



The Birth Defects and Early Hearing Programs in SC Public Health



Intro and Overview

- The SC Department of Health and Environmental Control is unique among state health departments.
 - Centralized – all state-level and county-level staff are in one agency
 - Health AND Environment
- 3 NBS Programs within the Bureau of Maternal and Child Health
 - Newborn (bloodspot) screening, EHDI, CCHD
 - Birth Defects is now in MCH





To Count and Serve – Part 1

• **Coordinative functions**

- Most NBS conditions and birth defects are “managed” via referrals to sources and systems of care
- Mostly short-term follow-up for NBS conditions
- Some longer-term follow-up is coordinated through the CYSHCN Program

• **Referrals**

- Re-testing
- Confirmatory testing
- Assistance for PCP and family to connect to specialists

• **Assistance**

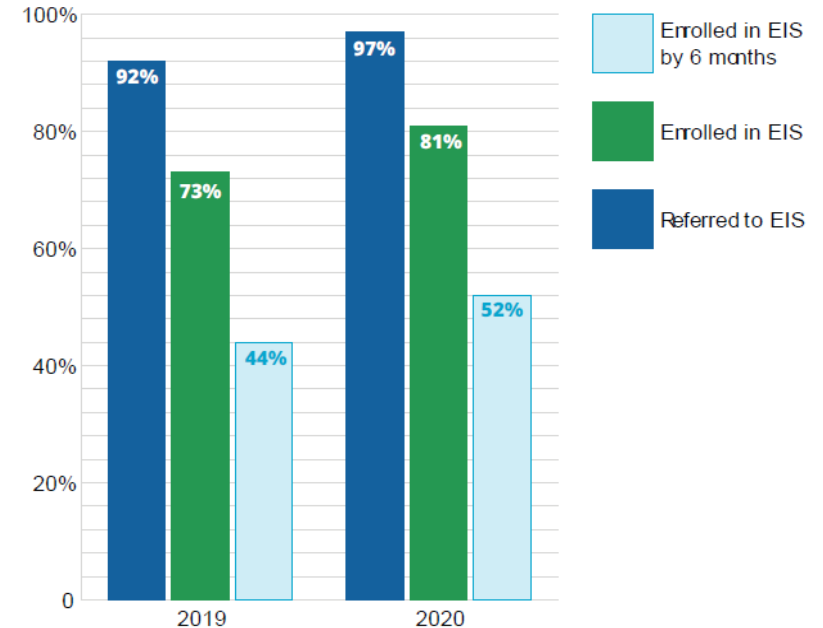
- Some \$\$ and similar (e.g., metabolic and other special formulas, factor for hemophilia clients)

To Count and Serve – Part 2

- Strong Epidemiology Focus
- Strong Referral Focus
- Strong Partnership Focus

Early Intervention for SC Infants with Permanent Hearing Loss

AAP Benchmark: 100% | 2018 National Average: 67%



To Count and Serve – Part 3

- *“Nothing about me without me.”*

by 6 months

Affirmations

I am still reaping the benefits of [newborn hearing screening program] to this day. I was born in 2002 and thanks to the (then) new legislation I was screened for a hearing loss at birth. Early detection helped my parents prepare for the hard road and decisions ahead; I was tested, and the testing showed that I did in fact have a severe bilateral hearing loss.

Thanks to my parents' decisions I became implanted, began speech therapy, and was able to “catch up” to all the other peers in my class at an earlier date. That is something I am thankful for to this day, because the further back for becoming implanted is pushed, the longer it takes for one to achieve (spoken) communication. Thanks to the newborn hearing screening program, teachers, and doctors, I am now in the professional field and have many hearing friends and coworkers that I can effectively communicate and interact with.

