

# Perspectives on Deafness:

Developing Culturally Competent Family-Centered  
Early Intervention for Children Who are Deaf or  
Hard of Hearing



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# Presentation Objectives

- To develop a better understanding of Deaf culture in the early intervention process.
- To gain a better understanding of the impact hearing loss has on families.
- To develop a better understanding of why it is important for families to have access to support, mentorship, and guidance from deaf and hard of hearing individuals.



# Why Is This Important?



**For many parents of deaf and hard of hearing children...**

**YOU** will be one of the first and most influential individuals they meet as they begin the journey into the world of deafness.

Some of the children you support will  
grow up **culturally Deaf** in families  
with only hearing members.



# Statistics & Facts About Deafness

- Hearing loss occurs in 5 out of every 1,000 newborns.
- 15% of children between the ages of 6-19 have a measurable hearing loss in at least one ear.
- Approximately 3 million children in the U.S. have a hearing loss; 1.3 million of them are under the age of three.
- Over 90% of deaf children are born to hearing parents.
- A mild hearing loss can cause a child to miss as much as 50% of classroom discussion.
- With early identification and appropriate services, deaf children can develop “communication skills” at the same rate as their hearing peers.

# Terminology

- Deaf – Big “D” Deaf or Culturally Deaf
- deaf
- Hard of Hearing (HOH)
- Oral deaf
- CODA – Child of Deaf Adult
- Hearing Impairment / Impaired – Medical or Pathological View
- Hearing Loss
- Hearing Differences

# Culture vs. Community

## Deaf Culture

- A group which has its own:
  - Language
  - Values
  - Rules of behavior
  - Traditions

## Deaf Community

- A group of people who live in a particular location, share the common goals of its members, and in various ways work towards achieving these goals.
- Persons who are not themselves Deaf, but who actively support the goals of the community and work with Deaf people to achieve these goals (e.g. interpreters, teachers, etc).



# The Medical / Disability Perspective

- Focus on hearing loss as a disability or pathological condition that should be detected, cured, and rehabilitated with surgery and/or amplification.
- Many etiologies (causes) of hearing loss have medical correlates that require medical treatment and management:
  - Vascular, renal and heart problems
  - Nervous and immune system disorders
  - Vestibular dysfunction
  - Tumors
  - Bacterial and viral infections (e.g., Meningitis; CMV)

# The Medical / Disability Perspective

- Often place greater emphasis on speech and spoken language development.
- Visual strategies (ASL) may not be introduced into the child's life until language delay becomes evident, resulting in critical years of early language delay being lost.

# The Sociolinguistic / Cultural Model

- Etiology, type and degree of hearing loss, and even onset make little difference to them as adults.
- Deaf culture, values, and customs is primarily transmitted through ASL
- Socialization with other Deaf persons is encouraged and supported – Deaf clubs and associations (Deaf Professional Happy Hour; NAD).
- Deaf history and heritage, literature, drama and art (ABC Stories).
- Residential Schools for the Deaf
- Assistive Technology / Devices (vs. Medical Treatment)

# American Sign Language (ASL)

- ASL is a distinct visual language with its own grammar and syntax.
- ASL uses space, location in space, speed, size for adjectives, adverbs, verb tense, subject, object, etc.
- No written form of ASL
- ASL has idioms, “homonyms”, “slurring” in sign language
- Regional signs or dialects

# The Truth About ASL...

- Though >90 percent of deaf children are born to hearing parents, only about 25 percent know ASL.
- Lip reading is the least effective way to communicate with those who are deaf.
- Research has shown that knowing sign language enhances the ability of deaf children to develop English.

# A Parent's Response...

**Pride** Why can't my child hear?!

*Will my child be able to speak/hear?* **SHAME**

Will I be able to understand my child and their needs?!

**Will my child be able to understand me?**

**Will my child learn to read/write?**

**GUILT** Will my child have friends?

Will my child go to college?

**ACCEPTANCE**

**WORRY**

*Will my child...?!?*

# Considerations When Working with Families...

- Do parents view deafness as a defect or disability...feel guilty?
- Deafness does NOT directly cause low self-esteem; experiences do:
  - Isolation
  - Difficulty communicating, learning, and/or interacting with peers and family members.

