

Swaddling Ear to Ear - Conceptualizing and supporting early intervention enrollment

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Disclosures

Torri Ann Woodruff-Gautherin

- Salaried position at UConn
- Working on grant from NIH
- Grant from EAA for work
- Board member CT Hands & Voices
- Co-chair CT EHDI Taskforce

Kathleen Cienkowski

- Salaried position at UConn
- Discipline Coordinator UCONN LEND
- Co-PI UCONN Audiology LEND Supplement Grant

Emily LaSpada



Intentions



Outline the barriers to early intervention access for families and children who are D/deaf and hard of hearing



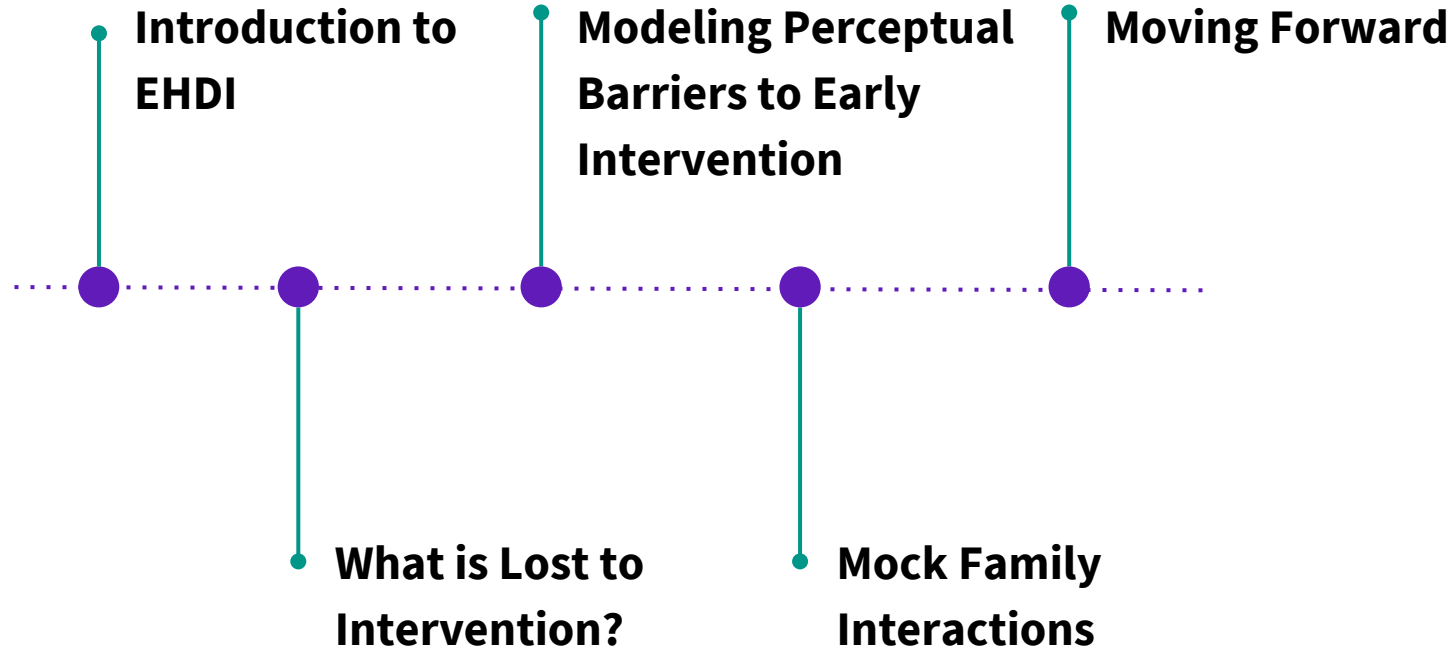
Describe the methodology of Swaddling Ear to Ear to support family decision making



Compare your clinical practice with the recommended procedures of Swaddling Ear to Ear



