

Colorado Families for Hands & Voices

Annual Report

July 1, 2012 — June 30, 2013

Celebrating Seventeen Years of Support, Information and Modeling



Focus of Efforts:

- ◆ Early hearing screening, identification and access to intervention: representation of families' needs in the system of care.
- ◆ Emotional, informational and modeling support for families with children who are deaf/hh, from birth to age 21
- ◆ Teaching advocacy strategies for IEP's, IFSP's, 504 plans and ADA rights in schools and the community.
- ◆ Collaborating with the Deaf, Educational and Medical Communities to improve access to communication and seamless services
- ◆ Modeling Cultural Responsiveness and full communication access
- ◆ Support at critical transitions: preschool, between programs, and leaving high school
- ◆ Proactive resources for school districts and other programs
- ◆ "Medical Home" Initiative for pediatricians and family practice providers, mental health resources
- ◆ Legislative issues: Insurance funding for Hearing Aids, Licensure Laws, the Deaf Child's Bill of Rights, ASL as a Foreign Language, & more
- ◆ Educational interpreting services and standards in the profession
- ◆ Child safety, prevention efforts, risks of child abuse, neglect and bullying, prevention and response education: OUR Children's Safety & Success Project
- ◆ Just in time resources for parents e.g. FM simulations, sign language supports, typical accommodations, creative social/emotional supports.

"The job of any nonprofit is to change the world."

Edward Gray, Gray Matters, El Pomar Nonprofit Day

Dear Families and Supporters,
The theme of this annual report is "Inspiring Change," which was a major focus for our work this fiscal year, July 2012—June 2013. For most of us, the very first person we ever meet with a hearing loss is our own child. We reach out to families with resources, parent to parent modeling, and emotional and informational support to assist parents in the critical work ahead of them in helping a child develop in all areas, including language. Our children, despite better early identification and intervention, still face lower literacy, graduation, and employment rates, and we believe early, effective parent empowerment is the way to change those statistics.

Our Mission: We are dedicated to supporting families with children who are deaf or hard of hearing without a bias around communication modes or methodology. We're a

parent-driven, non-profit organization providing families with the 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 Deaf and Hard-of-Hearing children to reach their highest potential.

Board of Directors: CO-Presidents, Shelley Strickfaden (parent) and Stephanie Olson. Secretary: Dinah Beams. Treasurer: Cindy Bacher. **Board Members:** Tracy McGurran, Melissa Tumblin, Richard Esparza, Terri Bazalewski-Austin, Lisa Weiss, Lonnie Burkholder, Denise Davis-Pedrie, Aaron Rose, and Kristy Murdock. The board is always comprised of 51% parents. **Staff:** Executive Director, Sara Kennedy, Special Projects: Janet DesGeorges, **Office Manager:** Jeannene Evenstad, **Webmaster:** Joe DesGeorges. **Event Coordinator:** Megan Humbrecht. GBYS staff listed on page 4.

Parent to Parent Support: Guide By Your Side

Parents report a connection with other knowledgeable parents is one of the most critical supports on their journey. The Guide By Your Side (GBYS) program supported over **200 families one-to-one** through home visits, phone calls, and hundreds of email exchanges and Facebook posts. Families of older kids and newly identified children are given the opportunity to connect with an experienced, trained Guide for emotional support, modeling, and resource sharing. Parents may be "matched" by geographic region or other criteria. 62 home visits were made this year.

Statewide guides are available for Spanish speaking families, those interested in Colorado School for the Deaf and the Blind, A Unilateral Hearing Loss parent guide provides unique supports. A Deaf guide position remains open. The GBYS program serves families from identification to age 21. Of note, 22 families found us on their own. The Guides include parents from diverse regions, backgrounds and communication modes. All have been trained in the philosophy of "what works for your child is what makes the choice right." Next year: a leveled recognition program begins for the Guides.

Family Support; Regional and Statewide Family Events and Workshops, Product Development

Resources for Parents and Professionals

On our website: www.cohandsandvoices.org

- ♦ Deaf Education reform documents
- ♦ a Deaf Plus resource section
- ♦ Spanish section with *Communicator* articles and more
- ♦ The OUR Children's Safety Project: (Observing, Understanding, and Responding to Child Abuse, Neglect and Prevention)
- ♦ Parent Roadmaps for Hospitals (56) and the web-based interactive roadmap with *Loss & Found* dvd, updated on a rotating cycle or as needed by regional teams.

