



Diving Deeper into VSV (Virtual Site Visit) Parent Materials

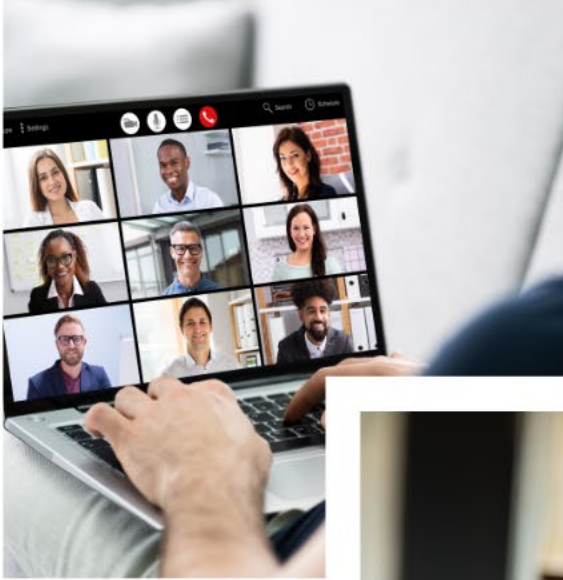
Presented by Carrie Balian

Learning Objectives



WELCOME

1. Identify at least 3 avenues in which providers can share the “What to Expect” handout.
2. Learn how to use the parent story builder to create awareness, recognition, identify areas for improvement and support funding requests.
3. Describe at least 3 benefits to utilizing and sharing the “Next Steps” document.



What is VSV?

- 6 states
- EHDI and Parent representatives
- Pandemic inspired
- Support services for NBHS



VSV Purpose

- ✓ State EHDl Coordinator & Parent Partner
- ✓ Work alongside NCHAM staff to develop and suggest
- ✓ Pilot test protocols & procedures
- ✓ Create guidebook
- ✓ Distribute guidebook & mentor others

The Parents



What to Expect

PREPARING FAMILIES

- Purpose of the document
- Where to share
- Dual language
- QR codes for additional learning





WHAT TO EXPECT • QUE ESPERAR

BABY TESTS PRUEBAS AL BEBE

Newborn Screening is done when your baby is 1 to 2 days old, before they leave the hospital. If your baby is not born in a hospital and did not receive any newborn screenings, talk to your baby's health care

provider about getting it completed at 1 to 2 days of age. • El examen de detección del recién nacido se realiza cuando su bebé tiene entre 1 y 2 días de edad, y antes de que salga del hospital. Si su bebé no nació en un hospital y no recibió ningún examen de detección hable con el proveedor de atención médica de su bebé para que lo complete entre 1 y 2 días de edad.

Screening Procedures Done After Birth • Examen de audición rápido

Even without a family history, some infants are born with serious but often treatable medical conditions. Newborn screening helps health professionals to identify and treat these conditions before they impact your baby's health.

Aunque no tenga antecedentes, algunos bebés nacen con condiciones médicas graves pero muchas veces se pueden tratar. Las pruebas de detección de recién nacidos ayudan a los profesionales de la salud a identificar y tratar estas condiciones antes de que afecten el desarrollo de su bebé.

What kinds of tests will my baby receive? Blood tests, hearing screening and heart screening are the core tests that will be given after birth.

¿Qué tipo de pruebas recibirá mi bebé? Los análisis de sangre, las pruebas de audición y las pruebas cardíacas son las pruebas principales que se realizarán después del nacimiento.



- <https://www.babysfirsttest.org/newborn-screening/screening-procedures>

Why does my baby need their hearing screened? Many people are surprised to learn that 12,000 babies a year in the U.S. are born with a permanent hearing loss. That makes hearing loss one of the most common conditions present at birth.

¿Por qué necesita mi bebé que le examinen la audición? Mucha gente se sorprende al saber que 12,000 bebés al año en los EE. UU. nacen con una pérdida auditiva permanente. Eso hace que la pérdida auditiva sea una de las condiciones más comunes presentes al nacer.



- <https://www.cdc.gov/ncbddd/hearingloss/screening.html#:~:text=Hearing%20screening%20is%20a%20test,usually%20only%20a%20few%20minutes.>

Specific Causes of Hearing Loss • Causas Específicas de la Pérdida Auditiva

There are many causes of hearing loss. The following are just a few examples:

Hay muchas causas de la pérdida auditiva. Los siguientes solo son algunos ejemplos:

Microtia/Atresia: Microtia is a condition where the outer ear does not fully develop. Atresia (also known as aural atresia) is the absence or closure of the external auditory ear canal. Refer to the Ear Community website for more information.

