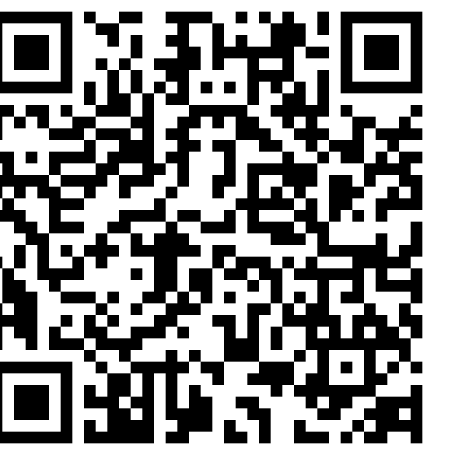


The first 5-year Progress following the Iowa Cytomegalovirus Legislation

Eun Kyung (Julie) Jeon, Au.D., Ph.D.¹ & Linda True, Au.D.²

¹Department of Communication Sciences and Disorders, The University of Iowa, Iowa City, IA

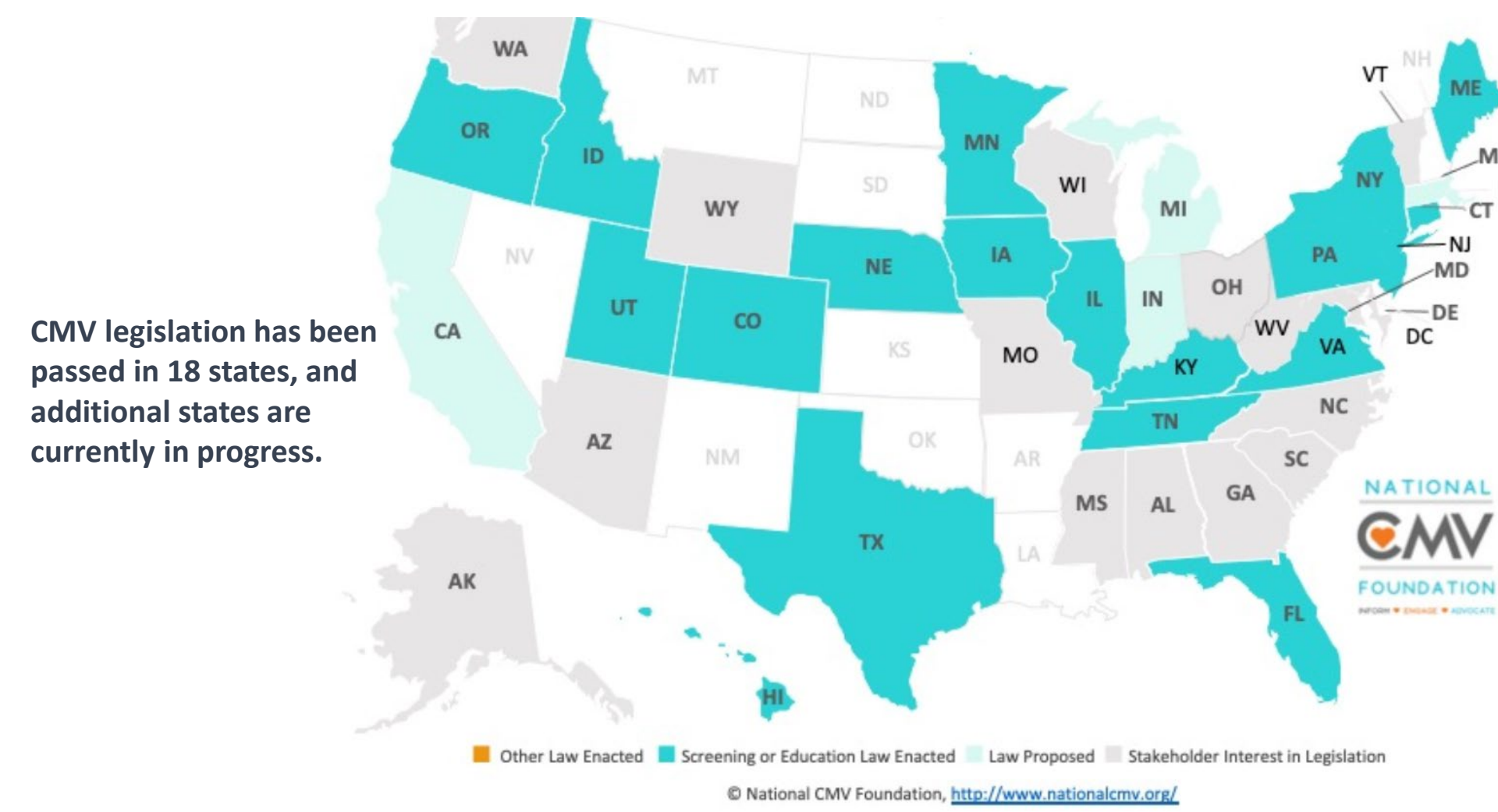
²Iowa Department of Health and Human Services, Des Moines, IA



