



# The Role of the Utah EHDI Parent Consultants: A Day in the Life

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**Rachel Hyde, B.S. & Heather Adams**  
EHDI Parent Consultants

**Stephanie Browning McVicar, Au.D., CCC-A**  
EHDI Director

# Disclosure



The content of this presentation does not relate to any product of a commercial entity, therefore the presenters have no relationships to report.

# HRSA-17-059



## Universal Newborn Hearing Screening and Intervention Program

- Address the importance of families!
- Develop formal partnerships with statewide, family-based organizations to provide family support to families/parents/caregivers of infants who are D/HH



# HRSA-17-059



Universal Newborn Hearing Screening and Intervention Program

**Develop collaborative leadership skills for members of family organizations that support infants and children who are deaf or hard of hearing**



# HRSA-17-059



## Universal Newborn Hearing Screening and Intervention Program



The mission of the Utah Parent Center (UPC or Center) is to **help parents** help their children, youth and young adults with all disabilities to live included, productive lives as members of the community. We accomplish our mission **by providing accurate information, empathetic peer support, valuable training and effective advocacy** based on the concept of **parents helping parents**.

# HRSA-17-059



## Universal Newborn Hearing Screening and Intervention Program



A *Family To Family* Health Information Center

Utah Family Voices was started as a volunteer effort in 1993, in partnership with our National Family Voices network [www.familyvoices.org](http://www.familyvoices.org), as a way of **helping to advocate for and assist families in navigating and accessing health care and family support services that are family-centered and culturally appropriate for all children and youth with special needs.** Families of children and youth with special health care needs and disabilities (**CYSHCN**) are the center of any system of care and are the necessary voices to help ensure safety and wellness to not only survive but thrive in home and community settings.

# Hiring



## GENERAL JOB SUMMARY:

As an employee of the Utah Parent Center (UPC or Center), works from the EHDI office at the Utah Bureau of Children with Special Health Care Needs and/or the Center's main office in Salt Lake City as a neutral party to assist parents of children who have been newly diagnosed as deaf or hard of hearing; works with parents and others individually and **provides information and peer support to parents** to help them work effectively with relevant providers and other agencies or organizations serving children who are deaf or hard of hearing to obtain services, resolve concerns, and **identify programs and services to meet the needs of their children and/or family**; helps parents gain the necessary skills to build effective partnerships with early intervention and professionals; **provides training and materials** for parents and professionals; provides information and referral to various agencies and service providers; **Serves as a parent representative on system-level committees** and any other duties as assigned; receives ongoing training, **including UPC staff meetings and professional trainings and conferences.**

# The Utah EHDI Team



Stephanie B. McVicar, Au.D.  
Program Manager



Krysta Badger, B.S.  
EHDI Data Coordinator



Jill Boettger, M.S.  
CMV Coordinator



Jenny Pedersen, Au.D.  
CHAP Coordinator



Shannon Wnek, Au.D.  
Audiology & Compliance  
Coordinator



Emma Thompson, M.S.  
Health Program Specialist



VACANT  
Follow-Up Coordinator



Heather Adams  
UPC Parent Consultant



Rachel Hyde, B.S.  
UPC Parent Consultant



Gina Pola-Money  
UFV Director/EHDI







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# EHDI Parent Consultants



EHDI Parent Consultant: Rachel Hyde, B.S.



RACHEL

[ehdiparents@utah.gov](mailto:ehdiparents@utah.gov)

[rahde@utah.gov](mailto:rahde@utah.gov)

(801) 584-8241



EHDI Parent Consultant: Heather Adams



HEATHER

[ehdiparents@utah.gov](mailto:ehdiparents@utah.gov)

[haadams@utah.gov](mailto:haadams@utah.gov)

(801) 584-0495



# Parent Consultant



UTAH DEPARTMENT OF  
**HEALTH**



Rachel Hyde

# Social Media




Utah EHD Family Support and Information

Secure | [https://www.facebook.com/utahehdi/?view\\_public\\_for=119634998711951](https://www.facebook.com/utahehdi/?view_public_for=119634998711951)

Utah EHD Family Support and Information

Rachel Home



Utah DEPARTMENT OF HEALTH  
Early Hearing Detection & Intervention

Utah EHD Family Support and Information  
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Utah EHD Family Support and Information  
February 19 at 8:20am · 🌐

Take a look at our 2018 Parent WebinEAR schedule! It's going to be a great year!  
Comment below and tell us which webinEAR you are most looking forward to 🗳️🗳️🗳️🗳️



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# Parent V

# Introducing:

UTAH DEPARTMENT OF  
**HEALTH**

parent

a facebook live series for far

# parent webinEARS

a webinar series for parents with deaf or hard-of-hearing children

Please join the 2nd Tuesday of each month as we explore a variety of topics related to our deaf and hard-of-hearing children. Tune in this January for the launch of our first webinEAR!