Microtia/Atresia: la microtia es una deformidad en la cual el oído externo no se desarrolla por completo. La atresia (también conocida como atresia auricular) es la ausencia o cierre del canal auditivo externo del oído. Para obtener más información, consulte el sitio web de Ear Community.



- earcommunity.org/microtiaatresia/where-do-i-begin/

CMV: Cytomegalovirus (sy-toe-MEG-a-low-vy-rus) or CMV, is a common, serious, and preventable virus. CMV can cause problems if infection occurs during pregnancy. Visit the National CMV foundation website to learn more including prevention tips.

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- <https://www.nationalcmv.org/overview/prevention-tips>

Risk Factors: Non-genetic hearing loss can result from a wide variety of illnesses and problems at birth. The link below shares about risk factors in more detail.

Factores de riesgo: la pérdida auditiva que no es genética puede ser resultado de una variedad de enfermedades y problemas al nacer. El enlace de abajo explica sobre los factores de riesgo en más detalle.



- babyhearing.org/non-genetic-hearing-loss

www.infanthearing.org



Getting Ready for Baby • Preparándose para el bebé

Here are some important things to consider doing before the baby arrives. The timeline below is a suggestion and meant to give you enough time to mark them as done, however, they can be completed at any time.

Aquí hay algunas cosas importantes que debe considerar hacer antes de que llegue el bebé. La línea de tiempo es una sugerencia y está disponible para darle suficiente tiempo para marcarlos como completados, sin embargo, se pueden completar en cualquier momento.

First Trimester • Primer trimestre

Get a special baby notebook or folder together. This is an easy way for you to store information from appointments, notes and special memories from pregnancy through your baby's first year.

Consiga un cuaderno o carpeta especial para su bebé. Esta es una manera fácil de guardar información de citas, notas y recuerdos especiales desde el embarazo hasta el primer año de edad de su bebé.



Second Trimester • Segundo trimestre

Save your money. Through the Affordable Care Act health insurance plans must provide breastfeeding support, counseling, and equipment for the duration of breastfeeding. These services may be provided before and after birth. Your insurance plan will often follow your doctor's recommendations on what's medically appropriate. Some insurance plans may require pre-authorization from your doctor. Talk to your doctor to find out what this means for you.

Ahorre su dinero. A través de la Ley del Cuidado de Salud a Bajo Precio, los planes de seguro médico deben brindar apoyo, asesoramiento y equipo para la lactancia durante la etapa de lactancia. Estos servicios se pueden brindar antes y después del nacimiento. Su plan de seguro seguirá las recomendaciones de su médico sobre lo que es médicamente apropiado. Algunos planes de seguro pueden requerir una previa autorización de su médico. Hable con su médico para averiguar qué significa esto para usted.



Third Trimester • Tercer trimestre

Take a tour. Set up a tour or virtual visit of the hospital location you plan to give birth at. This will allow you to learn more about your birthing options, see the birthing rooms, learn about resources the hospital provides and ask questions.

Haga un recorrido. Programe un recorrido o una visita virtual de la ubicación del hospital en el que planea dar a luz. Esto le permitirá aprender más sobre sus opciones de parto, las salas de partos, conozca los recursos que ofrece el hospital y haga preguntas.



Make a birth plan. A birth plan shares your wishes and goals for before, during and after labor and delivery. Making a plan before delivery will make checking into the hospital an easy process. Ask your hospital if they offer a birth plan handout.

Haga un plan de parto. Un plan de parto compartirá sus deseos y metas antes, durante y después del parto. Haciendo un plan antes del parto hará registrarse al hospital un proceso sencillo. Pregúntele a su hospital si ofrecen un folleto sobre el plan de parto.



Take a drive. If this is your first baby or if the hospital is new to you, it is always a good idea to do a test run and see not only how long it takes you to get there, but to make sure you know exactly where to park and go once you get there.

Dese una vuelta/un paseo. Si este es su primer bebé o si el hospital es nuevo para usted, siempre es una buena idea hacer una prueba y ver no solo cuanto tiempo le toma en llegar allí, pero asegúrese de saber exactamente dónde estacionarse e ir una vez que llegue allí.