Thanks,
Jay, Richland County

by 6 months



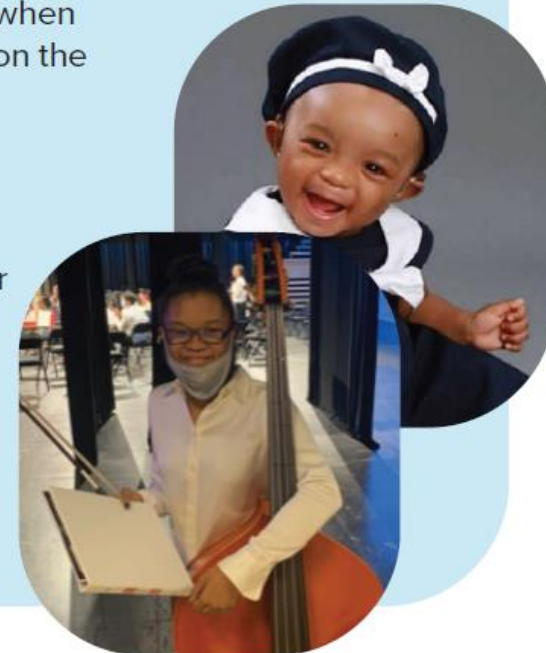
Affirmations

My name is Alyssa and I live in Lexington County. I am 12 years old, I wear two cochlear implants, and I am a 6th grader in middle school. I love school so much because I make lots of new friends. I am in Honors [classes], and I have great classes like PE, Orchestra, and Drama. I have good grades and I am a hard, smart worker. When I had Drama, it was perfect because we did some plays and learning how to pronounce every word you say clearly helped me understand what I am saying and what other people are saying.

I love playing sports and when I get older, I want to play on the Gamecocks Women's Basketball team.

I love being Deaf. Here are my words for D/HH people - “No matter what everybody says about your hearing, you are great in any kind of way and be you.”

Thanks, Alyssa,
Lexington County



We're from the government ...
And we're here to help.



Oregon Health Sciences University

South Carolina Birth Defects Program Resource Guide



A South Carolina where healthy births are promoted, every birth defect matters, and families impacted by birth defects are supported.



Ehdconference.org



Awhonminnesota.org



South Carolina Department of Health and Environmental Control
Healthy People. **Healthy Communities.**

SC Birth Defects Program Referrals

Vinita Leedom and Karen Revels, SC Birth Defects Program



Making a difference with surveillance data

- How can we make a positive difference in public health with the work we do?
 - Conversation with CDC health scientist
 - Research on conditions
- Data represent impacted lives



Defect-specific considerations

- Children with BD can have co-occurring conditions
 - Speech
 - Vision
 - Mobility
 - Cognitive/neurodevelopmental
 - Others
- Which children with BD would benefit from referrals?
- How old are the children at the time of referral?

Managerial considerations

- Office of General Counsel buy-in
 - Is it legal to do referrals?
- Partner organization capacity
 - Which entities can accept BD referrals?
- Stakeholder buy-in
 - Can Early Intervention handle an influx of referrals? Are efforts coordinated with internal partners?
- Staff/Resources
 - Is there time for staff to do referrals?
- Cost
 - Is there a financial cost associated with referrals?



SC Birth Defects Act: Legal authority

SECTION 44-44-30. South Carolina Birth Defects Program established; public health monitoring and referral.

(A) There is established the South Carolina Birth Defects Program within the Department of Health and Environmental Control to promote increased understanding of birth defects, prevent and reduce birth defects, and assist families with children who have birth defects.

(B) As part of this program, the department shall conduct public health monitoring, make appropriate referrals and provide other interventions related to birth defects. Information obtained pursuant to this subsection must be used for:

(1) public health and epidemiology purposes in which incidence, distribution, causes, risk factors, and trends may be studied. This data may be published and made accessible for education and research purposes. This information must be released in aggregate form only without identifying information;

(2) referral for service and treatment purposes so that referrals of the individual child and family may be facilitated for optimal care. The department or its employees must not provide referral services or counseling for the purpose of pregnancy termination by induced abortion, nor use any funds under this program for services or counseling for the purpose of pregnancy termination by induced abortion. Referral information is confidential and must be maintained in accordance with Section 44-44-140.



