

EHDI & FAMILY SUPPORT: PAST, PRESENT & FUTURE

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INTRODUCTIONS

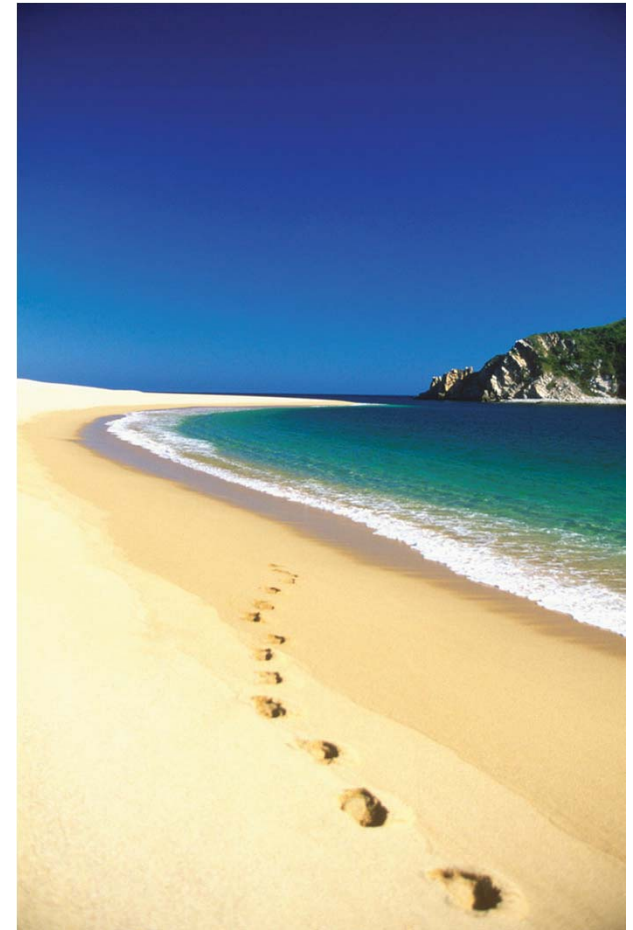
- The Past – Janet DesGeorges
- The Present – Curt Leitz
- The Future – Maria Rodriguez



“The reason people find it so hard to be happy is that they always see **the past** better than it was, **the present** worse than it is, and **the future** less resolved than it will be” –
Marcel Pagnol



**WHERE HAVE WE
COME FROM?**



WHY LOOK BACK?

- See how far you've come
 - Helps you when you are discouraged with present day crises
 - You can help others who are further behind the path than you
- Learn from the past
 - 'New' is not always better
 - Don't repeat the same mistakes
- Longingly look back on the "good 'ole days"
 - "I used to be thinner"



BACK IN THE DAY...

- Parent Support
 - Informal
 - No real networks
 - No 'peer' support to those offering support to other families
 - No real training
 - Family Support undefined in EHDI systems
- Topics *NOT* on the table -
 - Child Abuse and Neglect - Incidence in the population
 - Meaningful involvement of Deaf and Hard of Hearing Adults



STATS FROM THE PAST....

Parent Participation in Early Intervention Programs That Serve Deaf and Hard of Hearing Children

Percentage of Intervention Sites Reporting This Type of Activity (n 388)

Parent on Staff 9%

Parent paid as consultant 5%

Parent on board 13%

Parent on hiring committee 6%

Parent as co-trainer 14%

Parent reviews materials 15%

Stredler Brown A, Hoberg Arehart K. 2000. Universal Newborn Hearing Screening: Impace on Early Intervention Services in Yoshinag-Itano C., Sedey A, editors. Language, Speech, and Social Emotional Development of Chilfren Who are Deaf or Heard of Hearing: The Early Years The Volta Review 100:0042–8639 Yoshinaga-Itano C, Sedey A, Coulter Det al. 1998



A SNAPSHOT OF THE PAST -

- 2001 - Number of Presentations on Family Support at the first NCHAM EHDI conference: 1 (number of parents presenting: 1)
- 2011 - Number of Presentations this year: 13 (number of parents presenting: 19)
- 2001 - Hands & Voices: Number of Chapters – 1
- 2011 – Number of Chapters - 38



...GOING BACK EVEN FURTHER (40 YEARS!) ...AN INTERVIEW WITH IRENE.....

"Whatever happened to people helping people?"

...Only one professional in the early years that they got some feeling of emotional support from who said, "Some day there will be something for her. I hoped, and prayed that this would be true."