Agenda



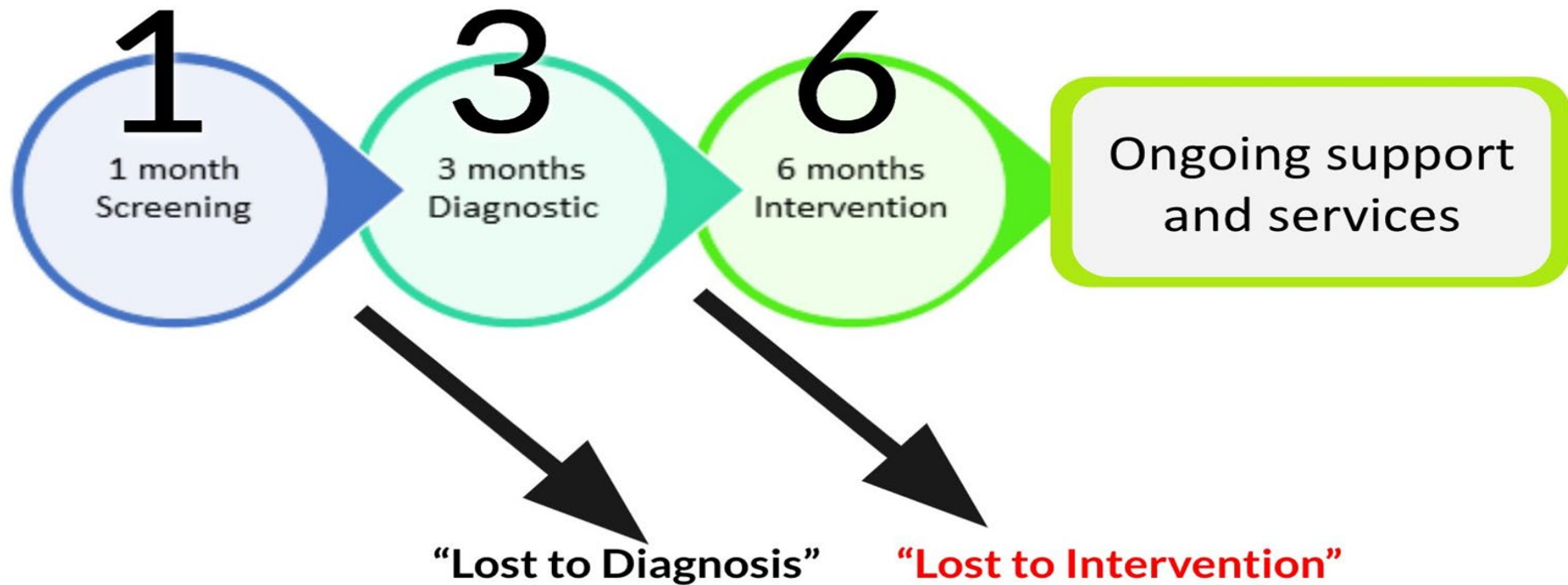
Introduction to EHDI

Just a foundation on guiding principles for OUR group

- What is the requirements of the system?
- How is screening done?
- How is identification done?
- How is intervention done?

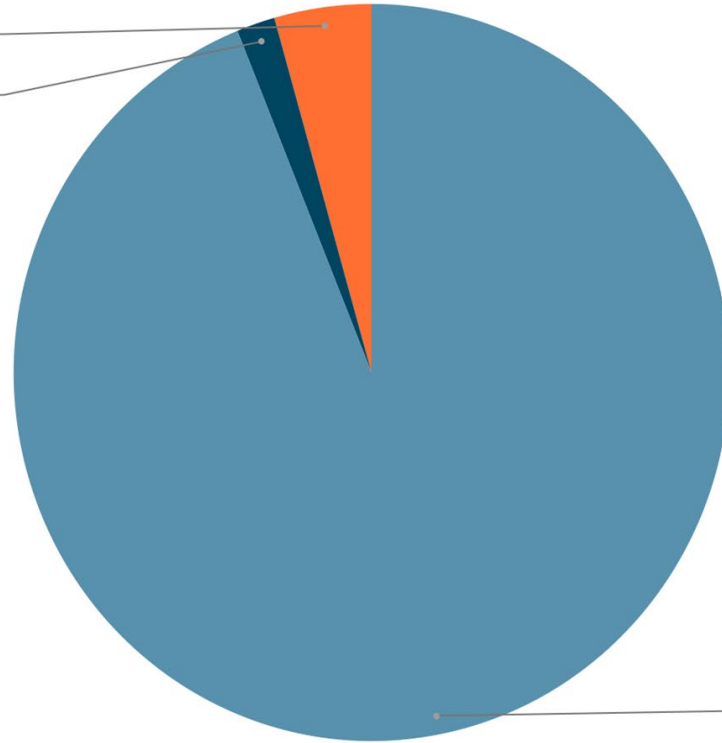


What are the guiding principle of the system?



How is screening done for the 3,573,446 births reported to EHDI?

Not screened
4.4%
Child required
1.7%



Passed the screening
93.9%

All data is publicly accessible from the CDC



How is identification done for the 63,570 children who refer on the screening?

