

# The Path to Successful Collaboration between EHDI Systems, Parents and Professionals

Presenters:

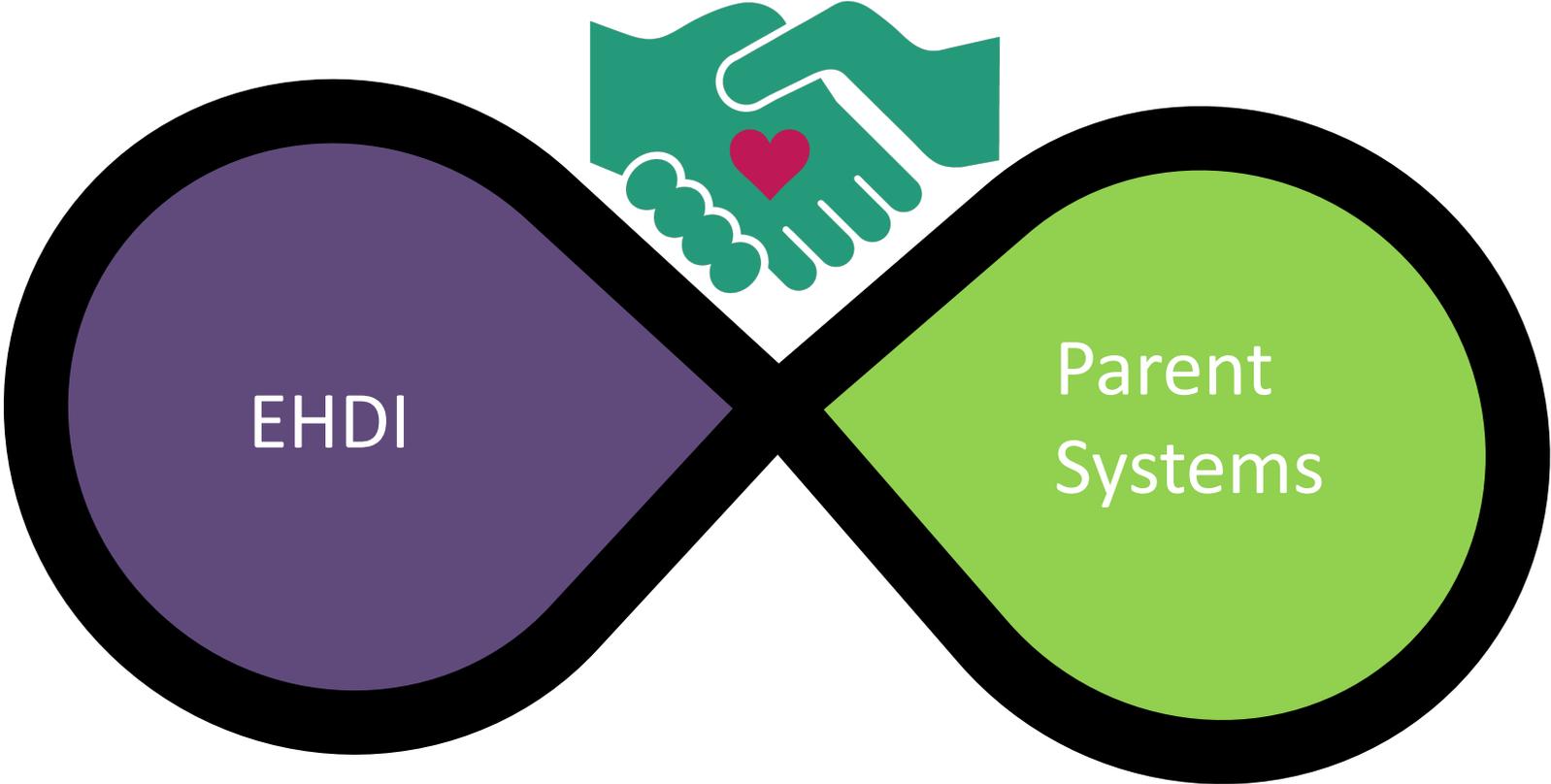
Daphne Miller  
Deepali Sanghani  
Terese Urban



# Objective

Provide methods to improve collaboration and communication between state agencies, professionals and parents in your state.