Regular dissemination of the following resources:

- ♦ The **Parent Funding Toolkit**: funding and insurance information for families, including appeals and FAQ on the hearing aid insurance mandate
- ♦ **Beyond the IEP: Families and Educators Working Together in School Programs** Booklet and PowerPoint Presentation
- ♦ **Bridge to Preschool: Transition from Part C to Part B** with companion PowerPoint presentations
- ♦ Quarterly publication of *The Communicator*
Fall 12: *Listening to Dads/NoLimits*; Winter 13: *What's Your Sign/DHH Plus: Learning from Evan*, Spring 13: *Equipment and Babies, Accommodations: One Size Doesn't Fit All/EHDI Pals*; Summer 13: *"Did You Help Anyone Today? H&V Parent Leaders/Advocacy Corner: Interpreting Services/Bullying/Deaf-Autism*
- ♦ Monthly E-news sent statewide and periodically to regions, twelve issues to approximately 1140 email addresses, with H&V and other group events shared along with other timely information
- ♦ Column for quarterly CHIP newsletter, other publications or websites (CSDB, regional newspapers, school district news); resources sent directly to families and professionals on request
- ♦ 68 copies of the *Book of Choice* and Welcome Bags shared with new families on a first GBYS contact.

Sampling of Events and Attendance:

- ♦ Early Years Presentation - Pikes Peak (12 parents)
- ♦ CU Audiology presentations (3) on parent perspectives
- ♦ Guide participating in Marion Downs Compass Clinic, 10 clinics, 19 families seen.
- ♦ **Regular playgroups** in Four Corners Jan—April 2012, 7-12 attending and Northern CO, April—June 2013.

Summer to Fall, 2012

- ♦ Support for Microtia/Atresia Picnic with Ear Community, Spanish speaking Guide attending
- ♦ Grand Junction Meet and Greet (12 parents) and CHIP training
- ♦ CSDB First Day of School: 60 parents and four more events
- ♦ Annual Family Picnic with MDHC and CHIP/CSDB: 150, including 14 Spanish speaking families.
- ♦ Dori's Discovery Days presentation on advocacy: 25 parents, three professionals present.
- ♦ Rosie's Ranch/Listen Foundation/AG Bell family day: 68 parents and children, Parker CO
- ♦ 12th Hands & Voices Gala "Life In Pictures", 225, three deaf/hh teen speakers, Families First Award Winner Vickie Thomson with Marion Downs Foundation, Spirit of Love film trailer preview
- ♦ 60 flyers/games dispersed: HEAR Project Safe Halloween event.

In October 2012, Maria Rodriguez was awarded the El Grupo Vida's Ellie Award. Janet DesGeorges and Sara Kennedy were recognized with the Peak Performance Award from the Colorado Audiology Association. Congratulations to our Spanish speaking parent guide and current and former chapter directors representing the spirit of H&V!

Winter to Summer 2012-13

- ♦ Denver area H&V/MDHC/CHIP Holiday Social- 150
- ♦ Two Inspiring Change stakeholder meetings: Feb and April 2013, 65 professionals, Deaf/hh adults, and parents at each, supported through a grant from CCDHH
- ♦ CI Consortium, CDE, at Children's Hospital CO: Attendance: 250+, info table, teen panel, remote sites with support of H&V
- ♦ Nat'l EHDI Meeting: 6 board and staff members presented
- ♦ Northern Colorado family picnic: 26 parents and 24 children, featuring Aspen Camp staff in Windsor
- ♦ What's In the Box: CI Family Workshop, Colo Springs (25 parents and children)
- ♦ Family Learning Retreat, CSDB - 6 Spanish speaking families, 2 parent guides attending
- ♦ Numerous school information night events: APS, DPS, Boulder, and Pikes Peak Transition Conference—150+
- ♦ Beyond the Audiogram class, w/Marion Downs, 12 parents, 18 kids

"Hands & Voices...has helped me to advocate in ways I did not know I could."