Missing data
42.4%

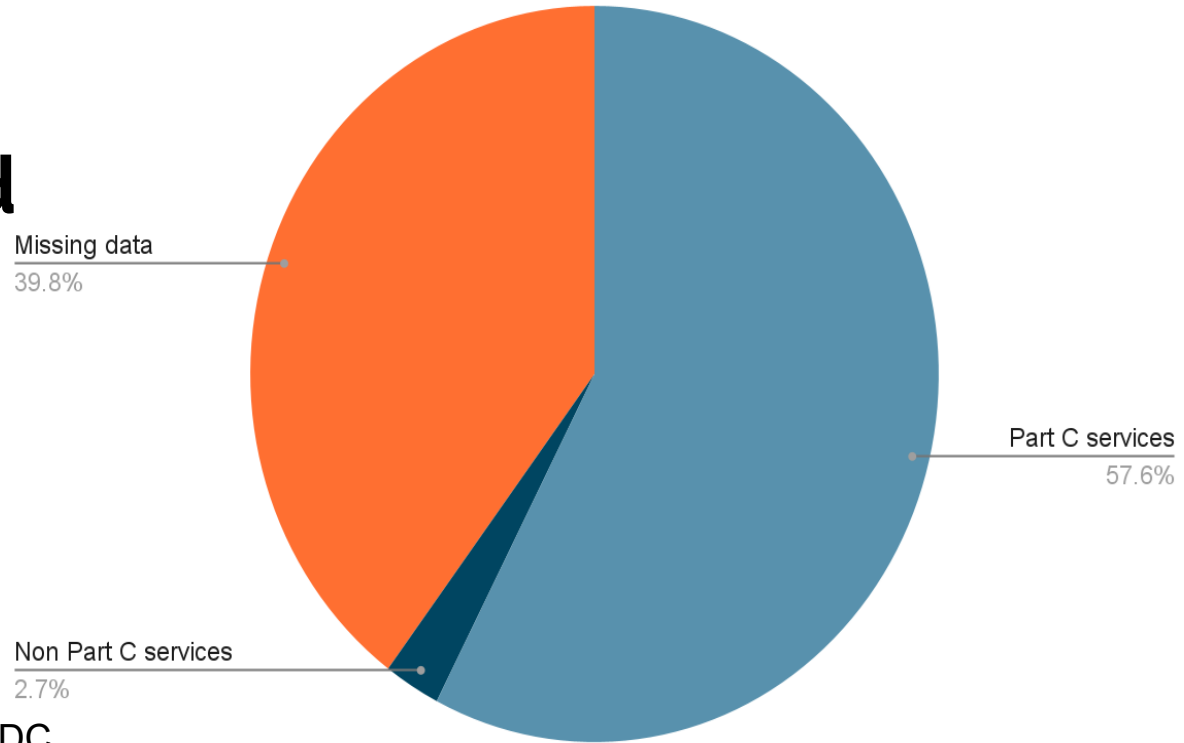
Hearing in the
47.4%

D/deaf or hard of
10.3%

All data is publicly accessible from the CDC



How is intervention done for the 6,518 children identified as D/deaf and hard of hearing?



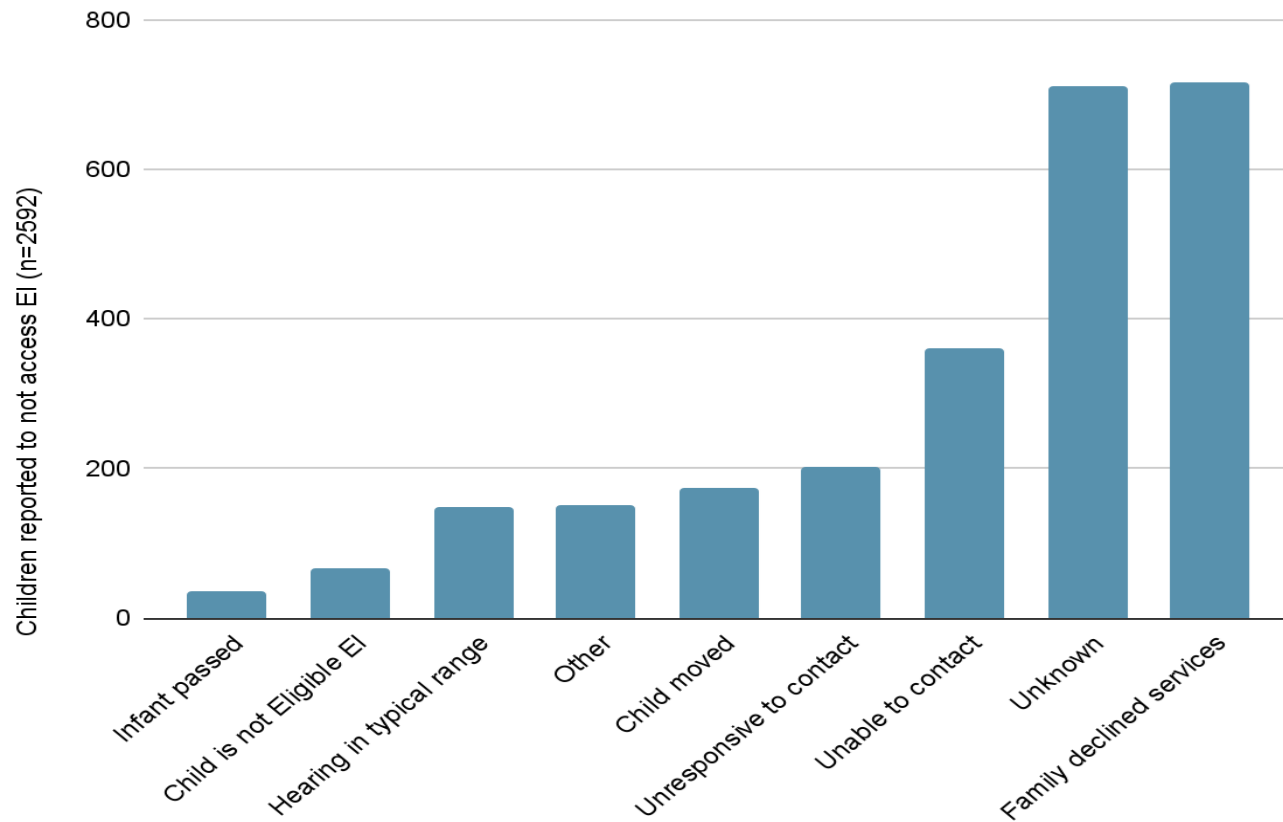
All data is publicly accessible from the CDC



