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Late Identification: Supporting Families

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Children's Hospital Colorado
Here, it's different.™



Overview

- 1 Partnership grant background
- 2 Common barriers & helpful supports
- 3 Suggested next steps



Barriers to Timely Identification

General barriers:

- Medical issues¹
- Parental choice to wait to evaluate¹
- Limited education²
- Access^{2,3}
- Lack of coordination across the continuum of care²
- Insurance/financial barriers²

COVID-19 related barriers:

- Increase in missed screens early in pandemic^{4, 7}
- Parental hesitancy^{4, 5, 7, 8}
- Staffing shortages⁵



Achieving 1-3-6⁶

	Screened by 1 month	Dx by 3 months		EI by 6 months	
		Of those diagnosed	Of “not passed” screens	Of those in Part C	Of those diagnosed
2019	97.7%	79.1%	49.1%	72.5%	44.7%
2020	97.2%	60.6%	36.3%	72.4%	44.5%





Project Background

- Concerns for increase in late identification secondary to pandemic
- CO EHDI state leadership & database transition
- What can we learn to improve resources for these families?

Partnership Development Grant
Colorado Clinical and Translational
Sciences Institute



Partnership Project: Late Identification

Qualitative Project:

“Late Identified” = greater than 6 months

- Advisory group with key stakeholders
- Online parent survey
 - English & Spanish
- Parent Focus Groups
 - English & Spanish
- Interview & educate midwives
- Interview & support birthing hospitals
 - Rural & urban
 - High ESL censuses

An opportunity to share your stories

1. Tell me about your experiences with the diagnosis of your child's hearing...
2. What was helpful during this process...
3. What were the challenges...



Online Parental Survey

- Shared through COH&V, audiologists, CO-Hears
- 38 respondents completed
 - English-speaking
 - Caucasian (83%), Latino (22%)
 - College educated (70%)
 - Government insurance (41%)
 - Passed NBHS (71%)
 - Mean Age Identified: 37 months
 - Degree of hearing loss:
 - Mild (39%)
 - Moderate (29%)
 - Moderately-severe (13%)



Parental Survey Results

Category		Percentage
NBHS	Fair/Poor Results	60%
	Fair/Poor Recommendations	67%
Delayed Dx	Appeared to hear well	38%
	Multiple NBHS (>2)	35%
	Delays in appt availability	21%
	Provider said not to worry	21%
EI referral	Hearing specific	35%
	Non-hearing EI	15%
	Not referred	35%
Family support referral		71.5%
Helpful resources	H&V Parent Guides	40%
	CO-Hear Coordinators	37%
	Family events	30%

I wish all providers knew what to offer late-identified families. I felt like I had to teach myself all about my daughter's needs.

-Rural parent of child identified with UHL at age 5 years





Virtual Focus Groups

- 10 participants
 - Fall 2020-Spring 2021
 - English-speaking
 - 40% rural
 - Three Spanish-speaking-only groups attempted



Focus Groups Themes

- Need for education for OB/pediatricians
- Didn't know what was typical in NBHS
- Didn't know how to choose an audiologist
- Need parent-friendly language
- Need for education for screening staff, scripts, protocol
- Wishlist for checklist for providers serving late-identified: listening fatigue, effects of distance, typical accommodations, FM/DM

We need specific resources for late ID in our area, a parent group, and (urgent) steps to take to close our kids' gaps.

- Urban parent of child identified at age three





POV: Parents

“He passed NBHS and “office test” at 3 years old.”

Can’t get into local audi, wait in Denver was 5 months out but they’d only schedule 3 months out, so kept delaying.”

“Couldn’t bring siblings during COVID.”

Medical hurdles delayed screening

*“Wait and see” - multiple tests first year
Military/rural/less experienced audi*

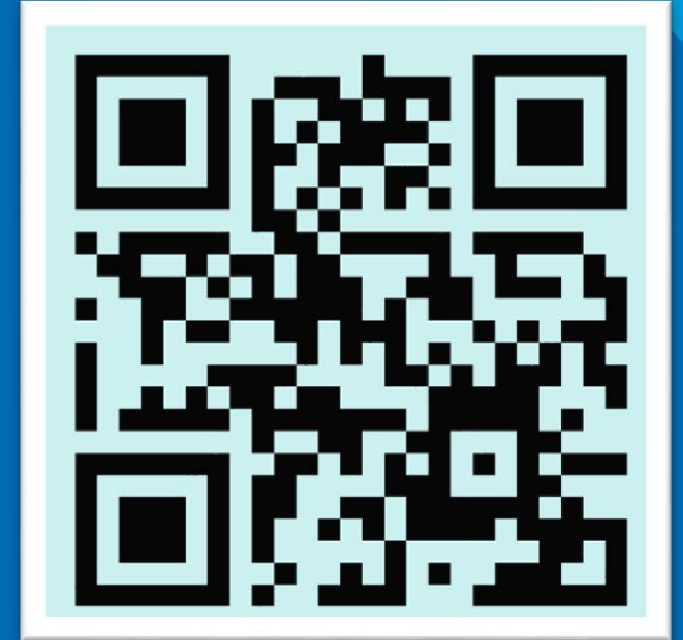
Emotions/Action Words in coding:

*Helpless*Guilty*Confused*Isolated*Regrets
Intuition*Activist*DIY*Grateful someone
walked me through*Gave me big picture*



Moving forward

- The need for coordinated care across professionals a theme in parent feedback²
 - Shared vision/plan & good communication
- Created a resource to support professionals re: later identified families and coordinating care
- Late ID specialty Parent Guide at CO H&V
- CO Hearing Resource Guide updates
 - Acronyms list for parents
 - Dedicated section for late identification



We need someone to take us under their wing and explain the big picture.

- Suburban, military parent of child identified at 2.5 years



Takeaways

- Be conscious of language/wording
- Be aware of family's journey
- Ease process for family
- Connect with resources for whole child/family support
- Family to family support

"I had to be very aggressive with finding my own way.

I wish there was a coordinator that met with us and told us all the options available.

I feel like one person had one piece of the puzzle and another had a different piece...but no one had the full picture."

-Suburban mother of child late identified with hearing loss at 42 months of age



One third of the families thanked us for hosting the survey and focus groups.

They valued having the opportunity to share their experiences to benefit future families and professional training.





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Hospital Colorado
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Thank you!

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