

## **A Proposal for Policy Change to SB 722 - Newborn Health Screening**

### **Yamile Marrero, JD, MPH, CSCS**

Clinical Assistant Professor  
Florida International University  
Nicole Wertheim College of Nursing and Health Sciences  
Modesto Maidique Campus  
11200 SW 8<sup>th</sup> Street, Miami, FL 33199, Building AHC-3, Room 321B, USA.

### **Chanadra Young Whiting Ed.D, MPH/HSA**

Clinical Assistant Professor  
Florida International University  
Nicole Wertheim College of Nursing and Health Sciences  
Modesto Maidique Campus  
11200 SW 8<sup>th</sup> Street, Miami, FL 33199, Building AHC-3, Room 321B, USA.

### **Lucia Sequeira**

Bachelors of Health Services Administration Student  
Nicole Wertheim College of Nursing and Health Sciences  
Modesto Maidique Campus  
11200 SW 8<sup>th</sup> Street, Miami, FL 33199, Building AHC-3, Room 321B, USA.

### **Marie Carole Sheen – 2853108**

Bachelors of Health Services Administration Student  
Nicole Wertheim College of Nursing and Health Sciences  
Modesto Maidique Campus  
11200 SW 8<sup>th</sup> Street, Miami, FL 33199, Building AHC-3, Room 321B, USA.

### **Maguy Simeon – 2569940**

Bachelors of Health Services Administration Student  
Nicole Wertheim College of Nursing and Health Sciences  
Modesto Maidique Campus  
11200 SW 8<sup>th</sup> Street, Miami, FL 33199, Building AHC-3, Room 321B, USA.

### **Peter Sosa – 4884857**

Bachelors of Health Services Administration Student  
Nicole Wertheim College of Nursing and Health Sciences  
Modesto Maidique Campus  
11200 SW 8<sup>th</sup> Street, Miami, FL 33199, Building AHC-3, Room 321B, USA.

### **Tiffany Taylor – 2564550**

Bachelors of Health Services Administration Student  
Nicole Wertheim College of Nursing and Health Sciences  
Modesto Maidique Campus  
11200 SW 8<sup>th</sup> Street, Miami, FL 33199, Building AHC-3, Room 321B, USA.

### **Nneka Williams – 1633055**

Bachelors of Health Services Administration Student  
Nicole Wertheim College of Nursing and Health Sciences  
Modesto Maidique Campus  
11200 SW 8<sup>th</sup> Street, Miami, FL 33199, Building AHC-3, Room 321B, USA.

**Mandira Young – 2101726 (Spokesperson)**

Bachelors of Health Services Administration Student  
Nicole Wertheim College of Nursing and Health Sciences  
Modesto Maidique Campus  
11200 SW 8<sup>th</sup> Street, Miami, FL 33199, Building AHC-3, Room 321B, USA.

**Manuel Zapata - 4707674**

Bachelors of Health Services Administration Student  
Nicole Wertheim College of Nursing and Health Sciences  
Modesto Maidique Campus  
11200 SW 8<sup>th</sup> Street, Miami, FL 33199, Building AHC-3, Room 321B, USA.

**Abstract**

---

*This paper aims to inform the reader and address the shortcomings of Florida law SB 722 - Newborn Health Screening. The law effective July 1, 2014 requires that every newborn in the state of Florida is screened for detrimental physical conditions including hearing impairment. Since hearing impairment can significantly affect the quality of a person's life it is of utmost significance that it is identified as early as possible so necessary treatment can take place. A proposed change to SB 722 - Newborn Health Screening is warranted as the cost of cochlear implants is minuscule in comparison to the cost to treat the condition over a lifetime. Likewise programs providing support to parents/guardians of affected infants are crucial.*

---

**Keywords:** Newborn Health Screening, Newborn Screening Saves Lives Act, Law, Policy

**Introduction**

With the health care industry constantly changing there are some changes that affects the public directly while others are indirect. In many cases the United States' legislation has served as a benchmark for new medical advances to other countries around the globe. One of the issues that affect many of our children is hearing loss or hearing impairment. In America, approximately 3 in 1000 newborn babies are born with permanent hearing loss (American Speech-Language Hearing Association, 2014). Fortunately, there are organizations and laws that can help alleviate this calamity and help relieve the burden felt by parents or/and caregivers. Children who receive early treatments have a better opportunity to adapt despite their condition and in the long run have a more stable life (American Speech-Language Hearing Association, 2014). With this in mind, Florida law SB 722 concerning Newborn Health Screening is of great significance to residents in our community.