What is Lost to Intervention?

- CDC Statistics
- Why is this a concern?





All data is publicly accessible from the CDC

Reason for not accessing EI

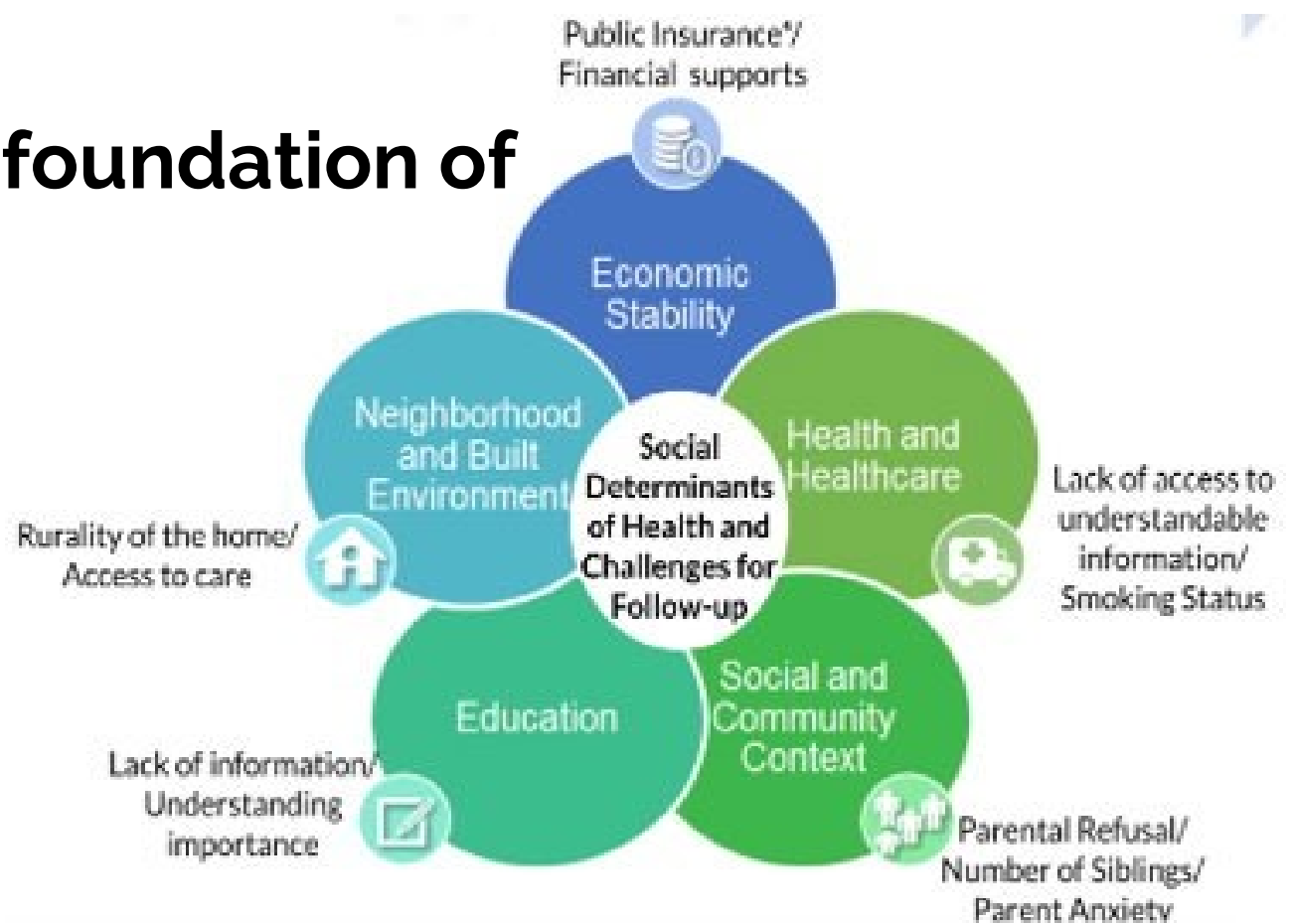


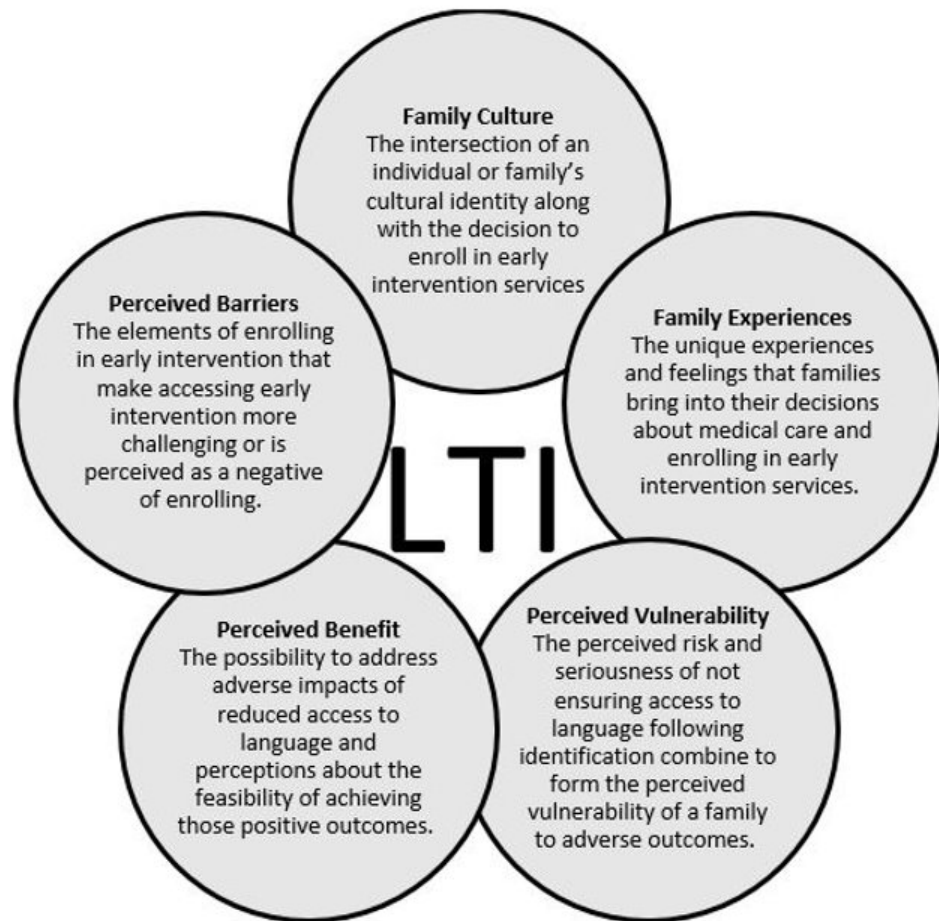
Modeling Perceptual Barriers to Early Intervention

- What is the foundation of this work?
- How was this done?
- What are the factors?
 - Family Culture
 - Family Experience
 - Perceived Vulnerability to Negative Sequelae
 - Perceived Benefits of Early Intervention
 - Perceived Barriers to Early Intervention



What is the foundation of this work?





Mock Interactions

- English
 - Recording
 - Materials
- Spanish
 - Materials



Performance objective	Determinants				
	Family Culture	Family Experience	Perceived Vulnerability	Perceived Benefit	Perceived Barriers
Attain results from diagnostic appointments before child is six months of age	<p>Describe family experience with hearing - views on etiology of hearing differences and hearing status of all members of the family and with individuals who are D/deaf and hard of hearing</p> <p>Explain the language used in the home and describe how to request interpretation services</p>	<p>Describe family experience with hearing - views on etiology of hearing differences and hearing status of all members of the family and with individuals who are D/deaf and hard of hearing</p> <p>Connect experiences with strengths-based observations provided from other families</p> <p>Match the job title of common EI providers with their general job descriptions, roles, skills, and value of involvement</p>	<p>Explain the importance of developmental needs and the impact of delayed intervention/language deprivation.</p> <p>Demonstrate the ability to interpret their child's audiogram including type, configuration, and recommendations</p>	<p>Match the job title of common EI providers with their general job descriptions, roles, skills, and value of involvement</p>	<p>Identify what logistical supports will be needed to meet needs - State that EI services are provided at little to no cost for families. List services to help meet needs associated with traveling to this meeting, such as gas card programs List potential funding opportunities for assistive technology. Identify funding sources to support diagnostic services (including insurance, assistance programs, payment plans, and state laws related to cost). List friends and family members that will be able to come with you to the meeting, help drive, babysit other children, or provide other supports during evaluations</p> <p>State the expectation that they will have questions during and after appointments</p> <p>Demonstrate the ability to interpret their child's audiogram including type, configuration, and recommendations</p> <p>State the EHDI guidelines for timely follow up (1-3-6)</p> <p>Request take home materials on topics covered</p>