# Additional Considerations When Working with Families...

- Even when deaf children do NOT identify with Deaf culture or community, they must still develop an identity that includes their deafness.
- Factors that influence identity development:
  - Parental attitudes
  - Use of sign language or speech in the home/school
  - Peer relations
  - Access to deaf role models



# Additional Considerations When Working with Families...

- Families often overestimate the quality of their communication with their deaf or hard of hearing child.
- They also tend to underestimate the capacity of their deaf child to communicate and use language.

# Effective Strategies:

When Working with Families Who are  
Deaf or Have Deaf and Hard of Hearing  
Children

# When Interacting with a Deaf Person...

- Use all the facial expressions and gestures you normally use—they show your interest and improve understanding.
- Be on the lookout for the “smile and nod” that signals lack of comprehension – this works both ways.
- Avoid asking the Deaf person “Yes/No” questions, particularly when you’re trying to find out if they understand you.
- If you are referring to written material or using visual aids, allow adequate time to review the written material before beginning the discussion.

# Communication with Deaf Families

- ASL is NOT English
- English is a second language
- Lip reading / writing are unreliable means of communication
- Use of ASL interpreters...it's the law (ADA)

# Use an ASL Interpreter...

- With a deaf parent of an infant or toddler for all:
  - Interviews
  - Evaluations
  - Interventions
  - IFSP meetings.



# When Using an ASL Interpreter...

- Look at the person NOT the interpreter.
  - Speak directly to the parent or child.
- Avoid locating the interpreter in front of a bright light or window.
- Establish a clear line of sight for the speaker, interpreter and deaf family member(s).
- Talk at your normal speed.
- Turn taking is extremely important. Do not “talk over” others.

# Provide Support Around...

- Medical and Audiologic Diagnostic Evaluations
  - Follow-up audiologic evaluation
  - Additional medical conditions / disabilities (35-40%)
- Amplification Choices
- Communication Choices and Development
- Relevant Resources and Technology

# Establish Connections...

- Provide children who are deaf and hard of hearing and their families connections to members of the deaf community / Deaf culture.
- The more interactions that families have with adults who are deaf and hard of hearing , the better they may envision their own child's future.



# Establish Connections...

- Providing families who are hearing with opportunities to learn more about being deaf or hard of hearing reduces family stress and promotes family support of the child.
- Families who have many contacts with adults who are deaf or hard of hearing exhibit increased competence re: raising their own child.
- When there are no other deaf family members, parents identify deaf individuals as one of the most important sources of support.

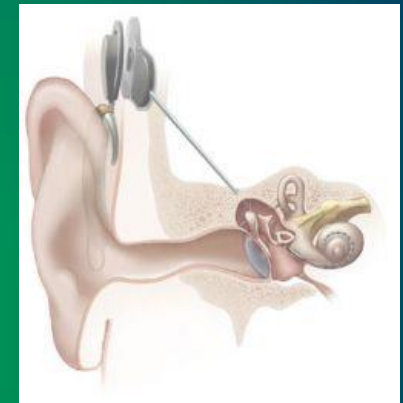
# ASL Opportunities...

- Should be available to all families.
- Following best practices, providers / teachers should be fluent in ASL. However, this is not always the case due to the availability of resources.
  - Rather than delay access to services, providers should at least possess experience using ASL.
- Research has shown that children of hearing parents exposed to a bilingual approach (ASL and English) have more positive outcomes.
  - Possess beginning knowledge and use of ASL
  - Develop English skills at a faster rate.



# Hearing and Assistive Technology

- Hearing Aids
- Cochlear Implants
- FM Systems
- Videophones
- Video Relay
- Alerting Devices