Introduced in the 1960s, Newborn Health Screening has become a notable and controversial tool in detecting infantile diseases and disorders. The Newborn Screening Saves Lives Act of 2007, enacted by President George Bush, was designated to provide new screening technology, and a broadened panel of tests, which suggested that the states test for twenty-nine core disorders and twenty-five secondary disorders. Once the new medical technologies were implemented, mandated, and publicly funded into a program for all children to be screened, it should have generated a vast amount of solid evidenced-based material (Alston, 2008). Unfortunately, the policies were not being properly assimilated or applied and the need for evidence-based programs surrounding newborn and infant hearing impairment require change.

Improvements such as demanding 100% of funding from insurance companies for cochlear implants, having more advertising campaigns in health care facilities throughout the state, as well as making workshops/presentations for parents whose children are hearing impaired are necessary. With these improvements the law has the potential to not only enhance awareness of hearing impairment in newborns, but increase the quality of life for these infants and their parents/guardians who are affected by this unfortunate condition.

**Methods**

The Florida International University Library was used to secure information for this paper. The search began on the library's website then "A-Z Databases & Resources List" was selected. "Academic Search Complete" was used to further isolate related information and the search term "CS/CS/CS/SB 722 - Newborn Health Screening" was entered in the EBSCO Host search engine. A total of 19,341 results came back and after careful scrutiny 4 articles were selected for inclusion in this proposed policy change. Another search using the search term "The Newborn Screening Saves Lives Act of 2007" yielded a periodical and a government summary of presidential documents, the periodical was used to provide supporting details to the proposed changes in this paper.

**Results**

The Newborn Health Screening law authorizes the State Public Health Laboratory to provide results of the hearing and metabolic tests or screenings to health care practitioners. It gives audiologists the opportunity to provide additional information to parents regarding results in order to make an informed decision on obtaining follow-up care when medically necessary. The law also promotes screening for all newborns identifying risk factors including but not limited to low income, poor education, and other high-risk illnesses related with an increased risk of infant mortality and morbidity to provide early engagement, remediation, and prevention services such as parent support and training programs, home visitation, and case management (The Committees on Judiciary; Children, Families, and Elder Affairs, 2014, p. 2)). The law also states the importance to identify screenings and provide intervention efforts prior to or immediately after birth and up to three months of age regardless of birthplace. Part of the law requires the patient to be referred to a primary care physician if diagnosed with an impairment in order to receive adequate treatment and follow-up care. Those infants diagnosed with an impairment from birth to 36 months of age are referred to Children's Medical Services Early Intervention Program for continued care management (The Committees on Judiciary; Children, Families, and Elder Affairs, 2014, p. 3). Specialists are encouraged to obtain authorization from parents to allow the release of their contact information to receive correspondence on early intervention programs directly from those providers. The Department of Health provides a list of specialized healthcare professionals by geographic areas to assist the parents in choosing a doctor.

There are potential risks of harm during treatments for those children identified as having hearing impairment; treatments may generate unnecessary worry, lead children to be labeled as having serious health problems, and have long-term consequences for insurability and employability. If there were at least fair evidence that an intervention was effective, the benefits could be large enough and certain enough to allow a rough judgment that they outweighed the potential harms (Shiffman & Spooner, 2001). Individuals who oppose this law might argue that it might also simply provide no demonstrable health benefit to the children while spending scarce resources. Given tight state budgets for newborn screening programs and other essential child care services, resource consumption without benefit must itself be considered a potential harm (Alston, 2008).

Having children labeled as having a potential problem with long term consequences is unacceptable. Furthermore, despite the fact that health insurance coverage for cochlear implant services has improved with the majority of insurance carriers covering this procedure, we propose that all insurance carriers cover the device, pre and post-operative procedures and any related services at 100% of the cost. The approximate cost of a cochlear implant and related procedures inclusive of rehabilitation can cost as much as \$100,000.00 (American Academy of Otolaryngology: Head and Neck Surgery, 2013). According to research conducted by the Johns Hopkins University and the University of California in San Diego, cochlear implantation ranks among the most cost-effective medical procedures reported. The results of the study demonstrate that cochlear implantation can result in a net savings of more than \$53,000 per child versus the more than \$1 million average expected lifetime cost of a child who has profound hearing loss prior to language development (American Speech-Language Hearing Association, 2014)

Even though this law currently has a good process in place as far as training programs, there is still some room for improvement. We propose that advertising campaigns be launched at hospitals, OBGYN offices, children stores, toy stores, etc. to raise awareness of the newborn health screening programs. In order to deviate from the representation of illnesses that are seen in a hospital setting, we propose that parent workshops be designed to take place at baby/toy stores, coffee shops, or private areas in restaurants. This will provide parents with a more comfortable environment and stray from the fact that their child has lifetime impairment.