Performance objective	Determinants				
	Family Culture	Family Experience	Perceived Vulnerability	Perceived Benefit	Perceived Barriers
Schedule evaluation appointments for the child with relevant CT EI before the child is six months of age	<p>Explain the language used in the home and describe how to request interpretation services</p> <p>Describe the unique role of each person in the family as it relates to the EI process</p>	Match the job title of common EI providers with their general job descriptions, roles, skills, and value of involvement	<p>State that their child is at risk for language deprivation as a result of their hearing levels, if not addressed thought intervention.</p> <p>Demonstrate record keeping by retaining notes from the call with EI and appointments in a dedicated handbook.</p> <p>List the benefits of EI compared to not accessing services.</p>	<p>Match the job title of common EI providers with their general job descriptions, roles, skills, and value of involvement</p> <p>Describe the EI services that families of children who are identified as D/deaf or hard of hearing are legally entitled to through Part C of IDEA. including, clinical service provision, family support, language acquisition, and family benefits</p>	<p>Locate a list of EI providers in the state in the same town or county as the family.</p> <p>Demonstrate record keeping by retaining notes from the call with EI and appointments in a dedicated handbook.</p> <p>Demonstrate the ability to interpret their child's audiogram including type, configuration, and recommendations</p>
Attend evaluation appointments with CT EI providers before the child is six months of age	<p>Explain the language used in the home and describe how to request interpretation services</p> <p>Describe the unique role of each person in the family as it relates to the EI process</p> <p>Match the job title of common EI providers with their general job descriptions, roles, skills, and value of involvement</p> <p>State the expectation that all families of newborns have hectic homes and this is expected by EI staff</p>	<p>Express confidence in ability to discuss child's development, needs, recommendations and current concerns of families and providers.</p> <p>Match the job title of common EI providers with their general job descriptions, roles, skills, and value of involvement</p> <p>State the expectation of having to travel to or have providers come into the home for these evaluations.</p> <p>List local family support services available in their town or county.</p> <p>State the expectation that all families of newborns have hectic homes and this is expected by EI staff</p>	<p>Explain the importance of developmental needs and the impact of delayed intervention/language</p> <p>State that their child is at risk for language deprivation as a result of their hearing levels, if not addressed thought intervention.</p> <p>State the EHDI guidelines for timely follow up (1-3-6)</p> <p>Match the job title of common EI providers with their general job descriptions, roles, skills, and value of involvement</p>	<p>Match the job title of common EI providers with their general job descriptions, roles, skills, and value of involvement</p> <p>Describe the EI services that families of children who are identified as D/deaf or hard of hearing are legally entitled to through Part C of IDEA. including, clinical service provision, family support, language acquisition, and family benefits</p>	<p>State the expectation of having to travel to or have providers come into the home for these evaluations.</p> <p>Identify what logistical supports will be needed to meet needs</p> <p>State the expectation that all families of newborns have hectic homes and this is expected by EI staff</p> <p>List local family support services available in their town or county.</p>



Performance objective	Determinants				
	Family Culture	Family Experience	Perceived Vulnerability	Perceived Benefit	Perceived Barriers
Receive results from evaluations before the child is six months of age	<p>Explain the language used in the home and describe how to request interpretation services</p> <p>Compare and contrast all language modes and their applications to the family</p>	<p>State that their child is at risk for language deprivation as a result of their hearing levels, if not addressed thought intervention.</p> <p>Match the job title of common EI providers with their general job descriptions, roles, skills, and value of involvement</p>	<p>Explain the importance of developmental needs and the impact of delayed intervention/language</p> <p>State that their child is at risk for language deprivation as a result of their hearing levels, if not addressed thought intervention.</p> <p>Match the job title of common EI providers with their general job descriptions, roles, skills, and value of involvement</p>	<p>Match the job title of common EI providers with their general job descriptions, roles, skills, and value of involvement</p>	<p>State the expectation that they will have questions during and after appointments</p> <p>Identify what logistical supports will be needed to meet needs</p> <p>Request take home materials on topics covered</p>
Schedule IFSP meeting with CT EI providers before the child is six months of age	<p>Explain the language used in the home and describe how to request interpretation services</p> <p>Describe the unique role of each person in the family as it relates to the EI process</p>	<p>Identify what logistical supports will be needed to meet needs</p> <p>State the expectation that this meeting will be scheduled at a time that works for the families.</p> <p>State that without an IFSP meeting, their child cannot enroll in EI.</p>	<p>List the benefits of EI compared to not accessing services.</p>	<p>State the expectation that this meeting will be scheduled at a time that works for the families.</p> <p>Describe the EI services that families of children who are identified as D/deaf or hard of hearing are legally entitled to through Part C of IDEA. including, clinical service provision, family support, language acquisition, and family benefits</p>	<p>Identify what logistical supports will be needed to meet needs</p> <p>Demonstrate record keeping by retaining notes from the call with EI and appointments in a dedicated handbook.</p>