<https://www.harriscomm.com/>





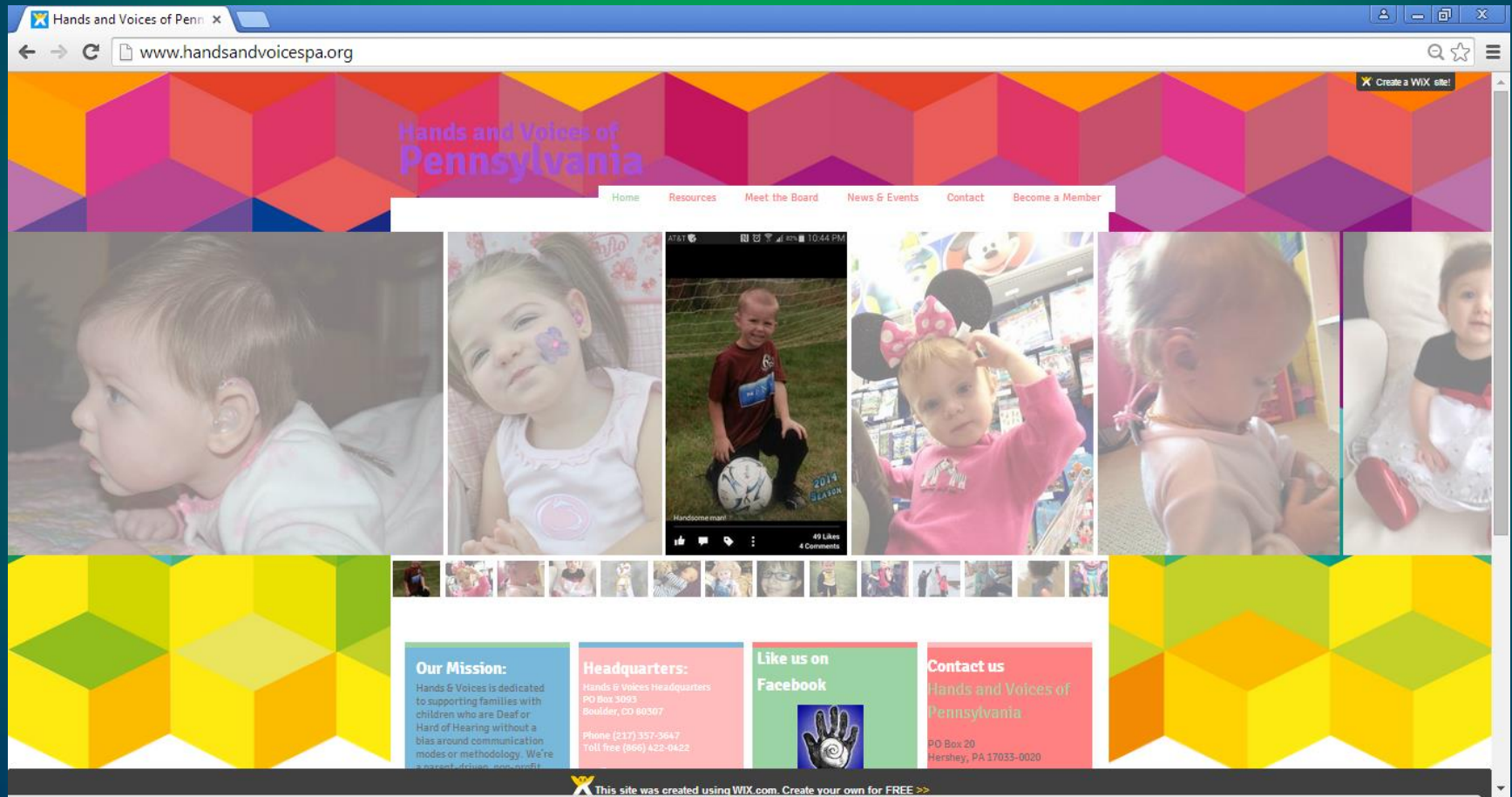
# Resources Available in Pennsylvania



PA Early Hearing Detection & Intervention Program




# Hands and Voices of Pennsylvania





# Guide by Your Side of Pennsylvania

- Provides support to families with newly identified children with hearing loss.
- Guides are specially trained parents of children who are deaf, hard of hearing, or deafblind.



**GUIDE BY  
YOUR SIDE™**

## WHAT IS HANDS AND VOICES GUIDE BY YOUR SIDE™ OF PENNSYLVANIA?

Hands & Voices Guide By Your Side™ of Pennsylvania (GBYS) is dedicated to directly supporting families and their infants and toddlers who are newly identified with hearing loss by offering them the opportunity to talk to or meet face-to-face with a Parent Guide.

