## Missouri Communicator

Missouri Commission for the Deaf and Hard of Hearing Winter 2017 Edition: Moving Missouri Forward



MCDHH works with individuals, service providers, businesses, organizations, and state agencies to improve the lives and opportunities of all Missourians with hearing loss.

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#### Language Delayed is Language Denied

Opeoluwa Sotonwa, MCDHH Executive Director

"Special needs families know their children best. And it is time we gave control back to those parents, to select the best possible education for their children. Every kid in the state of Missouri—whether in a public school, private school, or homeschool—deserves a fair shot at the American Dream."

Governor Eric Greitens, January 17, 2017

I had the honor of attending Governor Eric Greitens' State of the State Address where he made the above statement which I found profound in terms of his policy and a genuine desire to making the education of children with special needs a priority. It is the joy of all parents to see their children grow into productive adults; this altruism applies in particular for parents of deaf or hard of hearing children. Evidence abounds that a child born



Opeoluwa Sotonwa with House Speaker Todd Richardson

with a disability can be assisted to live a productive life if such disability is detected early and proper mitigating interventions are accorded to the child.

Hearing loss is one of the main disability challenges affecting American children. According to statistics obtained from the National Institute on Deafness and Other Communication Disorders (NIDCD), two to three out of every 1,000 children in the United States are born with a detectable level of hearing loss in one or both ears. More than 90 percent of deaf children...

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#### **Meet Our Commissioners**

**Donna G. Schreiner, Chair** Seat for Deaf or Hard of Hearing Member

**Dr. Thomas Horejes, Vice Chair**Seat for Deaf or Hard of Hearing Organizations

Mary E. Hale

Seat for Deaf or Hard of Hearing Member

Owen VandeVelde

Seat for Parent of a Deaf or Hard of Hearing Child

Wendy Jensen

Seat for Local Public School Administration

**Shelly Jones** 

Seat for Representative for Interpreters

**Ernest Garrett, III**Seat for DESE or MSD

**Dr. Katie Barton**Seat for Audiologist

#### **Meet Our Staff**

Opeoluwa Sotonwa Executive Director

> Dee Sanfilippo MICS Coordinator

Jessica Brown
Interpreter Certification Specialist

Christopher Ludvigsen Community Support Liaison

Emily Fry
Information Program Specialist

Laurie Lister
Office Support Specialist

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...are born to hearing parents. Similar surveys conducted by Centers for Disease Control and Prevention (CDC) have shown a declining trend in the disability, but the numbers remain high. Missouri, like other states, is faced with the challenge of initiating policies and legislation that will not only provide these mitigating interventions but equally ensure current laws and policies are implemented in a manner that would yield optimal results.

As a result of the clarion calls from community members to provide a direct response to the growing epidemic of language deprived deaf children in Missouri, Senator Gina Walsh (D) proposed Senate Bill No. 51. The same measure has also been introduced in the House by Representative Travis Fitzwater (R), making it a commonsense, bipartisan bill. The bill seeks to establish a language assessment program for deaf and hard of hearing children. The program will track and assess the development of language in deaf and hard of hearing children from birth to eight years with the objective of improving language acquisition abilities among this category of children and advising parents.

Under the provisions of the bill, every deaf and hard of hearing child who is less than nine years old will be given an annual language assessment. An advisory committee will be established to operate within the MCDHH to lay the platform for the development of the program. The members of the committee will be professionals with advanced knowledge and experience in teaching and developing language and curriculum for the deaf and hard of hearing. The committee will gather data on the condition of the program and develop a road map to

#### **Community leaders with Rep. Travis Fitzwater to discuss SB 51**

[Left to right: **Dr. Thomas Horejes**, Executive Director of DEAF, Inc. and MCDHH Vice Chair; **Cheryl Broekelmann**, St. Joseph Institute for the Deaf; **Rep. Travis Fitzwater**; **Opeoluwa Sotonwa**, MCDHH Executive Director; **Betsy Moog Brooks**, Executive Director of The Moog Center for Deaf Education; **Robin Feder**, Executive Director of Central Institute for the Deaf]

guide various stakeholders on implementation.

It should be noted that the bill is neither seeking to provide a mandatory way of learning a language to the detriment of others nor requesting that all parents of deaf and hard of hearing children should be forced to adopting a language. Rather, the program seeks to provide a yearly assessment so that the parent can make a timely and informed decision on how best to help their child.