Introduction

Cytomegalovirus (CMV) is the leading non-genetic environmental cause of childhood sensorineural hearing loss. In 2017, the Iowa Legislature passed a bill, [Iowa Senate File 51](#), for an act relating to a public health initiative for CMV and the testing of newborns for congenital CMV (cCMV). It came into effect on July 1st, making Iowa the 9th state to implement such requirements. **Figure 1** illustrates the current status of legislation related to congenital CMV (cCMV) in the United States.

Figure 1. Congenital CMV Legislation in the U.S.
(updated in February 2023)



Although CMV legislation varies by state, [Senate File 51](#) mandates two specific requirements: 1) education on cCMV for the public, including pregnant women and professionals, and 2) testing for cCMV in newborns who fail the newborn hearing screening, as outlined in **Table 1** below.

Table 1. Summary of Iowa CMV legislation

Iowa Senate File 51	
Section 1	Section 2
To raise awareness of CMV and cCMV	To test newborns with hearing loss for cCMV
<ul style="list-style-type: none"> The initiative requires the center for congenital and inherited disorders to collaborate with other organizations to develop and publish informational materials to educate pregnant women, expectant parents, parents of infants, and health care providers about CMV and congenital CMV. The materials must cover <ul style="list-style-type: none"> Incidence of CMV and cCMV Transmission to pregnant women Birth defects caused by cCMV Methods of diagnosing cCMV Preventive measures Early interventions and treatment The attending health care provider is required to provide the informational materials to a pregnant woman during the first trimester of pregnancy, and the department must make the materials available electronically to childcare facilities, schools, hospitals, and health care providers. 	<ul style="list-style-type: none"> A new subsection that requires birthing hospitals, birth centers, physicians, or other health care professionals to test newborns with hearing loss for congenital cytomegalovirus (CMV) before the newborn is 21 days old. If the newborn tests positive for CMV, the parents must be provided with information about birth defects caused by congenital CMV, as well as early intervention and treatment resources for children diagnosed with congenital CMV. If a parent objects to the testing, the healthcare provider must obtain a written refusal from the parent, document the refusal in the newborn's medical record, and report the refusal to the department according to departmental rules.

- Infants who test positive within the first 21 days after birth have the option of treatment with antiviral therapies, which may decrease the risk of permanent hearing loss.
- The Iowa EHDI Law and EHDI Administrative Code define the roles of providers, including primary medical care providers, ENT physicians, and audiologists, in reporting to referring providers and educating parents of children identified as CMV positive about their comprehensive care needs, such as timely hearing loss diagnosis and intervention, early intervention services, and family support.
- Unfortunately, the current Iowa Law does not specify a clear oversight mechanism for CMV testing to ensure that infants with cCMV who test positive receive monitoring of their hearing status and antiviral medications within the appropriate time frame.
- Nevertheless, note that cCMV is automatically considered a qualifying condition for early intervention services in Iowa.

