



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

El 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



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.