Install the car seat. A lot of places, such as police stations, fire departments and hospitals will offer car seat installation checks to make sure you've installed the car seat correctly.

Instale el asiento para el automóvil. Muchos lugares, como estaciones de policía, departamentos de bomberos y hospitales ofrecen lugares de instalación de asientos de seguridad para asegurarse de haber instalado el asiento para el automóvil correctamente.



Find a health care provider. Find and connect with your baby's health care provider / pediatrician for well visits and ongoing care. The hospital will ask which health care provider / pediatrician you will be using for your baby and tell you to make an appointment for the baby's first visit just days after leaving the hospital.

Busque un proveedor de atención médica. Busque y conéctese con el proveedor de atención médica de su bebé para las visitas de rutina y la atención que continuará. El hospital le preguntará qué proveedor de atención médica / pediatra usará para su bebé y le dirá que haga una cita para la primera visita del bebé pocos días después de salir del hospital.



How to use the QR code • Cómo usar el código QR



To quickly access the website link simply scan the QR code next to the link by opening your smart phone's camera. Without taking a picture the camera will recognize the code and take you to the link.

Para abrir rápidamente el enlace del sitio web, simplemente escanee el código QR junto al enlace abriendo la cámara de su teléfono. Sin la necesidad de tomar una foto, la cámara reconocerá el código y lo llevará al enlace.

www.infanthearing.org





Family Story Builder

Everyone has a story

- Purpose
- "How to" tip sheet



TIPS ON HOW TO COMPLETE YOUR OWN
FAMILY STORY
 CONSEJOS SOBRE CÓMO COMPLETAR LA HISTORIA ACERCA DE SU FAMILIA

Sharing your family's story is a powerful way to inspire change and improve the experiences of patients and families in healthcare. Hearing screening and diagnosis often requires many steps and healthcare professionals. Telling your story helps these providers understand the impact of their actions and where they fit in the larger picture of your journey. This template was created by parents for parents to help inspire your story. Each section addresses a specific part of the hearing screening process. The questions for each section are designed to help guide you while you write. Not every question may pertain to your story, and you aren't required to fill out every section if you don't want to. However, sharing more increases the opportunity that your story will create a meaningful impact for more professionals. Do not be afraid to share your successes, challenges, and how you felt throughout your journey. This is your story!

At the end of the Family Story document you will be asked to check a box agreeing that the information you submit can be read by a NCHAM professional and/or state EHDI representatives and may be made public on their websites. You may not want to include personal identifying information in the course of your story for this reason.

Do

- ✓ Use your own style - relax and be yourself
- ✓ Acknowledge your emotions
- ✓ Acknowledge what went well and/or what could have been better
- ✓ Offer suggestions or opportunities for improvement
- ✓ Assume that your reader wants to make things better
- ✓ Acknowledge your limitations - it's okay not to know everything
- ✓ Stay focused on the main points you are trying to share

Do Not

- ✓ Use slang or inappropriate language
- ✓ Speak negatively about specific clinics or professionals
- ✓ Name a specific provider or facility
- ✓ Assume that your experience is the only experience
- ✓ Lose your point in the details

Compartir la historia de su familia es una forma poderosa de inspirar cambios y mejorar las experiencias de los pacientes y sus familias en el cuidado de la salud. El examen y el diagnóstico de la audición requieren muchos pasos y profesionales médicos. Contar su historia ayuda a estos proveedores comprender el impacto de sus acciones y como serán vistos en general a lo largo de su situación. Esto fue creado por padres para padres para que ayuden a inspirar su historia.

Cada sección trata una parte específica del proceso de evaluación auditiva. Las preguntas de cada sección están diseñadas para guiarlo mientras escribe su historia. No todas las preguntas serán relacionadas con su historia, y no es necesario que complete todas las secciones si no lo desea. Sin embargo, al compartir más aumenta la oportunidad de que su historia creará un impacto significativo para más profesionales. No tenga miedo de compartir sus éxitos, desafíos y sus sentimientos. ¡Esta es su historia!

Al final del documento Historia De Una Familia se le pedirá que indique aceptando que se pueda leer la información que envíe por un profesional de NCHAM y / o representantes estatales de EHDI y pueden hacerse públicos en sus sitios web. Por este motivo, puede que no quiera incluir información de identificación personal en el curso de su historia.