Performance objective	Determinants				
	Family Culture	Family Experience	Perceived Vulnerability	Perceived Benefit	Perceived Barriers
Consent to a referral to CT EI before the child is six months of age	<p>Explain the language used in the home and describe how to request interpretation services</p> <p>Describe the unique role of each person in the family as it relates to the EI process</p>	<p>State that EI will only contact them/provide services if they provide consent</p> <p>State that their child is at risk for language deprivation as a result of their hearing levels, if not addressed thought intervention.</p>	<p>Explain the importance of developmental needs and the impact of delayed intervention/language</p> <p>State that their child is at risk for language deprivation as a result of their hearing levels, if not addressed thought intervention.</p>	<p>Describe the EI services that families of children who are identified as D/deaf or hard of hearing are legally entitled to through Part C of IDEA. including, clinical service provision, family support, language acquisition, and family benefits</p>	<p>Diagram the number of different steps of EI referral. Identify what logistical supports will be needed to meet needs - State that EI services are provided at little to no cost for families. List services to help meet needs associated with traveling to this meeting, such as gas card programs List potential funding opportunities for assistive technology. Identify funding sources to support diagnostic services (including insurance, assistance programs, payment plans, and state laws related to cost). List friends and family members that will be able to come with you to the meeting, help drive, babysit other children, or provide other supports during evaluations</p>
Respond/Answer attempts to connect from CT EI before the child is six months of age	<p>Explain the language used in the home and describe how to request interpretation services</p> <p>Describe the unique role of each person in the family as it relates to the EI process</p>	<p>Express confidence in ability to discuss child's development, needs, recommendations and current concerns of families and providers.</p> <p>List the different ways that EI may contact the families.</p> <p>Add the state hotline for EI referral to phone or address book</p> <p>State that their child is at risk for language deprivation as a result of their hearing levels, if not addressed thought intervention.</p>	<p>State that their child is at risk for language deprivation as a result of their hearing levels, if not addressed thought intervention.</p> <p>Demonstrate record keeping by retaining notes from the call with EI and appointments in a dedicated handbook.</p> <p>Add the state hotline for EI referral to phone or address book</p>	<p>Describe the EI services that families of children who are identified as D/deaf or hard of hearing are legally entitled to through Part C of IDEA. including, clinical service provision, family support, language acquisition, and family benefits</p>	<p>State the expectation of having to make calls to follow up with EI.</p> <p>State that EI will only contact them/provide services if they provide consent</p> <p>Demonstrate record keeping by retaining notes from the call with EI and appointments in a dedicated handbook.</p> <p>Add the state hotline for EI referral to phone or address book</p> <p>Match the job title of common EI providers with their general job descriptions, roles, skills, and value of involvement</p>



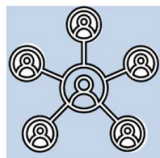
Performance objective	Determinants				
	Family Culture	Family Experience	Perceived Vulnerability	Perceived Benefit	Perceived Barriers
Attend IFSP meeting with CT EI providers by the time the child is six months of age	<p>Explain the language used in the home and describe how to request interpretation services</p> <p>Describe the unique role of each person in the family as it relates to the EI process</p> <p>Compare and contrast all language modes and their applications to the family</p> <p>Identify what logistical supports will be needed to meet needs - State that EI services are provided at little to no cost for families. List services to help meet needs associated with traveling to this meeting, such as gas card programs List potential funding opportunities for assistive technology. Identify funding sources to support diagnostic services (including insurance, assistance programs, payment plans, and state laws related to cost). List friends and family members that will be able to come with you to the meeting, help drive, babysit other children, or provide other supports during evaluations</p>	<p>Express confidence in ability to discuss child's development, needs, recommendations and current concerns of families and providers.</p> <p>Describe the EI services that families of children who are identified as D/deaf or hard of hearing are legally entitled to through Part C of IDEA. including, clinical service provision, family support, language acquisition, and family benefits</p> <p>State the expectation that the families will be able to ask for specific services to support themselves and their child.</p> <p>State the expectation of having to travel to or have providers come into the home for this meeting. -</p>	<p>Explain the importance of developmental needs and the impact of delayed intervention/language deprivation.</p>	<p>State the expectation that the families will be able to ask for specific services to support themselves and their child.</p> <p>State that the family is the most important component of the EI system while working to ensure that children who are D/deaf or hard of hearing do not experience language deprivation.</p>	<p>State the expectation of having to travel to or have providers come into the home for this meeting.</p> <p>Identify what logistical supports will be needed to meet needs - State that EI services are provided at little to no cost for families. List services to help meet needs associated with traveling to this meeting, such as gas card programs List potential funding opportunities for assistive technology. Identify funding sources to support diagnostic services (including insurance, assistance programs, payment plans, and state laws related to cost). List friends and family members that will be able to come with you to the meeting, help drive, babysit other children, or provide other supports during evaluations</p>



English Website



QR Code to
English Website



Welcome to the community of
families with children who are
D/deaf and hard of hearing!

You will meet lots of people on
your journey

- Audiologist - hearing
- Pediatricians - health
- Hearing screeners - first test



Your baby
can get
support

Reach out within a week of your
hearing test (even if it isn't fully done)

Call 211 - add to your phone!