### WHAT IS A PARENT GUIDE?

GBYS Parent Guides are parents of children who are deaf, hard of hearing or deafblind who have received special training that prepares them to function in this important capacity. This training provides a strong foundation in supporting families without a bias towards communication modes or methods, as well as a functional understanding of formal systems and services available to families and their children. Parent Guides are able to bring their direct experience, specialized knowledge, and personal compassion to their role while making the family's needs their primary focus. They have been where you are and are willing to listen and share their experience.

### WHO IS ELIGIBLE FOR THE PROGRAM?

Families of Pennsylvania infants and toddlers (ages birth to 3) who have a hearing loss.

## WHAT CAN THE GBYS PROGRAM DO FOR MY FAMILY?

GBYS Parent Guides located throughout the state provide:

- Timely emotional support at the point of diagnosis of hearing loss
- Direct parent/peer support and networking
- Unbiased information and resource sharing specific to hearing loss, including insights on navigating the systems from a parent perspective
- Support to families throughout the Infant/Toddler Early Intervention years by combining an experienced parent's insight with knowledge of Early Intervention and educational systems
- Information about other parent support opportunities


## HOW MUCH DOES THE GBYS PROGRAM COST?

The GBYS program is provided to families at no cost.

## HOW DO I REQUEST A GBYS PARENT GUIDE?

- Complete the GBYS Referral Form on the families page on [www.paearlyhearing.org](http://www.paearlyhearing.org)
- Or call the Hands & Voices Guide By Your Side™ of PA Program Coordinator at **800-360-7282 x3908** (in PA only) or 717-541-4980 x3908
- Or email [agaspich@pattan.net](mailto:agaspich@pattan.net)

Hands & Voices Guide By Your Side™ of PA is supported by the Pennsylvania Department of Health. Guide By Your Side has an office at the Pennsylvania Training and Technical Assistance Network (PATTAN) and shares resources with Early Intervention Technical Assistance (EITA).

