



HANDS &
VOICES™

HANDS & VOICES EHDI 1-3-6 FAMILY SURVEY



June 2019

Children who are deaf or hard of hearing

This survey was intended to gather parent and caregiver feedback for children ages 0-5 that have been identified with a permanent hearing loss and their awareness of Early Hearing Detection and Intervention (EHDI) programs and enrollment into Early Intervention (EI).

"This publication was supported by funding from the U.S. Centers for Disease Control and Prevention (CDC). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of CDC or the Department of Health and Human Services."

CONTENTS

| | |
|---|----------|
| BACKGROUND/INTRODUCTION..... | 2 |
| METHOD | 3 |
| RESULTS..... | 3 |
| CONCLUSION | 6 |
| APPENDIX A – SURVEY QUESTIONS..... | 7 |

Hands & Voices

EHDI 1-3-6 Family Survey

CHILDREN WHO ARE DEAF OR HARD OF HEARING

BACKGROUND/INTRODUCTION

Early Hearing Detection and Intervention (EHDI) programs were designed to assure that all infants born in the United States and U.S. territories have access to hearing screening in the first month of life, diagnostics and identification no later than three months of age, and entry into Early Intervention (EI) no later than six months of age. Screening and confirmation that a child is D/HH are largely meaningless without appropriate, individualized, targeted, and high-quality intervention.¹ State/territory EHDI programs typically have access to information about which infants are diagnosed as D/HH, but often face challenges in confirming whether they actually entered into intervention services. Barriers include understanding and administration of complex privacy laws and regulations related to EHDI about sharing of information, requirement of documentation for parental permission before data may be shared between state agencies and programs.²

Hands & Voices (H&V) staff members Vicki Hunting and Janet DesGeorges initiated this survey to gather parent/caregiver feedback for children ages 0-5 that have been identified with a permanent hearing loss about awareness of state/territory EHDI Programs and enrollment into EI programs. This information will help us better serve those who are on the same path of raising a child who is deaf or hard of hearing. The questions we were trying to answer with this survey are specific to the following areas.

- Do families have a general awareness of EHDI 1-3-6 in state/territory EHDI systems?
- Do families understand the process steps from time of diagnosis to enrollment into EI?
- Were parents/caregivers asked to sign a consent for release (signed or verbally) of information (data) when enrolled into EI?
- Are families living in metro or rural settings?

¹ Christine Yoshinaga-Itano, Principles and Guidelines for Early Intervention After Confirmation That a Child Is Deaf or Hard of Hearing, *The Journal of Deaf Studies and Deaf Education*, Volume 19, Issue 2, April 2014, Pages 143–175, <https://doi.org/10.1093/deafed/ent043>

² National Center for Hearing Assessment and Management (NCHAM), The impact of Privacy Regulations, How EHDI, Part C & Health Providers can ensure that children & families get needed services, May 2008, <https://www.infantheating.org/privacy/docs/PrivacyWhitePaper.pdf>

METHOD

The survey was created based on review of existing resources specific to entry into EI and distributed via all H&V social media networks (Email, Facebook, Twitter, Blog) as well as to all previous National Early Childhood Assessment Project (NECAP)³ participants via email. H&V Chapters, Guide By Your Side (GBYS) & Advocacy, Support, and Training (ASTra) programs were encouraged to share the survey widely. Distributing the survey in this method limits the sample to families who use these social media sites and are connected to the organizations who posted the survey. There was no way to verify that the respondents actually met the desired criteria, i.e.; caregivers of children who are D/HH, and it is not possible to know if someone completed a survey more than once. In addition, due to the small sample size we do not consider this representative of the whole U.S and therefore the conclusions cannot be generalized to the whole U.S.

There were 124 total respondents to this survey from 31 different States/US territories/Jurisdictions. Not every participant answered every question. All information is aggregated, and the individual state responses are confidential.

The survey was open from May 25, 2017 to August 14, 2017. Our survey was targeted to children ages 0-5; 77.51% were in this age range and 22.5% of children were older than 5 years old. The results below include only the target age of 0-5. Numbers of some questions skipped some by respondents seemed high.