# Mutual Communication



# Parent Collaborative Efforts

- Coffee shop meetings
- Attend social parent led events by:
  - Virginia Hands & Voices
  - Families to Families
  - Virginia Hearing Journey



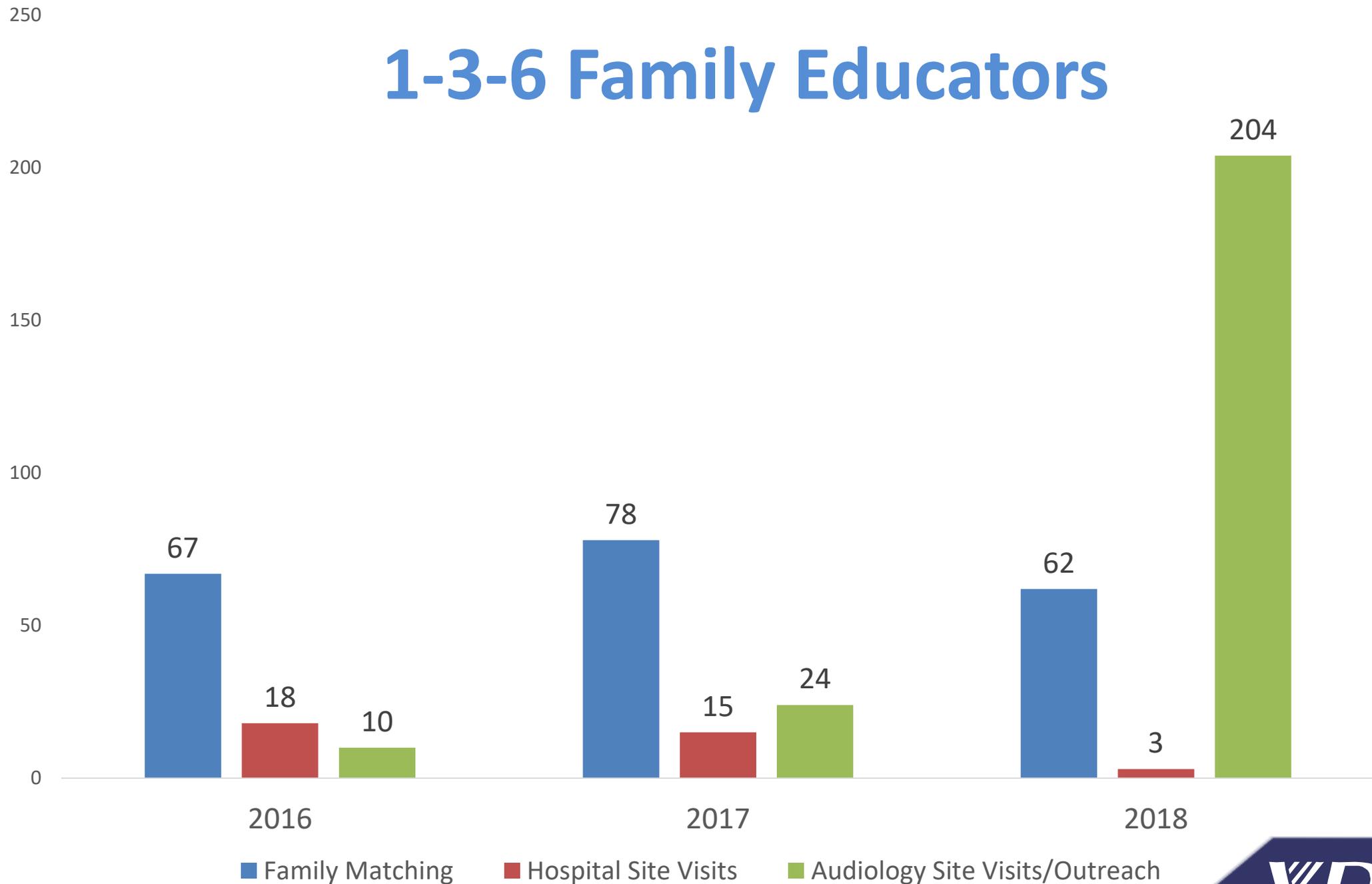
# Center for Family Involvement (CFI) at Virginia Commonwealth University (VCU)