• **January 9th, 2018 1-1:30pm** •

**Testing, Testing, 123:** A discussion about the different types of hearing tests and what you can expect from them

Presented by: Stephanie McVicar, Au.D., CCC-A

To Access this WebinEAR:

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Tune in at 1 pm and join us as we go 'live'

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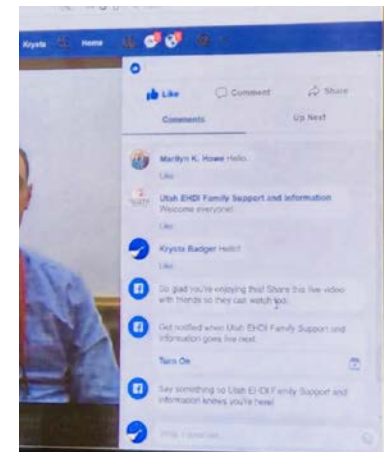


to request ADA accommodations please e-mail  
[ehdiparents@utah.gov](mailto:ehdiparents@utah.gov) by Jan. 5th

Tuesday  
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Advisory Board  
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personal contacts



January 9th: |

February 13th: |

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November 13th: Incl

December 11th: Liv

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# Contacting Families



UTAH DEPARTMENT OF  
**HEALTH**

Date	Type of Call	Child's Name	Child's Age	Child's (Who)	Was contact m	Did Parents Call B	How was	length of c	Was a text Sent?	Did they	What was discussed?	Contact Conclusion	Follow-Up
9/19/2017	Need Outpatient Screening		14 months old	Male	Mom	Yes	N/A	Telephone	< 10 minutes		Concerns addressed: finances, distance from testing	mom agreed to schedule additional testing	Called Mom back. Did not go in for further testing, doesn't plan to
9/19/2017	Needs DiABR		2 months old	Female	Mom	No	Yes	Telephone	> 5 min		Needed a follow-up ABR after mom had canceled an all	Left VM, provided ehdparents e-mail address	Mom called back, and refused to do any additional testing
9/19/2017	Needs DiABR		14 months old	Female	Mom	No	Yes	Telephone	> 5 minutes		Baby needed a follow-up ABR	Left VM, provided ehdparents e-mail address	Called mother again, and refused to do any additional testing
9/20/2017	Needs DiABR		13 months old	Male	Mom	Yes	N/A	Telephone	< 10 minutes		Concerns addressed: finances, schedule, importance o	Sent mom e-mail with ABR resources, mom agreed to read and follow up with me	Called mother again, reached her. Baby is now 18 months, is regul
9/20/2017	Needs Outpatient Screening		11 months old	Male	Dad	Yes	N/A	Telephone	> 5 minutes		Dad wants us to contact mom however, mom works ur	mom would contact us at ehdparents e-mail	**12/7/17 Mom hasn't followed up
9/21/2017	Needs DiABR		2 months old	Female	Mom	No	N/A	Telephone	N/A	Yes-11/9/17	**11/9/17 sent mom a text asking if she had follow-up hea	Left VM, provided ehdparents e-mail address	**11/9/17 Mom tested me back, saying she is working with an ENT
9/21/2017	Needs DiABR		2 months old	Male	Mom	Yes	N/A	Telephone	< 5 minutes	ges-12/4/2018	Too busy to make follow up call- stressed importance c	mom agreed to schedule additional testing	**12/8/17 Mom hasn't followed up
2/28/2018			7 months old	Male	Mom	Yes	N/A	Telephone	< 5 minutes		Called to see if she had gone back to Dr. Kingston's off	Mom went in a couple weeks ago but baby was	Mom has a follow-up appointment next week, and they are plannin
9/21/2017	Needs DiABR		2 months old	Male	Mom	Yes	N/A	Telephone	< 5 minutes	ges-12/7/17	Checked-in to ensure follow up testing was scheduled	DiABR was already scheduled for the end of th	Mom never went in for appointment
2/28/2018			7 months old	Male	Mom	No	N/A	Telephone	< 5 minutes		Left Mom VM asking if she was able to schedule that ABR-provided all my info		
9/21/2017	Needs DiABR		3 months old	Male	Mom	No	N/A	Telephone	N/A	ges-1/24/18	Left VM, provided ehdparents e-mail address		
9/22/2017	Support Call		4 months old	Male	Mom	Yes	N/A	Telephone	> 5 minutes		General support (discussed diagnosis), Explained EI an	Mom felt fine about diagnosis, no concerns, was given ehdparents e-mail	
9/25/2017	Support Call		15 months old	Female	Mom	Yes	N/A	Telephone	< 5 minutes		General support, mom is enrolled in EI, baby has trach a	I will follow up via e-mail with mom providing an	E-mail Sent: ASL learning resource list
9/26/2017	Support Call		5 months old	Male	Mom	No	no	Telephone	N/A				kiddo was fitted with HA through CHAP and is enrolled in EI