Most of the respondents (71.77%, N=89) were from an urban/city setting (50,000 or more population), 28.23% (n=35) indicated they lived in a rural setting (50,000 or less population).

When asked why they didn't enroll immediately into EI, one individual replied;
"We were told that Unilateral Hearing Loss didn't count for hearing loss in the state."

RESULTS

These results indicate parent/caregiver feedback for children ages 0-5 that have been identified with a permanent hearing loss about awareness of state/territory EHDI Programs and enrollment into EI programs. Thirty-six out of 160 respondents (22.5%) completing the survey indicated they had children over age 5, so these 36 respondents are not included due to age limits. Findings were consistent with what we believe we know or suspect to be the state of the understanding of parents/caregiver's awareness of this topic.

FAMILIES GENERAL AWARENESS OF EHDI 1-3-6 IN STATE/TERRITORY EHDI SYSTEMS

More respondents (67.97%) replied Yes, they remembered if they were contacted by a state/territory EHDI program, 20.39% indicated that No, they were not contacted and 11.65% could not remember.

Just over one-quarter of the respondents (28.43%, N=29) indicated Yes, they had heard of EHDI 1-3-6, and 71.57% (n=73) indicated that No they had not ever heard of EHDI 1-3-6. It was surprising that the number of those who had not heard of EHDI 1-3-6 was so high and indicates there are still opportunities to build awareness and increase marketing around this program and the resources and services available to families.

³ Christine Yoshinaga-Itano, NECAP: National Early Childhood Assessment Project – D/HH, <http://mdcresearch.net/index.php/necap/>

FAMILIES UNDERSTANDING OF THE PROCESS STEPS FROM TIME OF DIAGNOSIS TO ENROLLMENT INTO EARLY INTERVENTION

Many respondents (69.61%, n=71) indicated that Yes, someone did explain the next steps after their child did not pass newborn hearing screening (NBHS), 24.51% (n=25) indicated that no one had explained the next steps, 5.88% (n=6) didn't remember. It is encouraging that so many of the parents/caregivers had someone to explain the next steps.

Additionally, for those where someone did explain the next steps, 60.64% (n=57) indicated that the steps were clear to them, 34.04% (n=32) felt like the steps were not clear and they had to figure them out on their own, 5.32% (n=5) did not remember. Even though there was a fairly high percentage that indicated that the next steps were clear, there are still actions that can be taken to ensure information presented is clear and concise.

When asked if they remember if anyone from EHDl program talked to them about EI, 46.08% (n=47) replied Yes, they did talk about EI and 38.24% (n=39) indicated that no one talked to them about EI, 15.69% (n=16) did not remember.

Finally, when asked if their child "was/is" enrolled in an EI program in their state/territory, 87.10% (n=81) indicated they were.

It was great news to learn that when asked if their child "was/is" enrolled in an EI program in their state/territory, 87.10% (n=81) indicated yes, they were.

One individual's overall comment about their journey with EI;

"Our early intervention team changed our daughter's life for the better! We are so grateful for the early diagnosis AND the amazing team who came around our family to get our daughter the best care possible!"

PARENTS/CAREGIVERS ASKED TO SIGN A CONSENT FOR RELEASE (SIGNED OR VERBALLY) OF INFORMATION (DATA) WHEN ENROLLED INTO EI

It is important to note that not all states/territories require parents to provide consent to share data with other programs. Providing this consent to share data, either written or verbally varies widely between states and it is unclear why some require it and others do not. What are the rules or laws that exist in requiring it or not; are they covered by Memorandums of Understandings, Business Agreements between organizations that contain confidentiality statements or is it the function of public health and so a signed consent is not required? A high number of respondents to the questions on consent for release of information did not remember signing or providing verbal consent.

When asked if they signed an agreement or release of information form so that data could be shared with others to carryout referral services, just over half of respondents replied Yes (56.31%) they signed an agreement or release. Only 12.62% (n=13) indicated they did not sign a form, and 31.07% (n=32) could not remember if they signed such an agreement or release.

Almost half of respondents (48.91%, n=45) did not remember if their signed agreement was shared with the EHDl Program, 38.04% (n=35) indicated that Yes their agreement/release was shared with EHDl, and 13.04% (n=12) indicated that it was not shared with the EHDl program.