(800)505-7000

www.birth23.org

ANYONE CAN DO THIS

You are in
control and
pick services

Call 211

People are
here to help
you and your
baby learn at
no cost

Our Family To Do List

1 Call 211

2 Know your goals

3 Answer the calls

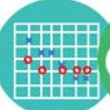


Audiograms try and show us
about listening

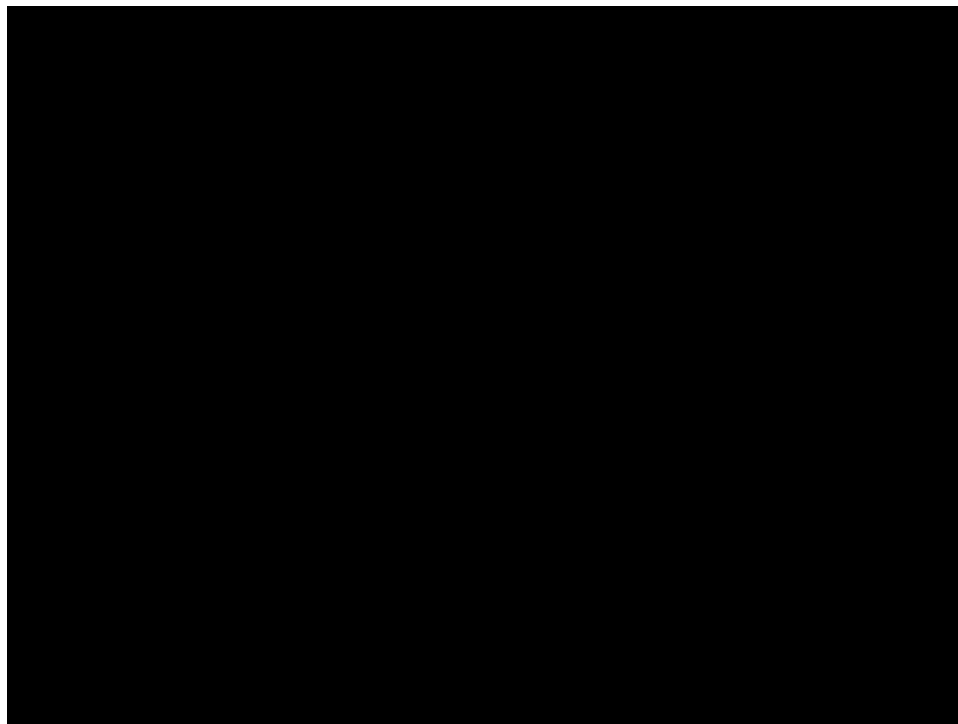
- Only sounds below the lines are heard
- The audiogram shows us what is heard, but learning language is about understanding
- You will have more than one audiogram

Your family understanding and
being comfortable is the most
important

- Ask questions, no one expects you to remember it all or understand first try
- Handouts can be a good way to help understand



English Mock Interaction



Spanish Website



QR Code to
Spanish Website

Resultados del examen de audición



¡Le damos la bienvenida a la comunidad para familias con niños sordos o con dificultades auditivas!

Conocerá a muchas personas en el camino

- Audiólogo – audición
- Pediatras – salud
- Evaluadores de audición – primer examen



Los audiogramas intentan mostrarnos la audición

- Solo se oyen los sonidos por debajo de las líneas
- El audiograma nos muestra lo que se oye, pero aprender idiomas consiste en comprender
- Se realizará más de un audiograma

Lo más importante es que su familia comprenda y se sienta cómoda

- Haga preguntas, nadie espera que lo recuerde todo o que lo entienda a la primera
- Los folletos pueden ser una buena forma de ayudarlo a entender



Su bebé puede recibir apoyo

Comuníquese con los servicios de intervención temprana de CT en un plazo de una semana luego de los exámenes auditivos, incluso si aún no los ha finalizado todos.

Llame al 211, ¡agréguelo a sus contactos!

(800)-505-7000

www.birth23.org

CUALQUIERA PUEDE HACERLO

Usted tiene el control y puede escoger los servicios

Llame al 211

Hay gente que le ayudará a usted y a su bebé a aprender sin coste alguno

Nuestra lista de pasos a seguir como familia

- 1 Llamar al 211
- 2 Conocer sus objetivos
- 3 Responder las llamadas



Moving Forward

- Family Culture
- Family Experience
- Perceived Vulnerability to Negative Sequelae
- Perceived Benefits of Early Intervention
- Perceived Barriers to Early Intervention
- Ongoing Research



How do we address this?


Implementation Science

Community Engagement

Funding

Translation

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Is your child D/deaf
or hard of hearing?

Are you interested in being a part
of hearing-related research?

Join the
HELLO Lab
participant
pool for
personalized
invitations



Primary Investigator: Derek Houston derek.houston@uconn.edu

UConn



HELLO Lab
HEARING EXPERIENCE LANGUAGE LEARNING OUTCOMES
UNIVERSITY OF CONNECTICUT



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