SC Birth Defects Act: Regulations

- **The Department may contact a family whose child is identified as having a structural birth defect either directly or through the child's health care provider in order to offer services.** Family acceptance of referrals is voluntary. Referrals shall be made in accordance with the Department guidelines and recommendations.
- South Carolina Birth Defects Program nurse abstractors will conduct surveillance activities, to include review of medical records for documentation of physician, social work or discharge planner referral for follow-up of children with birth defects. When there is no documented evidence of follow-up, **South Carolina Birth Defects Program staff may access other appropriate health and developmental systems or organizations for referral for early intervention, such as Babynet.** Babynet will provide regular feedback, as requested, to South Carolina Birth Defects Program on status of birth defects cases referred.



Partner buy-in

- SCBDP Advisory Council
 - SCBDP Strategic Plan:
 - Referrals Goal C.4 Refer families of infants
 - born with a birth defect to appropriate services
 - Activity 3: Ensure that all qualifying infants in the SCBDP system are sent to Baby Net for follow up



Implementation and initial evaluation

- Referred a backlog of cases
- Lead abstractor assessed workload
- Referred thousands of cases and learned BabyNet processes




Birth Exchange Engine referrals

REFERRALS

BabyNet Referral Made by SCBDP?

If No, Specify

BabyNet Referral Made by Hospital?

Date referred by SCBDP 



BabyNet (IDEA Part C) referrals form

Professional Referral

Child Information
(* = REQUIRED FIELDS)

Child's First Name *

Child's Middle Name

Child's Last Name *

Child's Suffix

Child's DOB *

Child's Gender * Child's Race *

Address *

City * State Zip Code * - County *

Primary Language

Is an interpreter needed? *

Birth Hospital

Parent child lives with *

Parent/Guardian First Name *

Parent/Guardian Middle Name

Parent/Guardian Last Name *

Parent/Guardian Suffix

Is this parent the child's legal guardian? * Is this child in foster care? *

Parent Phone * () -

Parent Email Address

NEXT Step 1 of 5



Referral form continued

Professional Referral

Professional Area(s) of Concern

For each area of concern, you will need to enter the Area of Concern and Describe Concern, then click "Save". Each concern entered will be displayed in the results area. After all concerns have been entered, click "Next".

To delete an area of concern, you will need to click on the "Delete" option beside the area of concern to be deleted.

(* = REQUIRED FIELDS)

Area(s) of Concern *

Describe Concern(s)

[BACK](#)

[SAVE](#)

[NEXT](#)

Step 2 of 5



Referral form continued

Professional Referral

Referral Source Information

Note: The referral source is the person making the referral.

(* = REQUIRED FIELDS)

Referral Source's Relationship to Child * Referral Source Name *

Agency/Company

Referral Source Contact Number * () -

Referral Source Address *

Referral Source City * Referral Source State * Referral Source Zip Code * -

Referral Source Fax () -

Referral Source Email Address *

Step 3 of 5

Referrals to Greenwood Genetic Center



- Birth Defects Prevention Program
- Recurrence prevention
- Counseling
- Health promotion



NTD Referrals

- Since 2006
- All pregnancy outcomes
- Legal agreement



First Sound – SC’s Early Hearing Detection and Intervention (EHDI) Program

- Congenital Hearing Loss
 - 3 per 1000 babies
- Per Legislation
 - Screening
 - Risk Factors (see following slide)
 - Follow-up
 - Diagnostics – audiological and/or medical evaluation
 - Early Intervention – confirmed hearing loss
 - Reporting
 - Hospitals
 - Audiologists
 - Early intervention

Audiologic Diagnostic Appointment Guidelines for Risk Factor Referrals

For infants who pass the newborn hearing screen, but have any of the following risk factors for hearing loss.