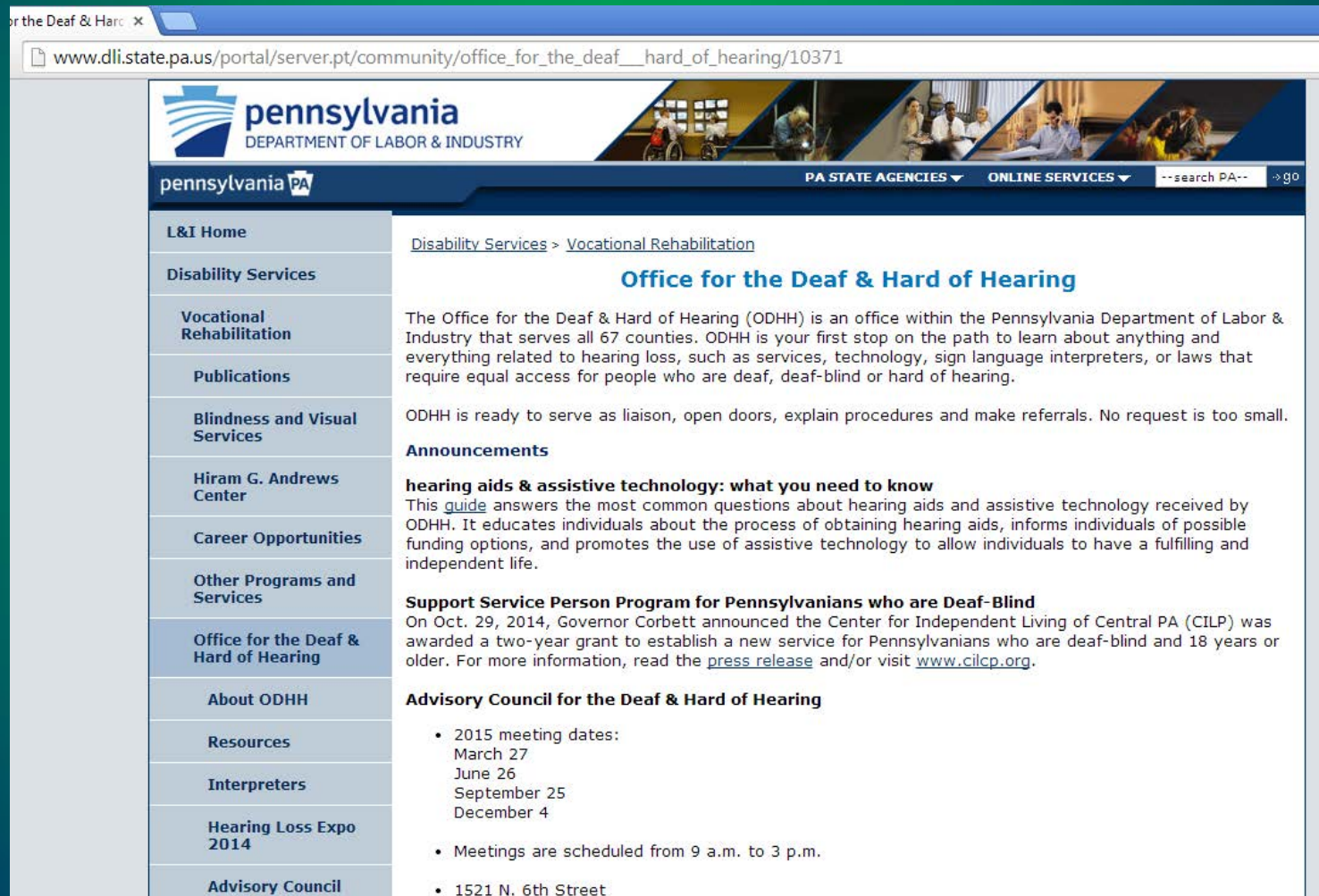


**GUIDE BY  
YOUR SIDE™**

**A program for families of a child who is deaf, hard of hearing, or deafblind**

Hands & Voices Guide By Your Side™ of PA  
6340 Flank Drive Suite 600, Harrisburg, PA 17112  
Anne Gaspich, Program Coordinator [agaspich@pattan.net](mailto:agaspich@pattan.net)  
800-360-7282 (in PA only) x3908 · 717-541-4980 x3908

# Pennsylvania Office for the Deaf and Hard of Hearing (ODHH)



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www.dli.state.pa.us/portal/server.pt/community/office\_for\_the\_deaf\_\_hard\_of\_hearing/10371

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DEPARTMENT OF LABOR & INDUSTRY

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**About ODHH**

**Resources**

**Interpreters**

**Hearing Loss Expo 2014**

**Advisory Council**

[Disability Services > Vocational Rehabilitation](#)

## Office for the Deaf & Hard of Hearing

The Office for the Deaf & Hard of Hearing (ODHH) is an office within the Pennsylvania Department of Labor & Industry that serves all 67 counties. ODHH is your first stop on the path to learn about anything and everything related to hearing loss, such as services, technology, sign language interpreters, or laws that require equal access for people who are deaf, deaf-blind or hard of hearing.

ODHH is ready to serve as liaison, open doors, explain procedures and make referrals. No request is too small.

### Announcements

**hearing aids & assistive technology: what you need to know**  
This [guide](#) answers the most common questions about hearing aids and assistive technology received by ODHH. It educates individuals about the process of obtaining hearing aids, informs individuals of possible funding options, and promotes the use of assistive technology to allow individuals to have a fulfilling and independent life.

**Support Service Person Program for Pennsylvanians who are Deaf-Blind**  
On Oct. 29, 2014, Governor Corbett announced the Center for Independent Living of Central PA (CILCP) was awarded a two-year grant to establish a new service for Pennsylvanians who are deaf-blind and 18 years or older. For more information, read the [press release](#) and/or visit [www.cilcp.org](http://www.cilcp.org).

### Advisory Council for the Deaf & Hard of Hearing

- 2015 meeting dates:  
March 27  
June 26  
September 25  
December 4
- Meetings are scheduled from 9 a.m. to 3 p.m.
- 1521 N. 6th Street

# Pennsylvania Society for the Advancement of the Deaf (PSAD)





# A World of Opportunity

- A guide for parents and families of children with a hearing loss.
- American Academy of Pediatrics

[http://www.portal.state.pa.us/portal/server.pt/gateway/PTARGS\\_0\\_75878\\_713507\\_0\\_0\\_18/World%20of%20Opportunity%20Brochure.pdf](http://www.portal.state.pa.us/portal/server.pt/gateway/PTARGS_0_75878_713507_0_0_18/World%20of%20Opportunity%20Brochure.pdf)