9/26/2017	Support Call		2 yrs old	Male	Mom	Yes	N/A	Telephone	> 5 minutes		Introduced myself: mom was in meeting	Mom asked if she could call back later	mom was enrolled in EI, never called back
9/26/2017	Support Call		4 months old	Female	Mom	Yes	N/A	Telephone	< 5 minutes		General support, mom is enrolled in EI, Mom is explor	Partnered to FB page for more information as well as my contact information	
9/26/2017	Support Call		5 months old	Female	Mom	Yes	N/A	Telephone	> 5 minutes		Introduced myself: Mom's english was poor, mom hung	Maybe a Spanish Speaker would have more luck	Confirmed family is Spanish Speaking still not enrolled in EI
9/27/2017	Support Call		3 months old	Female	Mom	Yes	N/A	Telephone	< 15 minutes		General support: Mom has an initial contact meeting w	Referred to FB page for more information as w	E-mail Sent: ASL learning resource list
9/28/2017	Needs EI		5 weeks old	Female	Mom	Yes	N/A	Telephone	< 5 minutes		Trying to track down babies follow-up diagnosis that cla	Mom will e-mail ehdparents with either docume	Mom never e-mailed, returned parent support binder, and has referu
9/28/2017	Needs DiABR		6 weeks old	Male	Mom	Yes	N/A	Telephone	< 10 minutes	ges-12/8/17	Follow-up make sure diagnostic testing was scheduled,	mom agreed to schedule additional testing	**12/8/2017 Mom responded via text and let me know they had beer
10/4/2017	Support Call		6 weeks old	Male	Mom	No	N/A	Telephone	N/A		Left VM, provided ehdparents e-mail address		
10/4/2017	Support Call		2 months old	Male	Mom	No	N/A	Telephone	N/A	ges-11/7/18	Left VM, provided ehdparents e-mail address		
10/4/2017	Support Call		2 months old	Female	Mom	Yes	N/A	Telephone	< 5 minutes		Addressed Concerns: Was prescribed antiviral for CMV	Said I would look into it further and follow up with	Found out the hold up was on the Medicaid end. Gave her the num
10/9/2017	Needs DiABR		9 months old	Male	Mom	Yes	N/A	Telephone	< 10 minutes		Called to see why mom never went in for diagnostic test	Suggested behavior testing at the UoU with Ad	**Mom did end up scheduling with Adrienne and has behavioral tes
10/10/2017	Support Call		6 weeks old	Female	Mom	No	N/A	Telephone	N/A		Left VM, provided ehdparents e-mail address		
10/10/2017	Support Call		9 months old	Male	mom	no	N/A	Telephone	N/A		Left VM, provided ehdparents e-mail address		
10/11/2017	Support Call		3 months old	Female	Dad	Yes	N/A	Telephone	> 1 minute		General Support call made	Dad hung up after I stated my name and why I w	Pip called to enroll in EI services. Dad refused services. Will not re
10/17/2017	Support Call		6 weeks old	Male	Mom	Yes	N/A	Telephone	< 15 minutes		General Support call: Mom was struggling with accepta	Connected mom with UTAH EHDI facebook sc	Mom liked and followed the page
#####	Support Call		2.5 months old	Male	Mom	Yes	N/A	Telephone	< 5 minutes		General Support call: Baby is back in NICU, mom is sup	Gave mom my contact info as well as the FB page information so that she could contact me if concern ever arise	
1/19/2017	Needs CMV Testing		2 months old	Female	MDm	No	N/A	Telephone	< 15 minutes		Discussed importance of follow-up CMV testing, Asma	Left VM, CMV follow-up call. Let Mom know I h	**Mom returned my call, discussed concerns and necessity for fo
1/19/2017	Needs Outpatient Screening		14 months old	Female	Family	No	N/A	Telephone	N/A	ges 12-8-17	Left VM with my name, number, and info		
1/19/2017	Needs DiABR		2 months old	Male	Mom	No	N/A	Telephone	N/A		Sent mom a text		
1/19/2017	Support Call		6 weeks old	Male	Dad	No	N/A	Telephone	N/A		Left VM, provided ehdparents e-mail address and my phone number		
1/13/2017	Support Call		2 months old	Male	Mom	No	N/A	Telephone	N/A		Left VM, provided ehdparents e-mail address and my phone number, referred her to FB page		
1/13/2017	Support Call		6 weeks old	Male	Mom	Yes	N/A	Telephone	< 5 minutes		General support call made: baby was released from NIC	That as things settled mom would get more answers. **I think this mom should receive another support call in a m	

