiet because you feel intimidated - and you're the one who sits down in the kid-sized chair at the table. You're afraid to ask the hard questions.
 7. Don't really have a grasp on the implications of your child's hearing loss in the "real world"/educational setting.
 8. Haven't prioritized your child's goals/accommodations from your perspective before the meeting.
 9. Don't have a clue what IDEA really says - so you don't know whether the IEP provides a FAPE (free, appropriate public education)
 10. Haven't created allies on your team before the meeting. Think you and IEP team can plan out your child's whole plan for the next year in an hour and a half meeting.

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