Lo que debe hacer

- ✓ Use su propio estilo: relájese y sea usted mismo
- ✓ Reconozca sus emociones
- ✓ Reconozca lo que salió bien y / o lo que podría haber sido mejor
- ✓ Ofrezca sugerencias u oportunidades para mejorar
- ✓ Suponga que la persona que este leyendo su historia quiera mejorar las cosas
- ✓ Reconozca sus limitaciones: está bien no saberlo todo
- ✓ Manténgase enfocado en los puntos principales que está tratando de compartir

Lo que no debe hacer

- ✓ Usar lenguaje inapropiado o con doble sentido
- ✓ Hablar de forma negativa acerca de clínicas o profesionales
- ✓ Nombrar un proveedor o centro específico
- ✓ Suponga que su experiencia es la única experiencia
- ✓ Pierde su punto en detalles

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- Top section in English
- Bottom is in Spanish
- Overview of the importance of sharing your story
- You don't have to respond to every leading question
- Check box to release their story for use
- "Do" and "Do Not" section



NEWBORN HEARING SCREENING

FAMILY STORY

Parent Name: _____ Today's Date: _____
Parent Contact Information (phone/email): _____
Hospital Name of baby's delivery / City / State / Year of birth: _____

This template is to help you create your family's story about your hearing screening experience. Sharing stories is a powerful tool to improve and help healthcare systems and providers have a better understanding of how their role can impact families just like yours. The questions below are only meant to help inspire your story and not all questions may apply to your family.

Pregnancy • Risk Factors • Delivery

What contributing factors may have existed? Did you have a full term delivery or preterm? Was your baby in the NICU or special care nursery? Did you contract CMV during your pregnancy? Any complications during delivery? Any other known risk factors? Any other conditions at birth (Deaf +)? How did you feel throughout the process?

Initial Screening Experience In Hospital

When did they screen your baby? Where did they screen your baby (ex. in the room, in the nursery, etc.)? Who screened your baby? What type of screening equipment was used, if known? How many times did they screen your baby? How was the process explained to you? Were you given any informational materials (brochure, video, handout)? Did you understand the process and what was happening? How did you feel throughout the process?

Messaging After Completed Screening

How did the screening staff convey your baby's results to you? What was said? Did you understand the results? Did you understand what to do next? Were any barriers to next steps addressed (ex. transportation, timing of appointments, childcare, etc.)? Were you handed any information documenting the results and how did you feel throughout the process?

Follow Up From Primary Care Doctor

Were the results discussed with your pediatrician or baby's primary care provider (PCP) during your initial visit or a following appointment? Did you discuss any hearing concerns with your baby's PCP? What was the recommendation from your baby's PCP? Were you provided any referrals from your baby's PCP for follow up testing or services? How did you feel throughout the process?

Diagnosis, Technology & Communication

When did you receive your formal diagnosis? What type of hearing loss? What recommendations were presented to you? What technology did you choose (ex. hearing aids, cochlear implants, nothing)? If any, when did your baby receive them? What was the process like? What communication modes did you explore? How did you feel throughout the process?

Early Intervention & Support

What interventions were presented to you? What services did you receive (ex. Early Intervention, Guide by Your Side or other Parent-to-Parent Support, Deaf Role Models, etc.) and when? How did you feel throughout the process?

Where Are You Now?

How old is your child? What grade? What are their interests? What are their strengths? How did this process contribute to who they are today? What advice would you give to providers serving families? What advice would you give to families who are just starting out?

By checking this box you agree that the information you submit can be read by a NCHAM professional and/or state EHDI (Early Hearing Detection & Intervention) representative and can be made public on the website.



Next Steps

- Raise Awareness
- Screenings
- What to do next
- Milestones / Risk Factors



NEWBORN HEARING SCREENING

NEXT STEPS

Many people are surprised to learn that 12,000 babies a year in the U.S. are born with a permanent hearing loss. That makes hearing loss one of the most common conditions present at birth. As a result, the EHHI (Early Hearing Detection and Intervention) Act authorized federal programs to support Universal Hearing Screenings at the state level.

Mucha gente se sorprende al saber que en los EE. UU. nacen 12,000 bebés al año con pérdida auditiva permanente. Eso hace la pérdida auditiva una de las condiciones más comunes al nacer. Por eso mismo, el Acta de EHHI (Detección e Intervención Temprana de la Audición) autorizó programas federales para apoyar los exámenes de audición universales a nivel estatal.