"We were
just told in
no
uncertain
terms
what
modality
we should
use"



"My saving grace in those days was that my neighbor was deaf and a friend, she could drive, and I would think, 'she's married, she has kids...I know Stephanie can be ok'"



LOOKING BACK AT MY OWN JOURNEY...



WHAT DID IT 'FEEL LIKE' BACK THEN?

- Parent – to – Parent Support
 - Methodology War in full swing
 - Seen as an 'add-on' to the system
- Systemic Parent Involvement
 - No other parents
 - Main issue was representing the *late I.D.* experience
 - Moments when I felt all alone
 - "...and the eradication of deafness is at hand" (resounding applause)
- On the positive side -
 - Great support from professionals who were open to parental involvement



WHAT WE DIDN'T KNOW WE WERE GETTING INTO....

“There are many people who think they want to be matadors, only to find themselves in the ring with 2000 pounds of bull bearing down on them, and then discover that what they really wanted was to wear tight pants and hear the crowd roar.” – T. Pearce





PART 2—CURT—WHERE WE ARE



WHERE WE ARE

1. **Conditions for success** of parent-to-parent support programs
2. **Examples** of H&V programs demonstrating these aspects
3. **Lessons learned** in developing parent-to-parent support programs



CONDITIONS FOR SUCCESS: PARENT-TO-PARENT SUPPORT PROGRAMS

- **Credibility:** By parents, for parents
- **Use-ability:** Offering different forums for support (phone, newsletter, workshops, meetings, conferences, informal, social)
- **Applicability:** Choosing topics “where the rubber meets the road”



CONDITIONS FOR SUCCESS, continued

- **Dependability:** Consistency
- **Realistically:** Will require funding or an institutional sponsor
- **Replicability:** TRAINED parents in every state



EXAMPLES OF H&V PROGRAMS DEMONSTRATING THESE ASPECTS

- Wisconsin



- Nebraska



- Wyoming



- Minnesota



WISCONSIN H&V



○ **Statewide Family Conference**

- Annual event; began in 2003
- 500 attendees/100 families served per year
- Planned by families, for families
- Partners with Wisconsin Dept. of Public Instruction—Deaf/Hard of Hearing Outreach

Further info: Laurie Nelson, Laurie.Nelson@dpi.wi.gov



NEBRASKA H&V

○ Playgroup

- Every 6 weeks
- Kids' activities
- Parents' discussion group
- Relaxed, family atmosphere
- Specific topics, flexible discussion



Further info: Laryssa Payne, laryssa@handsandvoicesne.org

<http://www.handsandvoicesne.org>



WYOMING H&V



“Family Gatherings” series of meetings

- Informal gatherings of parents, local professionals, and Hands & Voices leaders
- Site rotates from town to town
- Often held in conjunction with other D/HH events in the area
- Organized games for kids
- Separate discussion for parents

Further info: Wendy Hewitt, wendy@wyhandsandvoices.org



MINNESOTA H&V

- **Integrated part of EHDI system**
 - Legislative mandate in 2007
 - Referral and follow-up protocols
 - Reporting and quality improvement
 - Stable funding through bloodspot fee



LESSONS LEARNED

- Create support systems outside other agencies/bureaucracies/organizations
- Utilize existing local and regional resources
- Build or adapt a model of support specific to a region or locality
- Design multiple ways to deliver information and support



ADVANTAGES OF PARENT SUPPORT MODELS THAT EXIST OUTSIDE OF OTHER SYSTEMS

- “Age limited” systems: EHDI, Part C, Part B
- Professional support systems: medical, early intervention, school systems
- Philosophical systems/communication choice



UTILIZE EXISTING LOCAL AND REGIONAL RESOURCES

- Don't reinvent the wheel
- Don't allow your agency's budgetary or time limitations stand in the way of success
- Do collaborate and relinquish control
- A brief history of parent support in Minnesota:
 - Family Support Connection (2001)
 - Expansion to outstate region (2006)
 - Affiliation with Hands & Voices (2006)
 - Integrated part of state EHDI system (2007)



BE SPECIFIC TO A REGION OR LOCALITY'S DEMOGRAPHICS

- Rural settings and urban settings
 - Delivery of parent support
 - Accessibility of professional and educational services
- Home language/culture
 - Materials and media specific to language/culture groups
 - Parent mentors from language/culture groups
- Digital divide



DESIGN MULTIPLE WAYS TO DELIVER INFORMATION AND SUPPORT

- Face-to-face
- Telephone
- Online
- E-mail
- Social media
- Printed





PART 3—MARIA—WHERE ARE WE GOING?