Purpose of the Study

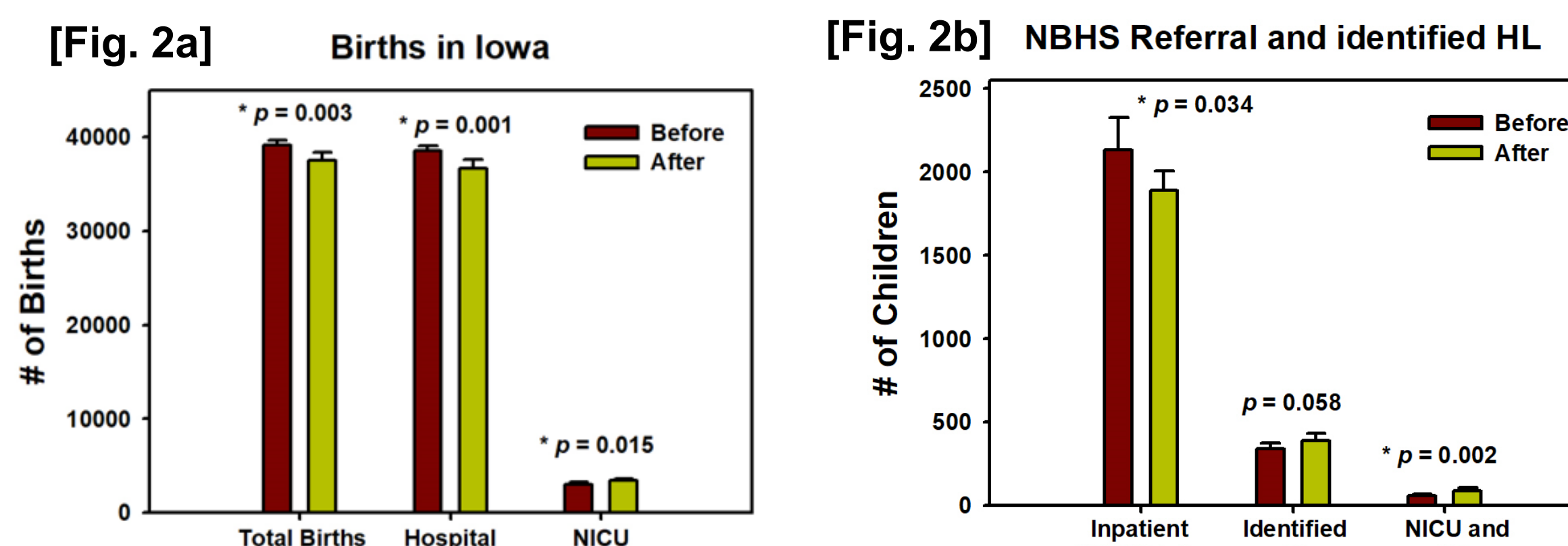
To assess the impact of the CMV public health legislation that has been implemented in Iowa over the past five years, as well as to investigate whether hearing-targeted cCMV screening could result in timely and improved care for infants with CMV infection.

Methods

Using the Iowa Newborn Screening Information System (INSIS), we collected and compared cCMV screening data for babies born post-Senate File 51 (2017-2021) with pre-law (2000-2016) data. We used various search criteria within INSIS to assess the births, the NBHS refer responses, the number of reported cCMV cases, reported cCMV with HL, etc. We also assessed the number of children with cCMV referred to and enrolled in early intervention and family support.