## Parent Support

- 48 calls made
- 58% of families were reached
- 75% of families contacted needed additional resources and supports
  - Finding community resources
  - Financial assistance
  - Emotional support

## Lost to Follow-Up

- 64 calls made
- **AFTER** attempts from the follow-up coordinator
- 42% were moved along in the EHDI process

# Parent Consultant



Heather Adams



China, March 3, 2014



Home, January 2018



Cochlear Activation

# Care Coordination



UTAH DEPARTMENT OF  
**HEALTH**

**Primary Provider:** \_\_\_\_\_  
 Clinic Address: \_\_\_\_\_  
 Phone Number: \_\_\_\_\_

**Patient Name:** \_\_\_\_\_  
 DOB: \_\_\_\_\_  
 Preferred Mode of Communication: \_\_\_\_\_

**Parent/Caregiver Name:** \_\_\_\_\_  
 Address: \_\_\_\_\_  
 Phone Number: \_\_\_\_\_  
 Insurance: \_\_\_\_\_

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**Diagnosis**

Type of Hearing Loss

Sensorineural  
  Conductive  
  Mixed  
  Neural  
  Undetermined

Severity of Loss: Left Ear

Mild  
  Mild/Moderate  
  Moderate  
  Moderate/Severe  
  Severe  
  Profound  
  No loss

Severity of Loss: Right Ear

Mild  
  Mild/Moderate  
  Moderate  
  Moderate/Severe  
  Severe  
  Profound  
  No loss

CMV Testing Results

Positive  
  Negative  
  No testing done

CMV Test: Type

Urine  
  Saliva  
  Blood Spot

Other Diagnosis: \_\_\_\_\_

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**Other Providers Seen**

Audiologist: Name: _____	Phone Number: _____	Clinic/Address: _____
Last Appointment notes: _____		
Recommendations: _____		
ENT: Name: _____	Phone Number: _____	Clinic/Address: _____
Last Appointment notes: _____		
Recommendations: _____		
Ophthalmology: Name: _____	Phone Number: _____	Clinic/Address: _____
Last Appointment notes: _____		
Recommendations: _____		
Other: Name: _____	Phone Number: _____	Clinic/Address: _____
Last Appointment notes: _____		
Recommendations: _____		
Other: Name: _____	Phone Number: _____	Clinic/Address: _____
Last Appointment notes: _____		
Recommendations: _____		

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**Interventions**

Has family been contacted by a Parent Consultant?  Yes  No

Was an EHDI Information binder sent?  Yes  No

Early Intervention Enrollment

Early Intervention Program: \_\_\_\_\_ Service Coordinator: \_\_\_\_\_ IFSP Date: \_\_\_\_\_

Early Intervention Services Received:

Occupational Therapy  
  Physical Therapy  
  PIP Services  
 Deaf Mentor  
  Speech Therapy  
  Other: \_\_\_\_\_

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**Technologies & Medications**

Technologies used (LEFT ear)

Cochlear Implant  
  Hearing Aid  
  BAHA  
  None

CI Brand: \_\_\_\_\_

Technologies used (RIGHT ear)

Cochlear Implant  
  Hearing Aid  
  BAHA  
  None

CI Brand: \_\_\_\_\_

Has the Family Been referred to the CHAP program?  Yes  No

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Medications

Past: \_\_\_\_\_

Current: \_\_\_\_\_

Allergies: \_\_\_\_\_

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**Family Background**

Health Development/Behavior History: \_\_\_\_\_

Parent Concerns: \_\_\_\_\_

Family Needs: (medical, social, financial, educational, language barriers, transportation, legal, etc.)

Page 2 of 2

# Questions?



[ehdiparents@utah.gov](mailto:ehdiparents@utah.gov)

Rachel: [rahyde@utah.gov](mailto:rahyde@utah.gov)

Heather: [haadams@utah.gov](mailto:haadams@utah.gov)

Stephanie: [smcvicar@utah.gov](mailto:smcvicar@utah.gov)



@utahehdi

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