

# Partnership Project: Late-Identification

## Background and Significance

- COVID-19 has impacted newborn hearing screening (NBHS) and follow up throughout the pandemic:
  - Increases in missed screens secondary to early discharges and temporary closures of NBHS programs early in the pandemic
  - Staffing shortages related to the most recent Omicron wave and/or The Great Resignation
  - More parental concerns about bringing in newborns for follow up appointments, as well as complications in access to services due to transportation, childcare, and financial concerns
- These impacts raise the concerns about delays in identification of hearing loss, as well as access to amplification, visual communication options, early intervention services, and parent-to-parent support.
  - 2019 CDC: 49.1% of infants are diagnosed before 3 months of age, including normal hearing.<sup>11</sup>
  - 2020 CO CDC data:
    - 18% of only 109 babies identified with permanent hearing loss were identified after three months of age.
    - 2,913 infants did not have screening results
    - During a survey of NBHS programs in May 2020, 82% of 27 respondents noted they needed access to the state database, 78% needed reliable current information for screeners and audiologists, including 64% who needed accurate referral information for missed or failed screens.
  - How many children missed follow up or well-baby visits?
  - 2020 CDC data is not yet available. 2021 data may also show delays. Thus, we expect a spike in late-identification.

### Revisiting the needs of families of "late-id" children remains critical

- Research has shown trends that families, regardless of age of identification, expressed the need for
  - access to coordinated care<sup>2,3,9</sup>
  - parent-to-parent support<sup>2,3,5,9</sup>
  - access to quality information<sup>5,7</sup>
  - meaningful partnerships between parents and professionals<sup>1</sup>
  - provision of a full array of information across content areas (e.g. funding sources, type of devices, early intervention resources, etc.) so parents can make informed decisions<sup>2,7</sup>

### Parents of later-identified children report

- Greater difficulty in accessing diagnostic services and experienced increased negative emotions surrounding these delays and potential delayed development, as well as missed learning time prior to diagnosis.<sup>2</sup>
- Delays of 3+ months between parental suspicion and confirmation of hearing loss (40%), with parental choice to wait to evaluate (41%) and medical issues (35%) as the most cited reasons for these longer delays. Approximately 1/5<sup>th</sup> of children whose hearing loss was later identified were in early intervention services prior to undergoing audiologic evaluation, indicating delays had already been identified in their child's development, potentially contributing to stress and guilt surrounding a later diagnosis<sup>10</sup>
- Supporting parents related to their adjustment and potential feelings of guilt<sup>6</sup> needs to be considered.

## Objective

- Due to the aforementioned concerns regarding NBHS during the COVID 19 pandemic, and no NBHS database since 2016, we initiated a Community Engagement project to determine what we could learn from families who were late-identified and the hospitals/midwives who serve them

## Methods

- Qualitative Methodology
- On-line parental surveys
- Focus groups
- Advisory group with Key Stakeholders
- Late identified infants were considered those identified >6 months of age

## Acknowledgements

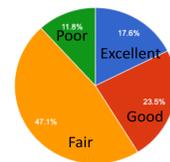
CCTSI = NIH/NCRR Colorado CTSI Grant Number UL1 TR001082 to CU AMC. Human Subject Protocol COMIRB# 21-3196 Project Advisory Board Parents and Professionals. Georgina Lucas, CCTSI Coach

## Late ID Parent On-Line Survey

- 70 Surveys were started and 45 were completed
- Demographics
  - The majority of participants were Caucasian (65%)
  - The majority of participants had at least a bachelor's degree (38%) or higher (31%)
  - Health insurance at time of birth, private insurance 52% and government insurance 43%
  - 56% of infants passed their NBHS before hospital discharge and 28% passed their OP NBHS
  - Majority of infants were diagnosed with a mild hearing loss (33%), followed by moderate (27%), and moderately severe (20%)
  - Of children identified with hearing loss, 58% had sensorineural hearing loss, 14% were unknown, and 8% were conductive

Figure 1

### Explanation of NBHS results



### NBHS Follow up recommendation

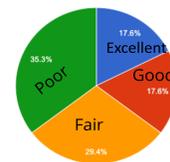
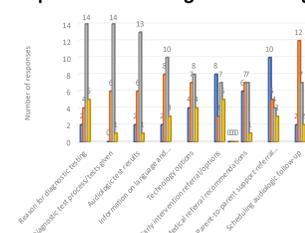
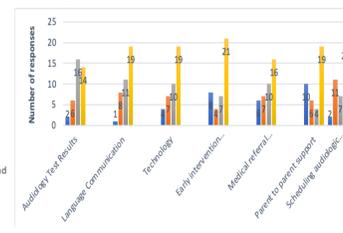


Figure 2

### Explanation for Diagnostic Testing



### Counseling Topics Rated by Families

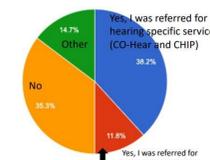


"I wish all providers knew what to offer late-identified families. I felt like I had to teach myself all about my daughter's needs."

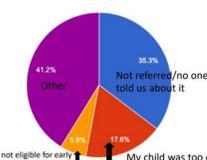
Rural parent, child with UHL identified at age 5

Figure 3

### Were you referred to EI?



### Why wasn't your child referred for early intervention? Select the best answer



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

Urban parent of child identified at age 3

## Parent Focus Groups:

10 Parents shared in-depth experiences with late-identification. 6 were from urban/suburban areas and 4 were in rural areas. 2 rural families are pictured (right) whose oldest children were identified at age 1 and 3.