TIER 1

- Cytomegalovirus (CMV) infection
- Bacterial meningitis & certain types of viral meningitis, especially herpes & varicella
- Parental or medical provider concern

Schedule audiologic diagnostic evaluation:
To occur by **30 days** post discharge
Notify First Sound, family and pediatrician of appointment

TIER 2

- Down Syndrome
- Cleft lip/palate
- Craniofacial anomalies (e.g. microtia/atresia, temporal bone anomalies)
- Syndromes associated with hearing loss (e.g. CHARGE, Treacher Collins, Pierre Robin, BOR, Waardenburg syndrome, etc.)
- Perinatal asphyxia
- ECMO
- Hyperbilirubinemia (> 20mg/dL bilirubin)
- Permanent childhood or young adult* hearing loss in immediate family (infant's parents or siblings)
- Neurodegenerative disorders

* excludes young adult hearing loss resulting from acute illness or trauma

Schedule audiologic diagnostic evaluation:
To occur by **3 months** post discharge
Notify First Sound, family and pediatrician of appointment

TIER 3

- > 10 days mechanical ventilation
- ≤ 32 weeks gestational age
- < 1500 grams birthweight
- Permanent childhood or young adult* hearing loss in extended family
- Herpes, rubella, syphilis, toxoplasmosis
- Head trauma
- Ototoxic medications (> 7 day course or in conjunction with loop diuretics)

* excludes young adult hearing loss resulting from acute illness or trauma

Schedule audiologic diagnostic evaluation:
To occur by **6 months** post discharge
Notify First Sound, family and pediatrician of appointment

IMPORTANT REMINDER
For NICU stay for >5 days advise parents it is recommended to have baby re-screened between 24-30 months old



First Sound – SC’s Early Hearing Detection and Intervention (EHDI) Program

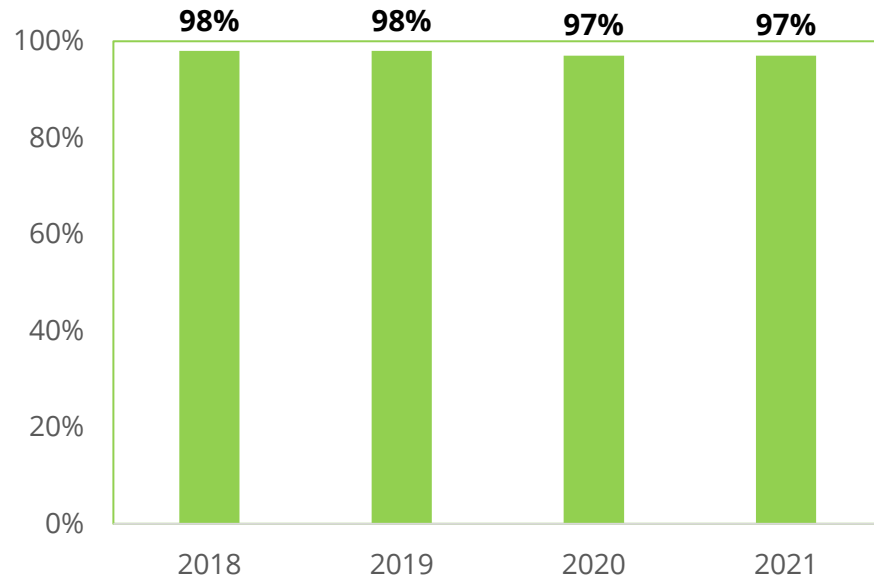
- Partners
 - First Sound staff – 3
 - Other DHEC Programs:
 - CYSHCN
 - Central office
 - Region offices
 - Newborn screening
 - SCBDP
 - Birth facilities – hospitals and birthing centers
 - Audiologists
 - BabyNet (Part C)
 - SC School for the Deaf and Blind
 - Family Support Organizations