# Pennsylvania EHDI Program

Browser tabs: Pennsylvania Department, Guide By Your Side of Pen, PA Early Hearing Detection

Address bar: www.paearlyhearing.org



## PA Early Hearing Detection & Intervention Program



American Academy of Pediatrics  
DEDICATED TO THE HEALTH OF ALL CHILDREN™  
Pennsylvania Chapter

Funded by the PA Department of Health

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**1** Hearing screening test for all babies no later than **1 month of age**

**3** Diagnostic evaluation by an audiologist no later than **3 months of age** if baby did not pass hearing screening test

**6** Early intervention no later than **6 months of age** if baby is diagnosed with a hearing loss



### Families

Information for families on newborn hearing screening and caring for babies and young children who are



### Physicians

Information on newborn hearing screening and follow-up of patients with potential or diagnosed hearing



### Audiologists

Information on caring for patients with potential or diagnosed hearing loss, parent support, and reporting



### Birth Facilities

Information on newborn hearing screening, parent education, and reporting to the PA Dept. of Health.

# The Described and Captioned Media Program

- The Described and Captioned Media Program (DCMP) is funded by the U.S. Department of Education and administered by the National Association of the Deaf (NAD).
- FREE for families, organizations, and schools.
- <http://www.dcmp.org/>



# Deaf Schools / Programs

- **DePaul School for Hearing and Speech**
  - Parent support and resources
- **Pennsylvania School for the Deaf (PSD)**
  - Educational Outreach: Parent support groups for hearing parents with young deaf children and deaf parents with young hearing children
- **Scranton School for the Deaf**
  - Community ASL classes and workshops
- **Western Pennsylvania School for the Deaf (WPSD)**
  - Outreach Program: Locations in Pittsburgh, Scranton, and Camp Hill

# Parent / Professional Resources

# Articles

Hintermair, M. (2000) Hearing impairment, social networks, and coping: the need for families with hearing-impaired children to relate to other parents and to hearing-impaired adults. *AAD*; 145: 41-53.

Moeller, M. et al. (2013) Best practices in family-centered early intervention for children who are deaf or hard of hearing: An international consensus statement. *JDSDE*; 18(4): 429-445.

Yoshinaga-Itano, C. (2014) Principles and guidelines for early intervention after confirmation that a child is deaf or hard of hearing. *JDSDE*; 19(2): 143-175.



# Books

*Choices in Deafness, 3<sup>rd</sup> Edition* by Sue Schwartz, Ph.D. (Ed)

*Deaf Transitions: Images and Origins of Deaf Families, Deaf Communities and Deaf Identities* by Mairian Corker

*Finding Zoe: A Deaf Woman's Story of Identity, Love, and Adoption* by Brandi Rarus and Gail Harris

*I Can Hear You Whisper* by Lydia Denworth

*Parents and Their Deaf Children: The Early Years* by Meadow-Orlans, Mertens, and Sass-Lahrer

*Raising and Educating a Deaf Child, 2<sup>nd</sup> Edition* by Marc Marschark

*Train Go Sorry: Inside A Deaf World* by Cohen

# Internet

Alexander Graham Bell Association for the Deaf and Hard of Hearing:  
<http://www.listeningandspokenlanguage.org/>

American Society for Deaf Children: <http://deafchildren.org/>

Educating Deaf Children:  
<http://www.rit.edu/ntid/educatingdeafchildren/>

Raising and Educating Deaf Children:  
<http://raisingandeducatingdeafchildren.org/>

Visual Language and Visual Learning:  
<http://vl2.gallaudet.edu/resources/>



# Questions?

**Dr. Smail**

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Phone: 410-480-4572

Videophone: 410-696-7445

# Thank You!

# Select References

- *A Journey Into the Deaf World* by Lane, Hoffmeister and Bahan
- *Deaf in America: Voices from a Culture* by Padden and Humphries
- *Deaf People: Evolving Perspectives from Psychology, Education, and Sociology* by Andrews, Leigh and Weiner
- *Deaf Plus: A Multicultural Perspective* by Kathee Christensen
- *Deafness and Hearing Impairment* by Clay Farris Naff (Ed)
- *Inside Deaf Culture* by Carol Padden and Tom Humphries
- *Sign Language and the Deaf Community* by Baker and Battison (Eds)