Workshops would consist of presentations by healthcare professionals who will promote the importance of newborn health screening at birth. Workshops for parents whose children have already been diagnosed will consist of hands on training on ways to properly care for their children's impairment.

### **Discussion**

Hearing loss in neonates and children under the age of 2 is not readily noticeable by routine clinical processes. Parents often report the suspicion of hearing loss and inattentiveness to sound before hearing loss can be confirmed. The average age of children with hearing impairments in the United States is reducing with informational forums and special programs; such as, Early Hearing detection and intervention (EHDI) programs (Joint Committee on Infant Hearing, 2000). Although children who are diagnosed with hearing impairments or disability can be identified before the age of 2, these children are often not acknowledged until school age because of the nature of hearing loss and the continuous unpredictable response to sound (Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs., 2007). The Joint Committee on Infant Hearing (JCIH) approves initial detection of hearing loss for children through state and national systems of universal newborn screening evaluations. The goal of EHDI programs is to maximize communicative competency and literacy development for children who are hearing impaired or deaf (Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs., 2007)

As of effective date July 1, 2014, delegates in the Florida House of Representatives in commission with the Health and Human Services Committee and Harrell joined together to pass the general law SB 722 - Newborn Health Screening (The Committees on Judiciary; Children, Families, and Elder Affairs, 2014). This policy not only exists in Florida, in fact another program similar to EDHI exists in Tennessee. This new technology is an electronic health record called Tennessee Child Health Profile (TN-CHP) developed for infants with disorders detected by the state Newborn Screening and Newborn Hearing Screening (NHS) programs (Holden-Pitt & Diaz, 2006, p. 74). The purpose of this project is to develop the Health Information Technology (HIT) Infrastructure in Tennessee to promote and improve the safety and quality of health care for Children with Special Health Care Needs (CSHCN); in addition, it will develop a comprehensive Child Health Profile for CSHCN based on the same principles of the Child Health Profile developed for infants identified by State Newborn Screening (NBS) and Newborn Hearing Screening (NHS) programs. Lastly, it will promote cooperative agreements between providers of health care for CSHCN and linkages of databases developed by each provider (Holden-Pitt & Diaz, 2006, pp. 75-76).

### **Conclusions & Recommendations**

In short, implementing special support groups for parents with children who are experiencing hearing loss and overcoming this impairment with hearing devices and implants of all sorts, especially cochlear implants is without question, imperative for the affected parties. Furthermore, by requiring all health insurance companies to cover hearing devices, pre/post-operative procedures, office visits, and therapy at no cost to the member, we believe will not only be cost-effective in the long run, but it will increase the development of a child's auditory skills and therefore allowing them to adequately keep up with children of their age when it comes to speech development.

For a parent who after the delivery of their child sees that he/she has all 10 fingers and 10 toes, they are alert and for the most part healthy, then a few days later is informed their child did not pass the Newborn Hearing Screening, questions like "where should I go?", "What should I do?", and "Who can help my child?" comes to mind. All parents want the best care available for their children. In today's economy, getting that can be a difficult thing to obtain. If our proposed changes are accepted, into SB 722, we can bring financial relief, provide clear directions on where to go, and supply those parents with support groups who can show them that there are people who care and are willing to listen when they have doubts and/or unanswered questions.

To date, Florida Law SB 722 has done a great job in advising new parents when their newborn has a hearing impairment in a timely manner, most times within the hospital, and they have pointed parents in the right direction if it is found the newborn did not pass the hearing screening. It is now time for Florida Legislation to not only point parents in the right direction, but give them the tools needed to help produce extraordinary citizens who overcame their hearing disability. It is essential to know, that hearing is one of the 5 main senses we as humans have. The ability to hear not only allows us to listen, but it has a great deal to do with the way we speak. Sometimes we take the ability to hear and speak for granted. But as healthcare professionals, we know, that giving a child the opportunity to hear his/her mother and father's voice for the first time is an emotional and gratifying experience.