# 1-3-6 Family Educators



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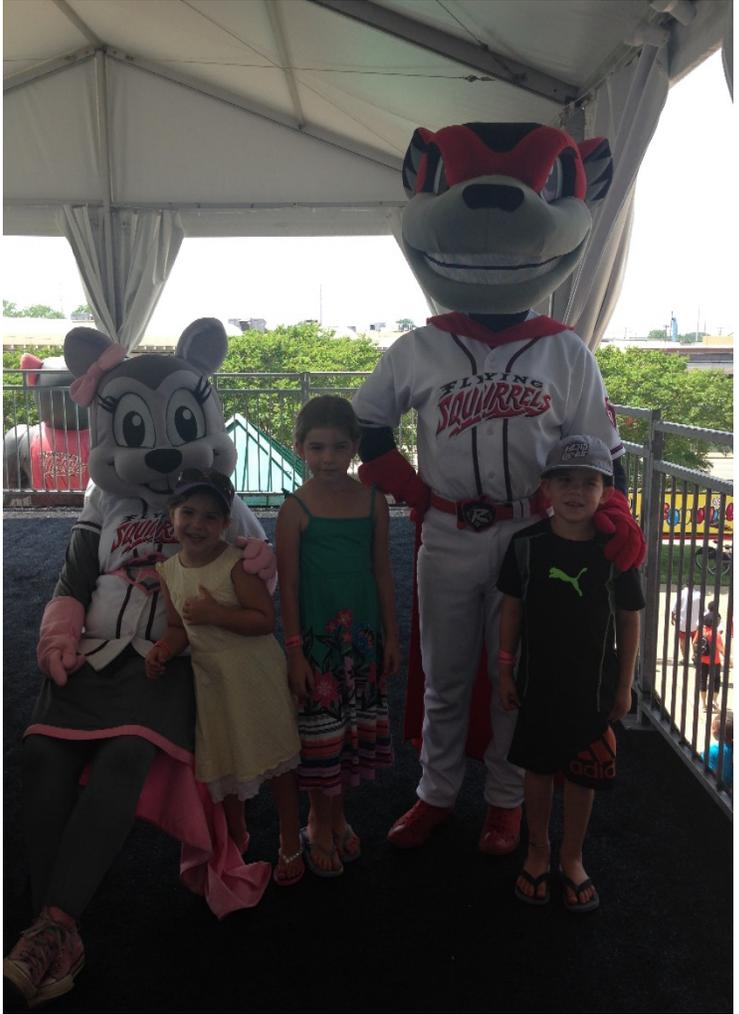