Results

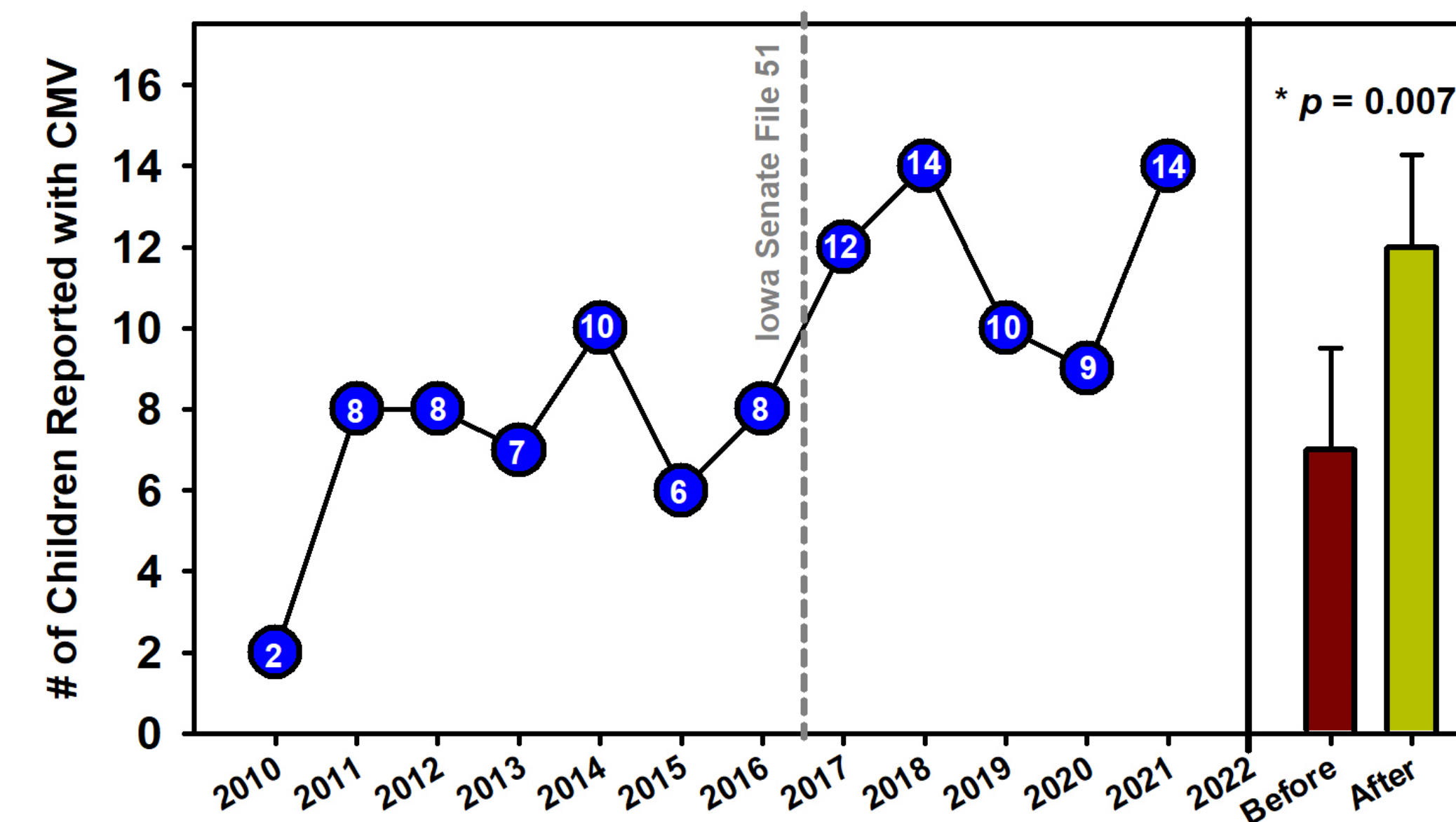
Figure 2 compares Iowa births (**Figure 2a**) and NBHS referrals and hearing loss cases by age 3 (**Figure 2b**) between 2000-2016 and 2017-2021, i.e., before and after the implementation of the CMV legislation.



- Before the CMV legislation, both the total number of births and hospital births in Iowa were significantly higher than after the legislation ($t(10) = -3.88, p = 0.003; t(10) = -4.58, p = 0.001$). However, the number of infants in the NICU was significantly higher after the legislation than before it ($t(10) = 2.94, p = 0.015$).
- Pre-legislation, NBHS "refer" responses were significantly higher (mean = 2134, SD = 196) than post-legislation (mean = 1892, SD = 116). Although no difference in hearing loss diagnoses, more NICU children had hearing loss post-legislation (mean = 91, SD = 16) than pre-legislation (mean = 60, SD = 10).