Laurie Pachl, Eastern Colorado parent and advocate

Representation on Statewide Forums & Collaboration with Other Groups

Colorado Families for Hands & Voices prioritizes opportunities to represent families through membership on various boards and task forces, and/or providing support to the following: The Colorado Interagency Coordinating Council; Early Intervention Colorado (Part C) and the Colorado Home Intervention Program (CHIP), the NICHQ Learning Collaborative; The Marion Downs Hearing Center Foundation, board and clinic, The CO Commission for the Deaf and Hard of Hearing; the Daylight Project; CO Infant Hearing Advisory Committee (CIHAC), CSDB and its Strategic Plan, Outreach, CO-Hears, Early Years and ELDI programs; HLAA OF CO; Colorado Children's Hospital/Bill Daniels Center for Hearing, Dept. of Health, regional EHDI teams and the CO Midwifery Assoc, Univ. of CO,

Colorado Families for Hands
& Voices takes *pride* in
collaborating with other
organizations and agencies

Boulder County Service Providers, the O.U.R. Children's Safety Project; Family Leadership Training Inst.; the CO Dept of Education (CDE) with the CI Consortium and Educ. Interpreter Task Force, Cued Speech of CO, PEAK Parent and Parents as Faculty, Parent 2 Parent of CO, the Ear Community, Family Voices, El Grupo Vida, the CO Academy of Audiologists, Moms on the Spectrum, AG Bell of CO, Am. Society for Deaf Children, Rocky Mountain Deaf School, The Listen Foundation, the CO Assoc. of the Deaf, Aspen Camp, Rocky Mountain Deaf School, Sertoma Clubs and Lodo Sertoma, Kidpower of Colorado Springs, Rocky Mountain ADA, the Colorado Registry for Interpreters for the Deaf, The Colorado Springs Independence Center, the HEAR project, Rosie's Ranch, and more.



GUIDE BY
YOUR SIDE™

CO Hands & Voices celebrated its 12th year as a national model for the H&V GBYS program. The Parent Guides improved their skills by attending several trainings this year, including in-house training with role plays, case studies, topics such as "dealing with difficult families," understanding Con-

"Your support is gold to me."

Parent of a three year old with newly identified progressive hearing loss.

nexin 26, Supporting Families Without Bias Organizationally, support of the gifted child, technology updates, Deaf Adult Role Models and other sessions at the Hands & Voices National Leadership Conference and the national EHDI conference. The **H&V Ambassador Program** is another way we maintain contact with programs and regions without a Guide in close proximity, through utilizing parent volunteers to ensure information dissemination to families.

Next year's focus: filling remaining positions including the Deaf Guide, and instituting a leveled recognition program.

Making Connections: CO H&V Facebook (English and Spanish), Database, Email Lists, and Survey Monkey

In an effort to increase timeliness and effectiveness in informing families about upcoming events, programs, products, and insights, our email distribution list has been developed. Monthly email updates were sent to interested parents and professionals at no cost, and also on a regional or topical basis as needed. **Emails were sent to 4,381 recipients over the course of the year.** Our database reflects an **increase of over 85 entries** over the current year, to create a current database of over 1387 on the mailing list. Our mailing contractor seeks to correct or delete addresses for returned newspapers (moved, incomplete) to reduce mailing costs. Constant Contact, Survey Monkey, Facebook, Gotomeeting.com and the Filemaker Pro program serve as the foundation for outreach through technology. Many of our families prefer texting and Facebook to telephone or email for an initial contact. As an outreach service to CSDB, the entire list of enrolled families is included in the database. Self-referrals rose. 79 to 198 and from 5 to 47 this year.

Presentations and Fairs H&V hosts or collaborates in regular presentations for professionals and families to further outcomes for our children. School districts, regional EHDI teams, parents using cochlear implants and hearing aids, the Colorado Home Intervention Program and the CO-Hears, El Grupo Vida, Colorado Audiology Association, and licensing organizations received presentations. Information tables were also shared at school districts, transition fairs, Colorado Registry of Interpreters for the Deaf, and Deaf Expos. Staff presented at the National EHDI meeting and the H&V Leadership as well.



ADVOCACY
SUPPORT &
TRAINING

THE Hands & Voices ASTRa PROGRAM

Advocacy means "to speak up on behalf of..." CO H&V's advocates provided individual support by attending over 27 IEP, IFSP or 504 Plan meetings. In addition, we responded to over 54 concerns about those plans with families, sometimes providing extensive support by phone or in preparation for a meetings. **Ongoing training for parent guides continued** this year, through a variety of methods: mentoring, case studies, and article dissemination.

This knowledge built upon the 2011 two day training supported through the CO Commission. Next year, we will also study the just published H&V Advocacy Guidebook for parents.