■ Family Matching

■ Hospital Site Visits

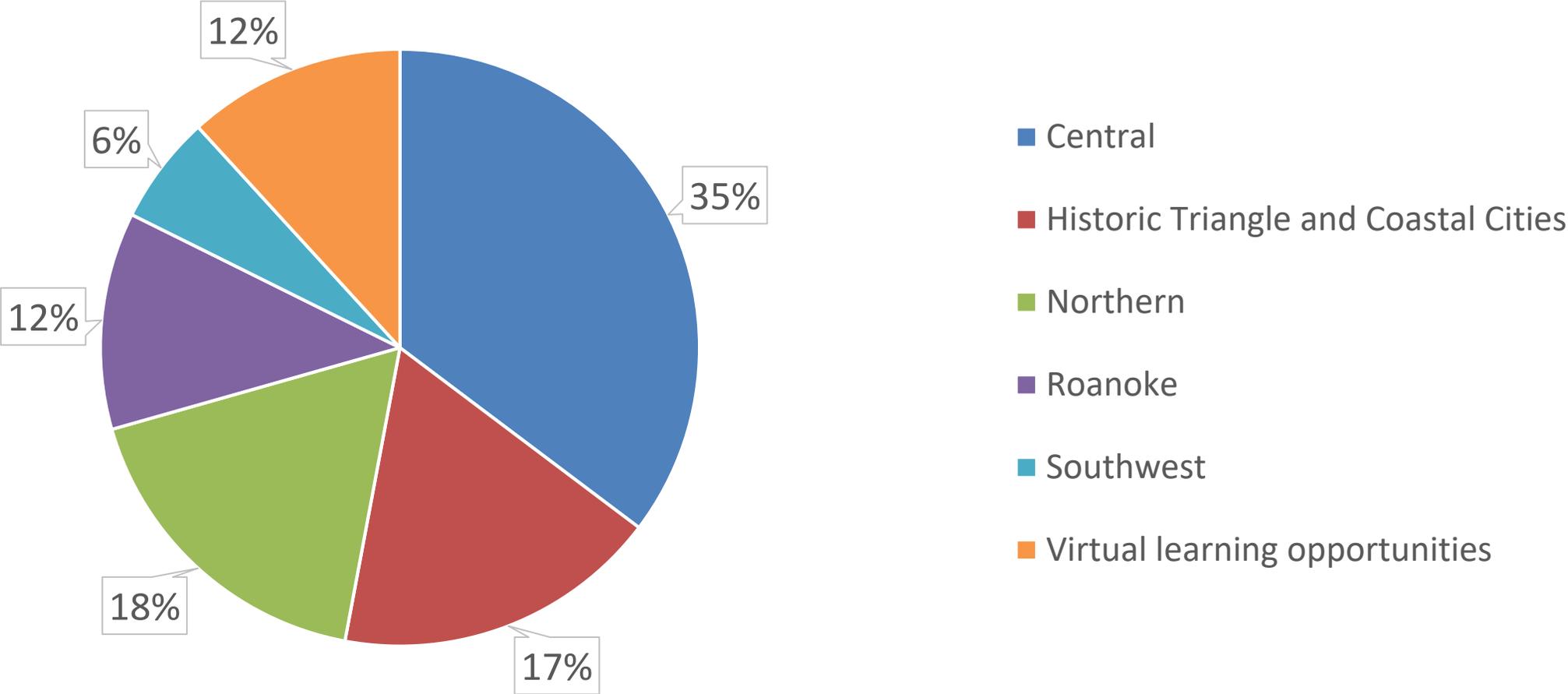
■ Audiology Site Visits/Outreach

# Virginia Hands & Voices





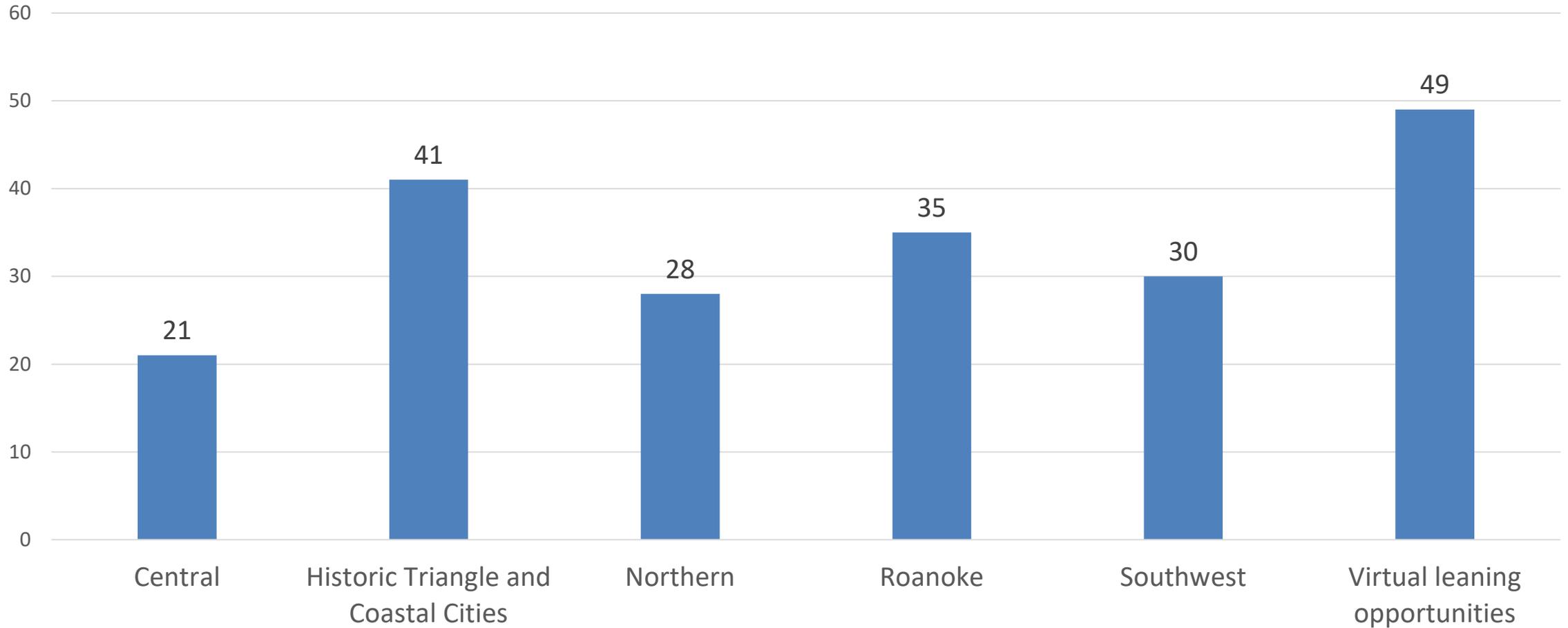
# Virginia Hands & Voices Events per Region – 2018



# List of Hands & Voices Events in 2018

- Parents and Professionals Lunch, **Fairfax**
- Presented at the 2018 Central Virginia EMS Education Expo on the topic “Building a Bridge: Improving Communication with our Deaf and Hard of Hearing Neighbors”, **Henrico**
- Co-hosted event with VSDB and Outreach Services at the Virginia Air & Space Museum, **Hampton**
- Gathered at The Lab at Convergence to see the play, *Outside the Lines*, **Alexandria**
- Family event at The Diamond, Richmond Flying Squirrels, **Richmond**
- Exhibitor at Kings Dominion for Deaf/Hard of Hearing Awareness Day, **Doswell**
- Hosted an Ice Cream Social at Starkey Park, **Roanoke**
- Gathered at Cartwheels & Coffee for *Coffee Chat*, **Richmond**
- Exhibitor at Opening Doors Unlocking Potential conference, **Midlothian**
- Co-hosted *Pizza in the Park* event with Families to Families at Veteran’s Park, **Williamsburg**
- Hosted a gathering at Skate Nation for family fun including laser tag and ice skating, **Richmond**
- Hosted a gathering at Launching Pad Trampoline Park, **Salem**
- Hosted a gathering at Whitehall Farms for fall family fun, **Clifton**
- Co-hosted event with Virginia School for the Deaf and Blind and Outreach Services at the Barter Theater, **Abingdon**