Almost three-fourths of the respondents (73.27%, n=74) indicated that they gave verbal permission to share their information with an EI provider, 9.90% (n=10) indicated they did not give verbal permission, and 16.83% (17) did not remember giving verbal consent.

Only 12.77% (n=12) of respondents indicated that they gave permission and that the EHDI 1-3-6 process was mentioned, and 41.49% (n=39) of the respondents indicated No it was not mentioned, 45.74% (n=43) indicated that they did not remember.

When asked who enrolled their child in EI, 50.00% (n=46) indicated that an EI provider contacted them, enrolled them and discussed next steps, 34.78% (n=32) indicated the family made the contact with EI to find out about services and next steps, only 1.09% (n=1) indicated they did not remember. Thirteen individuals (14.13%) indicated another way they were enrolled in EI. Some of those ‘Other’ free-form answers included; someone enrolled their child, but they never knew about it, they were not in EI due to ineligibility (unilateral), foster parents (timing), prematurity, providers not familiar with D/HH, late diagnosis, age of child.

Most respondents (63.44%, n=59) indicated that Yes the diagnosing audiologist referred them to a place or person that provides EI supports, 29.03% (n=27) indicated that the audiologist did not refer them, 7.53% (n=7) did not remember.

Over half of respondents (58.11%, n=43) enrolled immediately into Early Intervention. When asked why they didn’t immediately enroll, just under one quarter did not know how or where to get services. This lack of knowledge could be targeted by EI education of audiology providers about referral processes and EI marketing activities. Of those that chose the ‘Other’ as their response, 22.97% (n=17) their free-form answers included that; they didn’t know about it, weren’t referred due to mild loss, age/late diagnosis, other health concerns, ineligible, PCP told to disregard NB hearing screening, passed at 6 weeks old after failing NBHS 13 times in hospital, missed, NICU baby, parent denial of loss.

| Answer Choices (check all that apply) | Responses | |
|---|---------------|-----------|
| Not applicable – we enrolled immediately | 58.11% | 43 |
| Other (please Specify) | 22.97% | 17 |
| We did not know how or where to get services | 17.57% | 13 |
| There was a mix-up in the system and information was not sent to the right people | 8.11% | 6 |
| We chose to wait to see how our child was doing | 6.76% | 5 |
| There were no available services and/or there was a waiting list | 1.35% | 1 |
| Financial reasons (sorting out how the services would be paid for, etc.) | 1.35% | 1 |
| We did not want any of the available options in our area | 0.00% | 0 |
| Total (50 Skipped) | | 86 |

When asked why they didn’t enroll immediately into EI, one individual replied;
“Audiologist chose not to refer because she was only a “mild” hearing level.”

CONCLUSION

While Newborn Hearing Screening/EHDI programs have been in existence for almost twenty years, there is still work to be done from the parent/caregiver perspective around promoting awareness and understanding of EHDI and EI programs and their role in the journey for children identified with a permanent hearing loss. Responses clearly indicate that improvements are needed to:

- ensure clear communication between providers and families about next steps after a did not pass result,
- where to find diagnostic audiology specializing in infants and who to contact with questions
- educate system stakeholders working with D/HH children on eligibility and the importance of EI, D/HH children are considered to be Children and Youth with Special Health Care Needs (CYSHCN)
- educate and promote awareness among providers in local communities on their role in ensuring D/HH children's receipt of time-sensitive services and resources
- educating families about the EHDI 1-3-6 process and local resources available to them
- increase parental consent to have their child's data shared with EI when required

APPENDIX A – SURVEY QUESTIONS

EHDI 1-3-6 and Early Intervention Survey

Thank you for agreeing to take part in this important survey gathering parent/caregiver feedback about awareness of state/territory Early Hearing Detection and Intervention (EHDI) Programs and enrollment into Early Intervention (EI) programs. The information you provide will help us better serve you and others who are on the same path of raising a child who is deaf or hard of hearing. This survey should only take 3-5 minutes to complete. Be assured that all answers you provide will be kept in the strictest confidentiality.