Hearing Screening • Examen de audición rápido

What kind of hearing screenings are done? Two types of newborn hearing screening tests are used to check hearing in babies. The link below tells more about each test that may be used when a baby is first born.
¿Qué tipo de exámenes de audición se realizan? En los recién nacidos se utilizan dos tipos de pruebas de detección para evaluar la audición en los bebés. En el enlace debajo incluye más información sobre cada prueba que tal vez se utilizara cuando nazca el bebé.



- babyhearing.org/newborn-hearing-screening-tests

What do these screening results mean? Based on the screening results your baby may need a full hearing test also called a diagnostic test. Visit the following links to the Hear and Now or Baby Hearing websites to read more about what the results mean.
¿Qué significan estos resultados? Dependiendo de los resultados del examen, es posible que su bebé necesite una prueba de audición completa, también llamada prueba o examen de diagnóstico. Visite los siguientes enlaces a los sitios web Hear and Now o Baby Hearing para leer más sobre el significado de los resultados.



- hearandnow.org



- babyhearing.org/what-do-test-results-mean

What should I do if my baby did not pass (also called "fail" or "refer") the hearing screening? Some babies who do not pass the screening have normal hearing, but up to one in three babies that do not pass will have a permanent hearing loss. The link below explains more about why some babies need follow up testing.
¿Qué debo hacer si mi bebé no pasó (también llamado "reprobó" o "derivó") la prueba de audición? Algunos bebés que no pasan el examen tienen audición normal, pero uno de cada tres bebés que no pasan tendrá una pérdida auditiva permanente. El enlace debajo explica más sobre algunas razones por lo cual los bebés necesitan más pruebas.



- hearandnow.org

Developmental Milestones • Hitos/metás del desarrollo

The earlier children with hearing loss start getting services, the more likely they are to reach their full potential. If you are a parent and you suspect your child has hearing loss, trust your instincts and speak with your doctor. Here is a link to a developmental checklist located on the ASHA (American Speech-Language-Hearing Association) website for you to look at and track your baby's communication milestones.

Entre más pronto que los niños con pérdida auditiva comiencen a recibir servicios, es más probable que alcancen su potencial al máximo. Si es padre y sospeche que su hijo tenga pérdida auditiva, confíe en sus instintos y hable con su médico. Aquí hay un enlace a una lista de verificación del desarrollo, ubicada en el sitio web de ASHA (Asociación Estadounidense del Habla, el Lenguaje y la Audición) para que pueda ver y seguir las metas de comunicación de su bebé.



- asha.org/public/speech/development/chart/

Next steps after the hearing screening • Próximos pasos después del examen de audición rápido

Why should I follow up? Hearing loss can affect a child's ability to develop language and social skills to communicate. The earlier children with hearing loss start getting services, the more likely they are to reach their full potential. View the Hands & Voices Loss & Found video on YouTube to hear from other parents.

¿Por qué debo hacer una siguiente cita? La pérdida auditiva puede afectar la capacidad de un niño para desarrollar el lenguaje y las habilidades sociales para comunicarse. Entre más pronto que los niños con pérdida auditiva comiencen a recibir servicios, es más probable que alcancen su potencial al máximo. Vea el video de Manos & Voces Loss & Found en YouTube para escuchar de otros padres.



- youtube.com/watch?v=8NM6u8VOfrk

Where do we go for follow up testing? Some hospitals may set up a follow up appointment for your baby before you go home. If you need an appointment you can use this resource to find a pediatric audiologist who is able to properly test your baby. Go to the EHHI Pals website listed here to find a provider near you.

¿A dónde vamos para las pruebas que siguen? Algunos hospitales pueden hacer la siguiente cita para su bebé antes de irse a casa. Si necesita una cita, puede utilizar este recurso para encontrar un audiólogo pediátrico que pueda evaluar adecuadamente a su bebé. Puede ir al sitio web de EHHI Pals que aparece aquí para encontrar el proveedor más cercano a usted.



- ehdi-pals.org/Default.aspx

What are the next steps? You can view more tools and information on the NCHAM website. The first link you will take you to a PDF with a roadmap of the next steps. The second link will help you locate resources within your state.