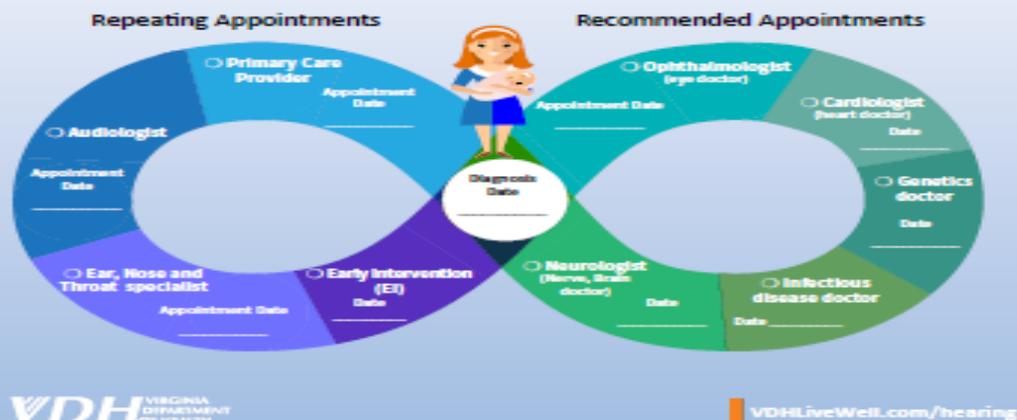
# Virginia Hands & Voices Average Attendance per Event - 2018





## Shared Plan of Care for Children with Hearing Loss

It is important to schedule your child's appointment with their PCP and other specialists as needed. Use the guide below to keep track of all your child's recommended appointments after diagnosis.



VDH VIRGINIA DEPARTMENT OF HEALTH

VDHLiveWell.com/hearing

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## VIRGINIA'S EARLY HEARING DETECTION AND INTERVENTION

# Shared Plan of Care for Children with Hearing Loss



**EHDI** VIRGINIA Early Hearing Detection & Intervention Program

VDHLiveWell.com/hearing

## For Children with Hearing Loss



# Shared Plan of Care

A group of parents and professionals worked together to design the Shared Care Plan for your child who has been diagnosed with a hearing loss. This plan should serve as a guide following diagnosis. The purpose is to provide the next steps in your child's hearing health care. The great news is that there are plenty of professionals and parents ready to support you.

### Key terms to know:

#### Audiologist

A professional trained to diagnose, manage and treat hearing or balance problems.

#### Early Intervention (EI)

A program that provides services and support to families to give them the skills they need to help their children reach their highest potential.

#### Family to Family Support

Family members who have experience caring for a child with hearing loss. They provide support and to help identify additional resources.



#### Primary Care Provider

A primary care provider (PCP) is a health care professional who practices general medicine, including pediatrics. PCPs are the first stop for medical care. PCPs can be a medical doctor, nurse practitioner and/or a physician assistant.

#### Ear Nose & Throat (otolaryngologist)

An otolaryngologist is a medical specialist who is focused on the ears, nose, and throat. These specialists are trained in both medicine and surgery. Also known as an ENT.

The Virginia Early Hearing Detection and Intervention (VA EHDI) program provides information and support to parents whose children have been identified with hearing loss. After diagnosis, make sure that VA EHDI has contacted you. If not, please contact us 804-664-7719.

“ I was feeling so overwhelmed with my newborn's hearing loss diagnosis. Being able to talk with another parent with personal experience of raising a child with hearing loss was like finding a beacon of light in the darkness. She was so supportive and an incredible resource, I am forever grateful. ”

-Sabrina, parent

#### VA EHDI should:

- Send information after your child is first diagnosed.
- Call with next steps in your child's hearing journey.
- Provide information about possible referrals.
- Connect you with Family-to-Family support and resources in your area.

### Next Steps After Diagnosis

- Write your questions for your next appointment.
- Contact your local EI program to schedule an appointment and understand what services they can provide for your child.
- Research communication options
- Connect with Family-to-Family support.
- Check with your insurance company about coverage related to hearing loss.
- Make appointments based on the referrals from your PCP or specialists.

## Choose a Communication Plan

#### Communications options:

You will be exposed to many professionals who should provide you unbiased information on communication options.