## Hospital Newborn Hearing Screening Interviews:

One large urban and one small rural hospital, both with a high ELL census

## Direct-Entry Midwives Interviews:

10 Contacted, 1 interviewed (rural) and 1 partial interview (rural)

## Barriers to Screening, Follow up and Diagnosis

100% of providers (hospital & midwives) did *not* utilize a script to give results to parents.

90% of parents noted lack of expertise during screening (baby not quiet/asleep, unsure of equipment use, screening until "getting a pass")

Of the children who referred, 100% reported comfort language "it's probably fluid," "most babies pass", "it's due to the fast birth" dissuaded families from follow-up.

Lack of following best practices: making appointment for follow up, providing information in writing

40% were referred to Family Support, all wished they had been referred sooner.

100% of parents felt guilty or regretful that they didn't listen to their intuition. 91% felt they could have acted earlier.

## Discussion and Conclusions

Findings from the parent survey and focus groups were consistent

Continued areas for improvement are:

- Utilization of scripts for NBHS results and recommendations
- Ongoing trainings in all counseling topics
- Awareness and implication for late-ID

A checklist for professionals of Late-ID families

- ✓ Overview of EHDI systems, intervention possibilities and acronyms
- ✓ Refer to EI (35% did not receive a referral)
- ✓ Connect to experienced family support org around D/HH identities
- ✓ Specific recommendations for "closing the gaps"
- ✓ Frequency progress monitoring in EI systems to ensure closing gaps
- ✓ Specific recs/education around IEP or 504 in Part B systems
- ✓ Help identify other needs (D/HH+)

### Limitations

- Despite multiple efforts, there was a lack of diverse sample, especially ELL families
- Research is primarily from white, English speaking, well-educated families.
- Higher maternal education is associated with earlier identification and hearing aid fitting.<sup>6</sup>
- Further information is needed to determine the needs and preferences of families outside this category.

## Future Work

- Creative solutions for service provision in light of the continually changing landscape of COVID restrictions and concerns continue to be needed to address parental preferences and needs.
- Determine best utilization of telehealth services reducing the burden of travel on families and which may provide more continuous support across the family's journey with hearing loss.<sup>7</sup>
- Increased awareness and utilization of Munoz et al.<sup>8</sup> eHealth program educating families on hearing aid management which was found to produce greater increases in hearing aid management knowledge, confidence, perceptions, and monitoring for parents that participated in the program.

## References

- DesGeorges, J. (2003). Family perceptions of early hearing, detection, and intervention systems: Listening to and learning from families. *Mental Retardation and Developmental Disabilities Research Reviews*, 9, 89-93.
- Fitzpatrick, E., Angus, D., Durieux-Smith, A., Graham, I., & Coyle, D. (2008). Parents' needs following identification of childhood hearing loss. *American Journal of Audiology*, 17, 38-49.
- Fitzpatrick, E., Coyle, D., Durieux-Smith, A., Graham, I., Angus, D., & Gaboury, I. (2007). Parents' preferences for services for children with hearing loss: A conjoint analysis study. *Ear & Hearing*, 28(6), 842-849.
- Fitzpatrick, E., Graham, I., Durieux-Smith, A., Angus, D., & Coyle, D. (2007). Parents' perspectives on the impact of the early diagnosis of childhood hearing loss. *International Journal of Audiology*, 46(2), 97-106.
- Grandpierre, V., Fitzpatrick, E., Na, E., & Mendonca, O. (2018). School-aged children with mild bilateral and unilateral hearing loss: Parents' reflections on services, experiences, and outcomes. *Journal of Deaf Studies and Deaf Education*, 23(2), 140-147.
- Holte, L., Walker, E., Oleson, J., Spratford, M., Moeller, M., Roush, P., Ou, H., & Tomblin, J.B. (2012). Factors influencing follow-up to newborn hearing screening for infants who are hard of hearing. *American Journal of Audiology*, 21, 163-174.
- Munoz, K., Rusk, S., Nelson, L., Preston, E., White, K., Barrett, T., & Twohig, M. (2016). Pediatric hearing aid management: Parent-reported needs for learning support. *Ear & Hearing*, 37(6), 703-709.
- Munoz, K., San Miguel, G., Barrett, T., Kasin, C., Baughman, K., Reynolds, B., Ritter, C., Larsen, M., Whicker, J., & Twohig, M. (2021). eHealth parent education for hearing aid management: a pilot randomized controlled trial. *International Journal of Audiology*, 60(sup1), S42-S48.
- Robinson, H., & Evans, R. (2001). Service provision for preschool children who are deaf: Parents' perspectives. *Early Child Development and Care*, 168(1), 63-91.
- Walker, E., Holte, L., Spratford, M., Oleson, J., Welhaven, A., & Harrison, M. (2014). Timeliness of service delivery for children with later-identified mild to severe hearing loss. *American Journal of Audiology*, 23(1), 116-128.
- CDC. (2018). Summary of Diagnostics Among Infants Not Passing Hearing Screening. *Centers for Disease Control and Prevention*, (0). Retrieved from <https://www.cdc.gov/ncbddd/hearingloss/2015-data/06-diagnostics.html>