## References

- Alston, W. D. (2008, June 9). Building a DNA Database. *New American*, pp. 21-23.
- American Academy of Otolaryngology: Head and Neck Surgery. (2013, January). *Cochlear Implants*. Retrieved from American Academy of Otolaryngology: <http://www.entnet.org/content/cochlearimplants>
- American Speech-Language Hearing Association. (2014, July 20). *Facts about pediatric Hearing Loss*. Retrieved from [www.asha.org/policy](http://www.asha.org/policy): <http://www.asha.org/aud/Facts-about-Pediatric-Hearing-Loss/>
- Holden-Pitt, L., & Diaz, J. (2006). Thirty years of the Annual Survey of Deaf and Hard-of-Hearing Children and Youth: A glance over. *American Annals of the Deaf*, 143(2), 72-76.
- Joint Committee on Infant Hearing. (2000). Year 2000 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. *Pediatrics*, 106(4), 798-817.
- Long Description for New Cochlear Implants in 2001. (2012, October 16). [NIDCD Health Information]. Retrieved July 22, 2014, from <http://www.nidcd.nih.gov/health/statistics/Pages/long-implants.aspx>
- Shiffman, R., & Spooner, A. (2001). Information Technology for Children's Health and Health Care. *Journal of American Medicine Information Association*, 8(6), 546-551.
- The Committees on Judiciary; Children, Families, and Elder Affairs. (2014). *CS for CS for CS for SB 722 Newborn Health Screening*. Retrieved from The Florida Senate: <http://www.flsenate.gov/Session/Bill/2014/0722/BillText/c3/PDF>
- U.S. Department of Health & Human Services. (2012, November). *Text Description for Age at Which Hearing Loss Begins*. Retrieved from National Institute on Deafness and Other Communication Disorders: <http://www.nidcd.nih.gov/health/statistics/pages/long-begins.aspx>
- Use of Hearing Aids by Adults with Hearing Loss. (2012, October 17). Use of Hearing Aids by Adults with Hearing Loss. Retrieved July 22, 2014, from <http://www.nidcd.nih.gov/health/statistics/Pages/hearing-aids-adults.aspx>
- Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. (2007). *American Academy of Pediatrics*, 898-921.

## Appendix

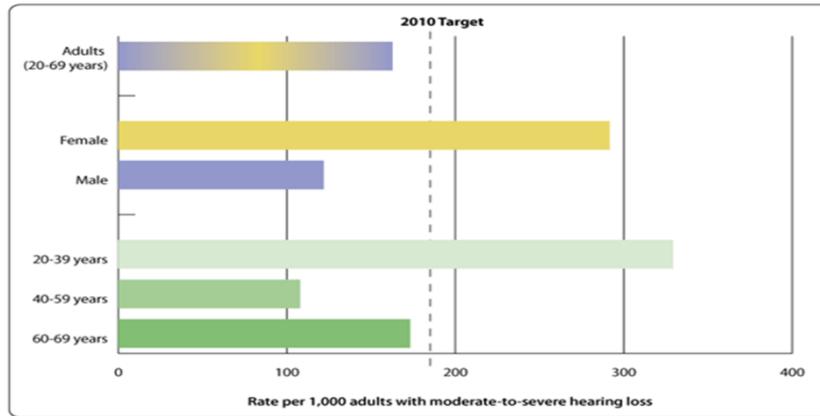
### Appendix A: Age at Which Hearing Loss Begins

The following table depicts the results from a National Health Interview Survey, conducted in 2007 and 2012. The data is organized by percentage distribution by sex and age, based on subjects' report of any permanent hearing loss (U.S. Department of Health & Human Services, 2012). When the impairment is identified at birth, the individuals and their parents can gain access to resources to help them.

	Female	Male
<b>Birth</b>	2	2
<b>0–2 years</b>	3	2
<b>3–5 years</b>	3	2
<b>6–19 years</b>	12	11
<b>20–39 years</b>	20	32
<b>40–59 years</b>	30	32
<b>60–69 years</b>	14	12
<b>70+ years</b>	16	8

**Appendix B: Use of Hearing Aids by Adults with Hearing Loss**

The National Institute of Health showcased the following graph on their website, the 2010 target lines represent the goals recommended by the Hearing Health group, which were discussed and approved by the Federal Interagency Working Group for Healthy People 2010 (Use of Hearing Aids by Adults with Hearing Loss, 2012).



**Appendix C: New Cochlear Implants in 2001**

This chart was created by the Health Promotion Statistics Branch, NCHS, CDC and the Epidemiology and Statistics Program, NIDCD, NIH. Notice the number of cochlear implants needed for children under 6 years of age per 10,000 deaf or very hard of hearing persons (Long Description for New Cochlear Implants in 2001, 2012).

**Rate per 10,000 Deaf or Very Hard-of-Hearing Persons**

All Ages, Male and Female	51
Female	64
Male	43
Under 6 years	1,035
6-17 years	84
18-44 years	48
45-64 years	54
65 years and over	18