The implementation of this program will not increase the public burden in financing its activities, but rather utilize the resources already available in the

state. A primary resource for the program may come from existing federal programs for Infant and Toddlers with Disabilities as provided in Part C of Individual with Disability Education Act (IDEA). This program avails funding to states to provide early intervention for children with disabilities.

Deaf & Hard of Hearing
Awareness Day
Six Flags St. Louis

Six Flags
St. Louis

Contact MCDHH to reserve your tickets
mcdhh@mcdhh.mo.gov
(573) 526-5205

Evidently, a child language delayed is a recipe and harbinger to the cognitive development of such child. Hence, language delayed is language denied. It is our responsibility as a state to initiate policies that provide every Missouri child the tools and resources to have a fair chance to succeed.



It is also worthy of note that the Missouri Department of Elementary and Secondary Education has launched Top 10 by 20. which is a major improvement effort that aims for student achievement in Missouri to rank among the top 10 states by 2020. Creating a Language Assessment Program will no doubt ensure our deaf and hard of hearing kids are not only kindergarten-ready but will also have the foundation to thrive in line with Top 10 by 20 goals.

#### **Accessing Hearing Aids**

Dr. Katie Barton, Audiologist, Mercy; Missouri Commission for the Deaf and Hard of Hearing, Seat for Audiologist



It is well known in the field of audiology that on average patients will wait over five years from the time they suspect hearing loss until the time they seek hearing care. Many other people with hearing loss are not seeking care at all. Of the 30 million people who experience age-related hearing loss, only about 14 percent use some sort of amplification device, according

to the National Academies of Sciences, Engineering, and Medicine. There are a multitude of reasons this may happen. We occasionally see patients who have waited to seek care due to concerns the aids will make them look older or less competent in their job. There are other patients who know they need help and desperately want to wear the products to communicate more effectively, but cannot afford the costs of evaluation and treatment. Other patients may want to seek help but are unsure of where to start: Do they call their primary care physician? Do they seek help at the local hearing aid storefront? Do they contact an ENT physician? Will they need an order for testing? Do they need a medical evaluation prior to purchasing hearing aids? Have they ever heard of an audiologist?

The question facing us is: How often are hearing aid accessibility issues--such as confusion, hurdles during the process of obtaining amplification, and cost of hearing aids--causing the patient to wait or ignore their symptoms? Hearing care providers see the consequences of this wait time far too often. When communication breaks down, frustration occurs. When the situation gets too frustrating, people begin isolating themselves or severing relationships. By the time the patient walks through the door, not only do they have hearing loss, but they may also be dealing with social issues, depression, anxiety, or job loss, all stemming from their communication difficulties. Recent movement on the issue of hearing aid accessibility from Washington, D.C. has put these issues front-and-center.

In December 2016, the FDA released a guidance document addressing accessibility issues for airconduction hearing aids. The document states that the FDA regulation requiring medical evaluation prior to fitting a hearing aid would no longer be enforced for consumers over the age of 18. Prior to this statement, any patient being fit with a hearing aid was required to either undergo a medical evaluation or sign a document waiving the medical evaluation requirement. guideline, which was established in the 1970s, was considered one of many hurdles that patients needed to jump prior to obtaining hearing aids. Of course, there are medical conditions needing treatment that could be detected or suspected during a hearing evaluation, and the FDA continues to advise that hearing health professionals require medical evaluation (preferably by an ear specialist) in these cases. This underlines the importance of having a qualified and knowledgeable individual performing the hearing evaluation.

Also in December 2016, a new federal bill was introduced into Congress to provide for the regulation of over-the-counter hearing aids for adults with mild to moderate hearing loss. Also mentioned in this bill is self-assessment of hearing loss. This bill addressed recommendations made from the National Academies of Science, Engineering and Medicine and the President's Council of Advisors on Science and Technology to allow for better access to hearing aids, expanding consumer choice, and opening the market to innovation in the industries of hearing aids and personal amplification systems.

While individual opinions vary greatly, many hearing health professionals have concerns with a widespread use of over-the-counter hearing aids and self-assessment tools. Another accessibility issue that can be seen is the patient that has tried some sort of amplification device, but the particular device was inappropriate or ineffective. This not only causes the patient to be unwilling to try other devices in the future (even much more appropriate devices), but the individual may tell all his or her friends and family about how

the "hearing aids" were terrible and didn't work. This further spreads negative information and stigmas about hearing aids, and leads to others ignoring symptoms or not seeking care. As a hearing care professional, this is extremely frustrating to see, especially when these patients finally commit to trying appropriate amplification and report that they "wish they would have done this years ago."