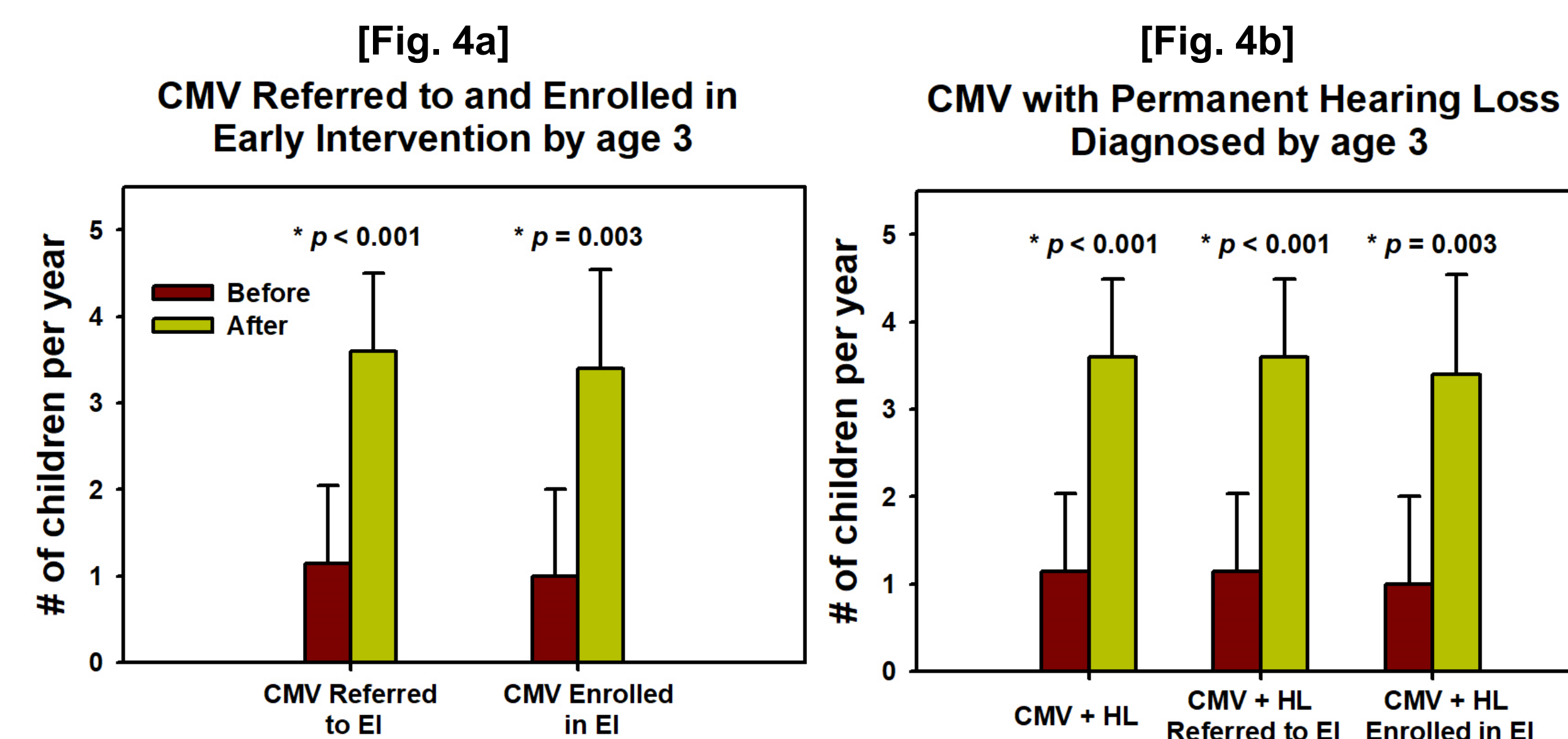
Figure 3 shows the number of children reported with CMV in Iowa from 2010 to 2021. Also, it compares the mean number of children identified with CMV between the two groups: before and after the legislation.

[Figure 3] Number of children reported with CMV



- Between 2010 and 2021, the number of children reported with CMV each year (shown in blue circles) ranged from 2 to 14. The number of reported CMV cases were significantly higher ($t(10) = 3.38, p = 0.007$) after the CMV legislation (Mean = 12/year, SD = 2.28) than before the legislation (Mean = 7/year, SD = 2.51).

Figure 4 compares the number of children with CMV referred to and enrolled in early intervention (**Figure 4a**), and children with CMV and diagnosed with permanent hearing loss (**Figure 4b**) before and after the legislation.