First Sound – SC’s Early Hearing Detection and Intervention (EHDI) Program

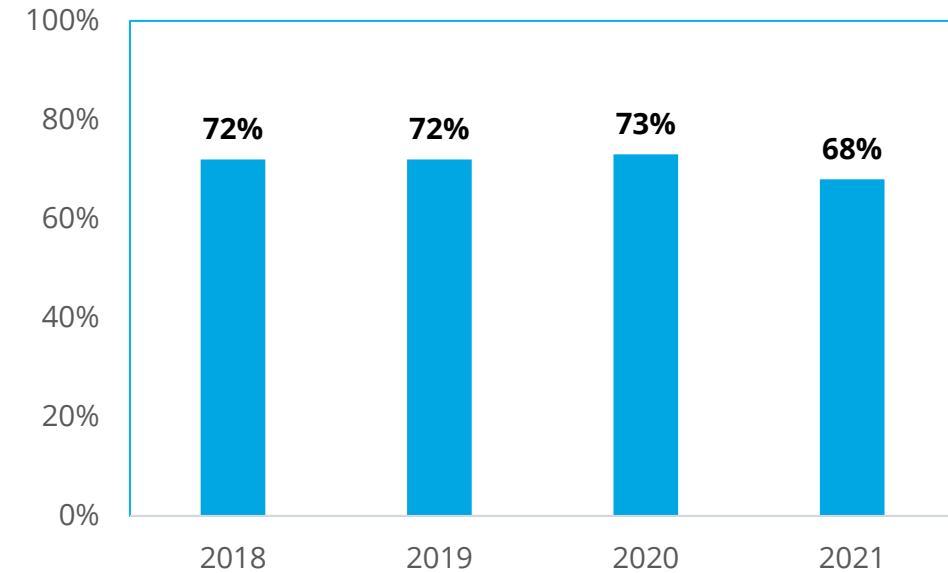
SC Newborn Hearing Screening Rate

AAP Benchmark: 95% | 2020 National Average: 97.7%



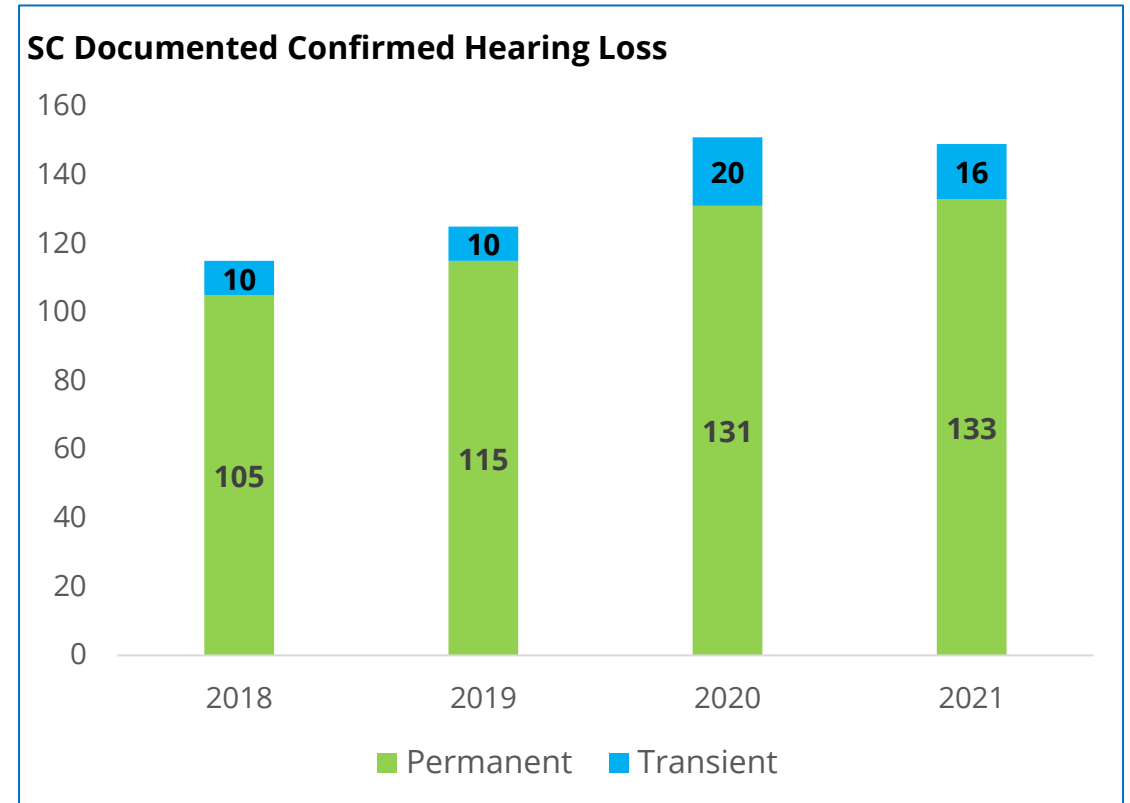
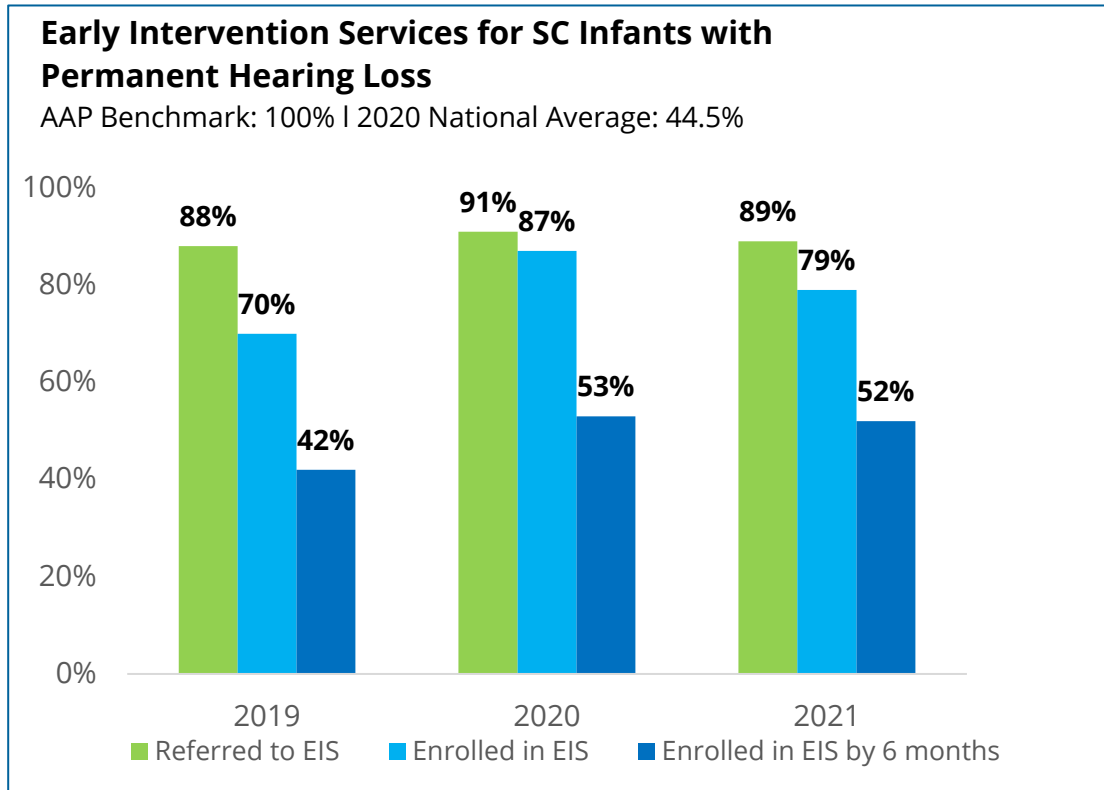
SC Infants with Hearing Loss, Where Loss is Confirmed by 3 Months

AAP Benchmark: 100% | 2020 National Average: 60.6%





First Sound – SC’s Early Hearing Detection and Intervention (EHDI) Program



Referrals to EHDI

- Partnership with SC EHDI program (First Sound)
 - Reciprocal Referrals
 - Shared Data System
- Organically created idea; built on good relationship
 - SCBDP to First Sound
 - First Sound to SCBDP
- Closing gaps for both programs

INFORMATION



- Hospitals
- Early Intervention
- SCBDP
- Family Support
- Audiologists
- CYSHCN
- NBS
- Other



Contact Us



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Dr. Michelle Myer

Stay Connected