As hearing aid accessibility advances, it will be interesting to see how both the consumer and hearing care professional navigate the new market. Will consumers be satisfied with self-assessments and over-thecounter personal amplification devices? Will the influx in information and accessibility into the hearing healthcare world eventually lead a larger percentage of the population with hearing loss to more traditional devices? Will hearing healthcare specialists find better ways to compete with lower cost

amplification options, such as unbundling services and providing lower cost options?

As a hearing healthcare professional, I fear that these advances may not solve the issues with accessibility they were designed to solve. If patients have a poor experience with self assessment and treatment, or dump too much money into ineffective hearing devices, it could actually cause accessibility to appropriate and effective care to worsen. With advances in accessibility and widening of the amplification field, consumers need to be informed of the options available to them,

#### Save the Date!

#### **24th Annual Missouri Interpreters Conference**

October 13-14, 2017 Holiday Inn Executive Center Columbia, MO



Stay tuned for more details!

whether in an over-the-counter model or from a hearing care professional, and be made aware of the differences between the two.

Dr. Katie Barton is an audiologist with Mercy in the St. Louis area and sits on the Missouri Commission for the Deaf and Hard of Hearing as a representative for audiologists. This piece was written from Dr. Barton's personal perspective and professional experience as an audiologist and does not reflect an official position of the Missouri Commission for the Deaf and Hard of Hearing.

# 2017 Legislative Priorities

Each year, MCDHH selects a handful of issues to focus on during the legislative session. The choices are dependent on a variety of factors: current needs, funding availability, community and organizational support, and climate of the legislature, among other things. The following are priorities that MCDHH will be focusing on throughout the 2017 legislative session:

#### **Language Assessment**

**Goal**: To establish an advisory committee that will oversee a statewide language assessment program for Deaf and Hard of Hearing children ages 0-8.

Why this is needed: Closely monitoring language skills—in both English and ASL—will provide more information for parents to make decisions about their child's education. Without an early understanding of language skills, many Deaf and Hard of Hearing children experience language delay or deprivation, which can have a negative long-term impact on their learning.

SB 51 sponsored by Sen. Gina Walsh HB 1076 sponsored by Rep. Travis Fitzwater

## **Hearing Aids for Low- Income Missourians**

**Goal**: To use existing funding for the statewide telecommunications equipment distribution program to provide financial assistance for hearing aids for low-income individuals.

Why this is needed: Many Missourians with hearing loss are not able to afford hearing aids; giving them access to hearing aids can improve communication in the workplace and in relationships with family and friends.

HB 903 sponsored by Rep. Mike Kelley

#### **Funding for Statewide SSP Program**

**Goal**: To fund the SSP program established last year by the passage of House Bill 1696.

Why this is needed: Last year, Missouri's Deaf, DeafBlind, and Hard of Hearing Community came together to advocate for HB 1696, which gave MCDHH the authority to set up a statewide program to train SSPs and provide support services to DeafBlind individuals. While MCDHH has been working to develop the program structure, it is essential to obtain funding in order to put the plans into action.

MCDHH is working to see that funds are appropriated in the FY 2018 Budget.

#### Text-to-911

**Goal**: To make 911 emergency services available to Deaf and Hard of Hearing individuals statewide.

Why this is needed: If a Deaf or Hard of Hearing individual is in an emergency situation, it may be difficult or impossible for them to communicate their needs via a telephone voice call. If it were possible to send text messages to 911 operators, the quality and timeliness of the first responder services would increase for Deaf and Hard of Hearing individuals. In these situations, a delay of only a few minutes can be the difference between life and death.

Rep. Lyle Rowland has filed HB 1094

#### **Movie Captioning**

Goal: To make movie theatres more accessible for Deaf and Hard of Hearing individuals.

Why this is needed: It is a common standard in today's theater industry to have captions available on all films, but it is rare that a theater projects them for the entire audience. In order for Deaf or Hard of Hearing individuals to access the dialogue of a film, they must request captioning devices. This creates extra work for the movie-goer that still results in an experience of unequal quality.

Legislation not yet filed

Across Missouri

Conversations Across Missouri (CAM) is a creation of MCDHH and part of a broader mission to serve our community, our great state, and our world through engagement and dialogue.