If your child is 0-5 years old and has been identified with a permanent hearing loss, then please click “NEXT” to continue.

1. **What state or US Territory did you live in when your child was diagnosed with a hearing loss?**
 - a. Pulldown list of all states/territories
2. **Would you say that you live in a mostly urban/city setting or more rural/small town setting?**
 - a. Rural – 50, 000 or less
 - b. Urban – 50, 000 or more population
3. **How old is your child?**
 - a. birth through 2 years old
 - b. 3 - 5 years old
 - c. Older than 5 years old

Early Hearing Detection and Intervention (EHDI) programs work to ensure newborns have their hearing screened no later than ONE month of age, if they do not pass the screening then diagnosis is confirmed no later than THREE months of age, and those identified with a permanent hearing loss are referred and enrolled in Early Intervention no later than SIX months of age (EHDI 1-3-6). EHDI programs are sometimes housed within the state Department of Public Health, Department of Education, or University settings. Typically, once a child has been diagnosed with a permanent hearing loss, information about the hearing loss and family contact information is shared with other state agencies (Early Intervention, EHDI Programs) for ensuring follow-up.

4. **Do you remember if you were ever contacted by a state/territory EHDI program?**
 - a. Yes
 - b. No
 - c. I don't remember
5. **Did you sign an agreement or release of information form so that data about your child could be shared with others to carry out referral services?**
 - a. Yes
 - b. No
 - c. I don't remember
 - i. If yes, do you recall if the information was shared with the EHDI program?
 1. Yes
 2. No
 3. I don't remember
6. **Did you give permission verbally that it was okay to share your information (contact info) with an Early Intervention provider?**
 - a. Yes
 - b. No
 - c. I don't remember
 - i. If yes, was the EHDI 1-3-6 process mentioned?
 1. Yes
 2. No

3. I don't remember

7. Have you ever heard of EHDI 1-3-6?

- a. Yes
- b. No

8. At any time during your journey did anyone explain the process (next steps) after your child did not pass the newborn hearing screening?

- a. Yes
- b. No
- c. I don't remember

i. If yes, were the steps clear to you?

- 1. Yes
- 2. No, I had to figure them out on my own
- 3. I don't remember

9. Do you remember if anyone from the EHDI Program talked to you about EI?

- a. Yes
- b. No
- c. I don't remember

The next questions are asking about how your child got into Early Intervention (EI). *EI* is a system of services that helps babies and toddlers with developmental delays or disabilities. Early intervention focuses on helping eligible babies and toddlers learn the basic and brand-new skills that typically develop during the first three years of life. Early Intervention in your state may go by a different name.

10. Was/Is your child enrolled in an EI Program in your state/territory?

- a. Yes
- b. No
- c. I don't know

11. Our Child was enrolled in Early Intervention...

- a. By an Early Intervention provider who contacted us to enroll in services and discuss next steps
- b. We contacted Early Intervention ourselves to find out about services and next steps
- c. I don't remember
- d. Other (please describe):

12. Our child's diagnosing audiologist referred us to a person/place that provides EI supports.

- a. Yes
- b. No
- c. I don't remember

13. If you didn't enroll immediately into Early Intervention, why was that? (check all that apply)

- a. Not applicable – we enrolled immediately
- b. We chose to wait to see how our child was doing
- c. There were no available services and/or there was a waiting list
- d. There was a mix-up in the system and information was not sent to the right people
- e. We did not know how or where to get services
- f. We did not want any of the available options in our area
- g. Financial reasons (sorting out how the services would be paid for, etc.)
- h. Other (please describe)

Thanks for taking the time to answer our questions.

If you are interested in participating in future/follow-up surveys or being included in a drawing for a Starbucks or Target gift card, please include your email address:

Use the links below for more information about:

- Center for Disease Control, free Hearing Loss materials - <https://www.cdc.gov/ncbddd/hearingloss/freematerials.html>
- State/territory EHDI Programs: http://www.infanthearing.org/states_home/
- Early Intervention: <https://www.healthychildren.org/English/health-issues/conditions/developmental-disabilities/Pages/Early-Intervention.aspx>