¿Cuáles son los siguientes pasos? Puede ver más recursos e información en el sitio web de NCHAM. El primer enlace lo llevará a un PDF con una hoja de los próximos pasos. El segundo enlace lo ayudará a encontrar recursos dentro de su estado.



- infanthearing.org/documents/ParentRoadmap.pdf



- infanthearing.org/states/index.html

Specific Causes of Hearing Loss • Causas específicas de la pérdida auditiva

There are many forms of genetic hearing loss. However, there could be other causes or situations where hearing loss can occur in children. These are just a few examples:

Hay muchas formas de pérdida auditiva genética. Sin embargo, puede haber otras causas o situaciones en la cual la pérdida auditiva puede ocurrir en niños. Estos son solo algunos ejemplos:

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- nationalcmv.org/overview/cmv-symptoms

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- babyhearing.org/non-genetic-hearing-loss

How to use the QR code • Cómo usar el código QR



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NURSE MANAGER WORKSHEET



Bonus

What hospitals should consider



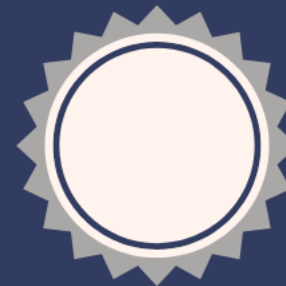
Both sides of the road

Hillary's experience



Great Teamwork

Parent think tank - Coordinators ran with it





NURSE MANAGER

WORKSHEET

NEWBORN HEARING SCREENING

The Virtual Site Visit Nurse Manager Worksheet is a tool to systematically review the current processes of your Newborn Hearing Screening (NBHS) program and determine areas for improvement and updating. The worksheet provides a central place to document key aspects of your NBHS program that are important in training new staff and with transitions of leadership to support continuity of care. This document should be kept in a central place, both hard copy and electronically, for ease of staff access.

This document shall be stored electronically at:

This document shall be stored physically at:

Contact Information

INDIVIDUAL COMPLETING THE WORKSHEET

Date of Completion:

Contact information for the individual completing the worksheet:

Name:

Hospital's Official Name:

Address:

Address 2:

City, State, Zip Code

Phone:

Email:

STATE AGENCY ADMINISTERING THE EHDI PROGRAM

Name:

Address:

Address 2:

City, State, Zip Code

Phone:

Email:

Website:

PEDIATRIC AUDIOLOGY SUPPORT (if applicable)

Name:

Clinic Name:

Phone:

Email:

FACILITY CONTACT FOR STAFF TRAINING (if applicable)

Contact information for the facility's clinical educator:

Name:

Phone:

Email:

Support Materials

POLICIES AND PROCEDURES:

Location for policies and procedures:

How often are policies and procedures updated?

BROCHURES:

Does your facility provide newborn hearing screening informational brochures? Yes No

When does your facility provide the brochures to the parent/caregiver? (select all that apply)

- At OB appointments
 At pre-natal classes
 At bedside
 At discharge in parent education packet
 Other:

Which informational brochures are provided to parents by the facility? (select all that apply)

- About newborn hearing screening (prior to screening)
 About results and next steps (after screening)
 Other:

Does the state EHDI Program provide content requirements or guidelines on newborn hearing screening brochure content? Yes No

Citation for guidance:

In what languages are the brochures available?

Weblink where brochures may be printed on-demand:

Is there a cost for the brochures? Yes No

Indicate cost of the brochures:

Who is responsible for ordering the brochures?

Contact Information for where brochures may be obtained:

Name:

Address:

Address 2:

City, State, Zip Code:

Where are the newborn hearing screening brochures stored at your facility?

VIDEOS:

Does your facility provide informative videos for parents/caregivers on newborn hearing screening? (e.g. Hands & Voices: Loss and Found, NBS video) Yes No

Does your facility provide informative videos for parents/caregivers on Cytomegalovirus (CMV) screening? Yes No

How can parents/caregivers access the videos?

Relaying Results

RELAYING RESULTS AND INFORMATION TO PARENTS:

Which staff member(s) inform(s) the family about newborn hearing screening prior to screening?

Does your facility have a designated consent form for newborn hearing screening? Yes No

If yes, citation?

Up Ahead

- States implementing features of the VSV work
- IL HV GBYS using Next Steps document

[LEARN MORE](#)





Questions?

THANK YOU...



Carrie Balian



ILHVGBYS@gmail.com



224-343-1873

Thank You