ABOUT ME...

- Maria Rodriguez
- 7 yr old daughter, Born Profoundly Deaf
- Bilateral Cochlear Implants
- Spanish Speaking Parent Coordinator for Colorado Families for Hands & Voices



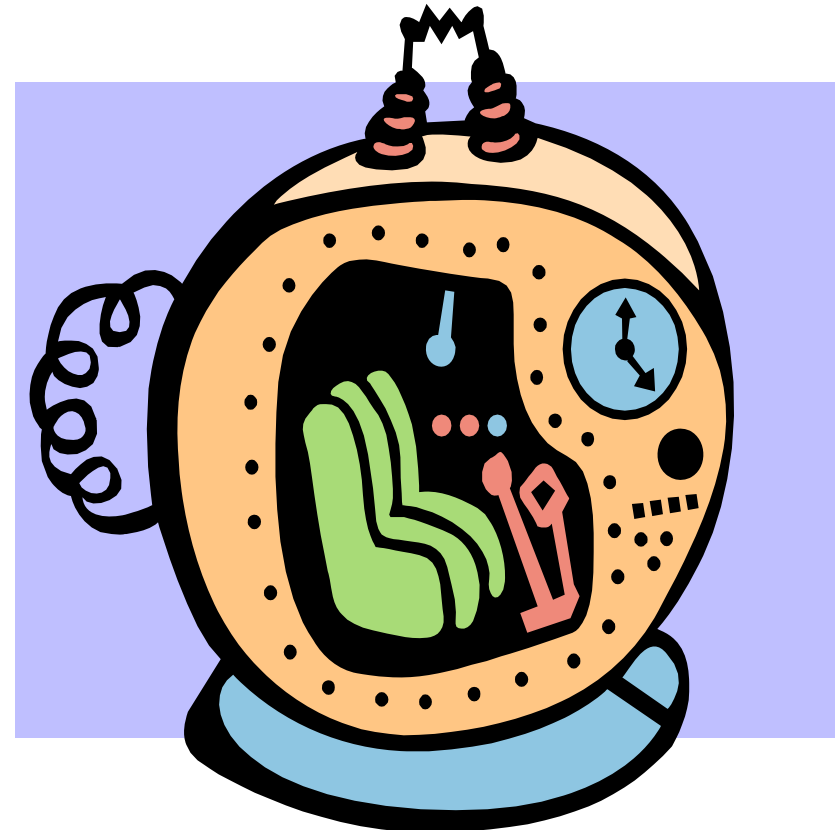
LOOKING FORWARD

- Even though we talked about the present, I would like to say a little about we are now in CO..
- Spanish parent to parent support
- Guides? (only me.... for now) 11 English Speaking guides
- Early Home Intervention, CHIP=Colorado Home Intervention Program
- The “diagnosis” (for families that are non-English speaking, Not only Spanish speakers)
- Challenges , it’s not only about the “language” it’s more about the “culture”



WHAT HAS CHANGED?

- Technology, Cochlear Implants, Better Smaller HA's, Social Media (Facebook, Twitter, Google, etc)
- Education, Parents & Professionals
- Economics
- Community & State services
- Society's "perspective"
- That won't happen to us "mentality"



IN A PERFECT WORLD.....

- Picture a brand new family, with a baby, just identified? What happens next?
 - The Labor & Delivery staff is well informed about hearing loss
 - The family goes home, ready to know what to do next
 - Audiologist contact info, follow up appt set (perhaps)
 - Early Home intervention
 - Hearing loss information, (it's not your fault)
 - Feeling (Your baby is still perfect)
 - Parent Connections (community services, organization)
 - Make it “all about the family” Not “we have to comply with the law”
 - Permission to be contacted for GBYS, from the Hospital



IN A PERFECT WORD CONT.....

- In Co and possibly other states, More Spanish Speaking Guides, There's only 1 (me) on Co now
- H&V chapters in every state on the U.S.
- Spanish speaking guides for every chapter
- Family involvement (specially fathers)
- Make Hearing loss awareness, have the same awareness that PKU has, by Doctor's/OB/GYN's, Labor & Delivery Team informed
- Make Parents the “pros”, because we can't hold our child's hand forever...

- What happens when the next “referred” baby
- May be up to you!



Thank You

Gracias

धन्यवाद

Hvala

Grazie



Merci

Obrigado!



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