CO FAMILIES FOR HANDS & VOICES

PO Box 3093
Boulder, CO 80305

Phone: 719-634-2328

VP: 720-445-7720

Email: cohv@cohandsandvoices.org

Website: www.cohandsandvoices.org

*What works for your child is what makes
the choice right.*

We're on the Web!
www.cohandsandvoices.org

Evaluation

Hands & Voices implemented ongoing program evaluation tools. Evaluations through Survey Monkey and event evaluations are distributed at events, and feedback is solicited following every parent contact, and analyzed to inform our services and event planning, and to modify our topics according to the needs of individuals. Constituents provide information through the website and a feedback form disseminated through "The Communicator." Facebook topics are also analyzed for

areas of need. Evaluations for staff are requested annually. A survey on our outreach efforts was analyzed this year and found that parents rate our supports at a highly satisfactory level, but aren't always aware that we provide services past the early childhood years. To rectify that gap, we have altered our regularly given handouts in the Welcome Bags and devoted a portion of the e-news, Facebook, and newspaper to issues of middle and high school students.

Revenue/Expenses

We are grateful for the support and vote of confidence shown by our diverse set of funding sources and individuals. Our operating funds came from the following contracts, grants, or contributors:

The Maternal Child Health Bureau grant administered through the University of Colorado, Denver: 100,000, funding the majority of the Guide By Your Side program efforts.

The Carol Timm Estate, 22,000 (partial carryover from last year) Memoriams for the Bacher family, honorariums for the Brinkman family: donations from the Stoecker, Olson, Burkholder, Gabbard, Cosner, Novinger, Sullivan, Baitis, Flores, DesGeorges, Merenstein, Tumblin, Beams, Thomas, Klein, Bacher, Witte, Bell, Goberis, Johnson, Kennedy, DePasse, Mussmaker, and Meyer families were received through Colorado Gives Day. Later donations through the ColoradoGives.org program and individual contributions throughout the year totaled more than \$4,000. Thank you, donors!

The Colorado Commission for the Deaf/Hard of hearing competitive grant, 10,000 funding the two Inspiring Change meetings and follow up, with approximately 65 parents and professionals attending each.

The Colorado School for the Deaf and the Blind, contributed 10,000 funding parent outreach efforts statewide and 4,000 for a parent guide with a child who is attending the campus program.

Resources for Families and Professionals

Website - www.cohandsandvoices.org

Hands & Voices has established a comprehensive, growing website for families in Colorado and beyond. Families will find the interactive Parent Roadmap, detailing information needed at the time of identification and entry into diagnostics and early intervention, as well as links to the GBYS Parent Guides, parent stories, a Deaf Plus section, and several specialized resource guides. An upcoming events section is kept active and up to date through a link to the chapter Facebook page. Articles in Spanish are available, and a section on OUR Children's Safety is also highlighted.

Resource Guides

The *Colorado Resource Guide* will be revised from its 2011 version next year in both English and Spanish.

Other Resource Guides: The Bridge to Preschool, The Parent Funding Toolkit and Beyond the IEP. The Educational Interpreter Handbook (2012) was a product COHV participated in creating as members of the Advisory Board to CDE. Also new this year is the Silence is not an Option document and the Educational Advocacy Handbook through HQ.

Newspaper: The Hands & Voices publication, "The Communicator" is disseminated quarterly. Circulation has reached 6,000 copies per issue nationally, with over 1400 recipients in CO alone. COHV is a regular contributor to the CHIP newsletter for providers of birth to three services. **A monthly e-news** with topical information is disseminated to more than 1200 recipients.

Our Facebook pages (Colorado Chapter Hands & Voices



and Manos Y Voces) both provide timely resources to families requesting topics or asking questions. At print, membership had reached **275 parents and professionals** and **32 for the Spanish Manos Y Voces Facebook page**.

Guide By Your Side: The low tech, high touch program of Guide By Your Side is available to every family with a child who is deaf or hard of hearing in Colorado. Guides include Liesel Thomas, Denver, Jennifer Richter, Pikes Peak, Valerie Walker, Northeast, Holley Ezzell, Four Corners, Jodi Dietrich, Glenwood Springs, and statewide, Maria Rodriguez, Spanish speaking, Chresta Brinkman, Unilateral, Tracy McGurran, CSDB, and a DHH Guide position is currently open. Guides use a variety of communication methods and have differing personal stories, expertise and live in a wide variety of regions. Along with the director, they can assist with issues from identification and language development to advocacy issues in the community and for IFSP, IEP and 504 Plan supports. Guide stories are posted on the website.

Customized information: Each new family receives a copy of the Book of Choice and other documents in a Welcome Bag. Books received for review are shared with other families. Families requesting information receive customized packets through email or standard mail as needed.