- After the implementation of the CMV legislation, both the number of children with CMV referred to (mean = 3.60, SD = 0.89, $t(10) = 4.68, p = 0.0009$) and enrolled in early intervention (mean = 3.4, SD = 1.14, $t(10) = 3.87, p = 0.0031$) were significantly higher than before the legislation (referral mean = 1.14, SD = 0.90; enrollment mean = 1.0, SD = 1.0).
- After the implementation of the CMV legislation, the number of children with CMV diagnosed with HL (mean = 3.60, SD = 0.89, $t(10) = 4.68, p = 0.0009$) were significantly higher than before the legislation (referral mean = 1.14, SD = 0.90). Additionally, both the referral and enrollment numbers for children with CMV diagnosed with hearing loss were higher after the legislation than before it.

Conclusion and Discussions

This study evaluated the impact of the enacted CMV public health legislation in Iowa during its first five years. The results indicated that hearing-targeted cCMV screening identified more babies with cCMV compared to before the law, resulting in improved habilitative care. Children with CMV and hearing loss were significantly more reported after the implementation of the CMV legislation than before. Our findings also revealed more referral and enrollments for children diagnosed with CMV in early Intervention programs.

- These results align with data from other states, such as Utah, which reported similar outcomes after five years of the law's implementation in 2017. However, according to Diener et al. (2017), 14 (6.0%) of the 234 infants tested within 21 days of birth were positive for cCMV, and 6 (42.9%) of those infants had confirmed hearing loss. In contrast, our data shows that after the law, only 59 (2.76%) out of 2,134 infants who failed NBHS were positive for cCMV, and 18 (30%) of those infants had permanent hearing loss. In other words, our data shows a lower percentage of infants with cCMV and a lower percentage of hearing loss.

This raises the question: why might this be the case?

Current Challenges

Collecting data and ensuring proper monitoring and medication for cCMV-positive children presents significant challenges.

- Iowa Law lacks specifications for overseeing CMV testing, which could impact the reporting of results to medical providers after hearing screenings.
- There is no designated site for reporting CMV screening results, and there are no protocols for differentiating between symptomatic and asymptomatic CMV.
- No funding is available for overseeing CMV testing and data collection.
- There are no established protocols and funding for parent education on CMV during prenatal and postnatal care, or for addressing the risk of progressive hearing loss associated with cCMV.

Future Considerations

To ensure that mandates are met, a working group could collaborate with legislators to amend the current Iowa Law. This could address budget allocation, oversight, antiviral medication monitoring, and reporting requirements, including a designated reporting site. The amended legislation should also consider professional development for providers to provide prenatal and postnatal education about cCMV risks.

- We hope that the national cCMV working group's statement could guide states towards sustainable and uniform cCMV management.
- We suggest that the Iowa Departments of Education (DOE) and Health & Human Services should develop a coordinated alerting system for audiologists to monitor children with CMV and those referred for Part C services. The system should detect delayed or progressive hearing loss by utilizing the current reporting database systems for the DOE and EHDI, namely ACHIEVE and INSIS respectively.

Acknowledgements

We would like to acknowledge the following for their support: Iowa Health and Human Services Office of Early Hearing Detection and Intervention, Tammy O'Hollearn (Iowa EHDI Coordinator), Kimberly Piper (Iowa Center for Congenital and Inherited Disorders Executive Officer), and Tori Carsrud (Iowa Department of Education Deaf/HOH Education Program Consultant).

References

- National CMV Foundation (retrieved in 2023). <https://www.nationalcmv.org/>
- Iowa Legislature Senate File 51 <https://www.legis.iowa.gov/docs/publications/LGE/87/SF51.pdf>
- Iowa Code section 135.131 (Iowa EHDI Law) <https://www.legis.iowa.gov/docs/code/135.131.pdf>
- Iowa Administrative Code 641 Chapter 3 <https://www.legis.iowa.gov/docs/iac/chapter/02-08-2023.641.3.pdf>
- Diener et al. (2017). Outcomes From a Hearing-Targeted Cytomegalovirus Screening Program. *Pediatrics*, 139(2), DOI: [10.1542/peds.2016-0789](https://doi.org/10.1542/peds.2016-0789)

Author's contact information

Eun Kyung (Julie) Jeon: eunkyung-jeon@uiowa.edu
Linda True: linda.true@idph.iowa.gov

Presented at the 22nd EHDI Annual Conference, Cincinnati, Ohio, March 5 – 7, 2023