### Repeating Appointments

#### Audiologist should:

- Refer your child for a repeat Auditory Brainstem Response (ABR) test if needed to determine their hearing sensitivity.
- Explain the child's hearing loss.
- Answer the questions you prepared about hearing loss.
- Provide an understanding of Early Intervention services.
- Discuss communication options.
- Explain choices for amplification (optional).
- Refer your child to an Ear Nose & Throat specialist (otolaryngologist or ENT).

#### Ear Nose & Throat Specialist should:

- Examine your child's ear.
- Discuss hearing loss and treatment options.
- Provide medical clearance for hearing aids - if needed.
- Refer for further tests if needed.
- Answer questions you may have.

#### Primary Care Provider should:

- Meet with you to discuss your child's hearing loss and next steps.
- Discuss referrals your child may need:
  - Ophthalmologist (eye doctor)
  - Cardiologist (heart doctor)
  - Neurologist (Nerve, brain doctor)
  - Infectious disease doctor
  - Genetics

#### Early Intervention (EI) should:

- Contact you to explain the EI services.
- Schedule a first visit.
- Do an initial assessment with your child.
- Develop an Individualized Family Service Plan (IFSP) - a plan to identify individualized supports and services that will enhance your child's development.
- Assign a service coordinator to work with your child.
- Discuss communication options for children diagnosed with hearing loss (see options above).
- Help you understand your child's insurance benefits.
- Discuss what to expect at your medical appointments related to hearing loss.



For more information, visit [VDHLiveWell.com/hearing](http://VDHLiveWell.com/hearing)

# What is my baby hearing?



## Did you know?

- Three in 1,000 newborns have a hearing loss. Which makes hearing loss the most common birth defect.
- Around nine weeks of pregnancy, the very first part of your baby's ears should start to form.
- Your baby will start to hear sound at 18 weeks of pregnancy and will begin responding to noise at 25 weeks of pregnancy.
- Although it may be muffled, your baby will start to recognize your voice by the third trimester.
- Newborn hearing screening ensures that your baby will receive a hearing test before hospital discharge. Talk to your doctor about early hearing screening.

Visit our website for resources, family stories and trainings or call 804-864-7719.



**Early Hearing Detection  
& Intervention Program**



[VDHLiveWell.com/hearing](http://VDHLiveWell.com/hearing)

# Are you sure your baby hears... Everything?



## Did you know?

- With hearing loss, early identification and intervention are very important. Children identified and enrolled into early intervention services within their first six months are more advanced in language and social skills.
- If it remains undetected, even mild or in one ear, hearing loss may impact your child's language.
- Schedule your child's hearing test with an audiologist during nap or feeding time. Your child should be sleepy during the hearing test.
- Almost 90 percent of deaf and hard of hearing children are born to hearing parents. Talk to your doctor about infant hearing.
- You can also find a Pediatric Audiologist in your area to schedule an appointment at: [www.EHDIPALS.org](http://www.EHDIPALS.org).

Visit our website for resources, family stories and trainings or call 804-864-7719.



**Early Hearing Detection  
& Intervention Program**



[VDHLiveWell.com/hearing](http://VDHLiveWell.com/hearing)



# Future Goals of VA EHDI

- Increase parent engagement to 35%
- Increase cultural diversity among parents
- Encourage new parent involvement
- Improve transparency and communication

# Resources

- [Virginia Early Hearing Detection and Intervention Program](#)
- [Center for Family Involvement at VCU](#)
- [Virginia Hands & Voices](#)
- [Virginia's Resource Guide for Children with Hearing Loss](#)
- [Virginia's Resource Guide for Children with Hearing loss- A Companion Guide for Children in Elementary School](#)
- Published Articles:
  - “Early Experiences within an EHDI State-based Learning Community” EHDI Express: October 2017
  - “Engaging Parents in System Design to Reduce Loss to Follow-Up” – available at: <https://digitalcommons.usu.edu/jehdi/vol3/iss2/1/> Journal of Early Hearing Detection and Intervention: Volume 3 Issue 2

# Contact Information

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