CAM are gatherings of people for self-guided discussions on topics relevant to the Deaf, DeafBlind, Hard of Hearing, service providers, and their families.

CAM will be hosted across Missouri from time to time in our efforts to learn, listen, think and Knowledge Knowledge Listening Experience inspire genuine conversations that will lead to real change at all levels and to make Missouri a model for others.

JOIN or INVITE us to initiate REAL CONVERSATIONS!

# Deaf, DeafBlind, and Hard of Hearing LEGISLATIVE DAY At The Missouri State Capitol

April 26, 2017 | 10 am-5 pm

Join MCDHH to show your support of the many issues legislators are considering that impact our community, including language assessment, hearing aid financial assistance, and movie captioning. This event will include remarks from legislators and community leaders, informational booths, and meetings with your representatives. A full schedule will be announced before the event.



## Setting Our Children Up For Success

Senator Gina Walsh, Senate Sponsor, SB No. 51



Next year, the Missouri Commission for the Deaf and Hard of Hearing (MCDHH) will celebrate its 20th anniversary. From providing assistance with federal and state disability statutes to conducting workshops and training programs related to sign language and interpretation, the Commission has done some truly great work in the last two decades.

As it looks ahead to the next 20 years, I cannot think of a better place from which to draw inspiration than that of our youngest Missourians affected by hearing loss.

For the 2017 legislative session, I have filed legislation to ensure all of Missouri's children who are deaf or hard of hearing gain an advantage in their language development. Quite simply, Senate Bill 51 establishes a language assessment program for children who are deaf or hard of hearing from birth through the age of 8. The assessments will be provided either through early intervention services administered by the Commission or through the child's school district, provided the child is 3 years or older. The program will be coordinated by the MCDHH

The need for this legislation was brought to my attention during a meeting with a local constituent and LEAD-K supporter in May 2016. LEAD-K is a

# Learn More About Senate Bill 51

Read the Bill in full and keep track as it progresses through the legislative process.

Visit
http://www.senate.mo.gov/legislation/
Click "List of 2017 Senate Bills"
Click "SB 51" in the list

national campaign that promotes language acquisition and kindergarten-readiness for toddlers and youth, ages 0-5, who are deaf or hard of hearing.

Far too often, deaf children, who are visually oriented, arrive at kindergarten without adequate language skills — not because of an inability to learn and understand language, but because of our society's focus on traditional speech skills development. LEAD-K is working to improve the way educators teach language to deaf babies and children. If signed into law, SB 51 will provide the Commission with the additional resources and support they need to continue improving the lives of children in Missouri who are deaf or hard of hearing.

### Community leaders with Senator Gina Walsh to discuss SB 51.

[Left to right: Betsy Moog Brooks, Executive Director of The Moog Center for Deaf Education; Cheryl Broekelmann, St. Joseph Institute for the Deaf; Robin Feder, Executive Director of Central Institute for the Deaf; Senator Gina Walsh; Opeoluwa Sotonwa, MCDHH Executive Director; Dr. Thomas Horejes, Executive Director of DEAF, Inc. and MCDHH Vice Chair]









Watch episodes of MCDHH's new vlog series, Coffee with Ope, on our YouTube channel! In these videos, Ope invites leaders in the community to discuss contemporary issues in Missouri's Deaf and Hard of Hearing world. The first vlog features Commissioner Ernest Garrett, III, Superintendent of Missouri School for the Deaf.

# Mark Your Calendar! For Upcoming MCDHH Events

#### - March -

29: BCI Meeting 30: Commission Meeting

#### - April -

26: Deaf, DeafBlind, and Hard of Hearing Legislative Day

#### - May -

8: Truman Day - Office Closed 29: Memorial Day - Office Closed

#### - June -

3: Six Flags St. Louis Deaf & Hard of Hearing
Awareness Day
29: Commission Meeting

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# What do YOU want to see in the next Communicator?

Share your ideas with us.
Submit your article topics,
newsletter themes, photos,
or Community Perspective
proposals to the editor at
Emily.Fry@mcdhh.mo.gov for
consideration.



## Missouri Commission for the Deaf and Hard of Hearing

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Sotonwa, Emily Fry

Looking for ways to support Missouri's 600,000 Deaf and Hard of Hearing citizens?

Send an email to MCDHH@mcdhh.mo.gov to discuss ways you can contribute to the Commission's mission to improve the lives and opportunities of Missourians with hearing loss.