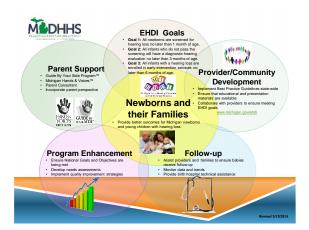
IMPROVING OUTCOMES FOR CHILDREN WHO ARE DEAF OR HARD OF HEARING

The Impact of Early Identification, Parent Support and Early Intervention

Amy E. Miller, M.N.S., CCC-SLP, Ingham Intermediate School District Michelle Garcia, Au.D., MDHHS – Early Hearing Detection and Intervention (EHDI) Program Kristen Carmany, MICC, Parent Representative Alternate, C.O.O.R. Intermediate School District







MICHIGAN 2010-2013 SCREENING NO LATER THAN I MONTH

Birth Year	< 1 Mc	onth	I-3 Months	> 3 Months	Age Unknown
2010	108,011	97%	2.1%	0.8%	0.4%
2011	106,983	96%	2.5%	1.1%	0.3%
2012	106,118	96%	2.5%	1.2%	0.2%
2013	107,074	97%	2.5%	0.9%	0.08%
*Age at hea	ring screen an	nong infan	ts born in MI: MI EF	IDI Data, 2010-2013.	

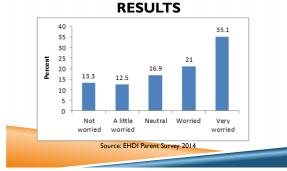


PARENT PERSPECTIVES

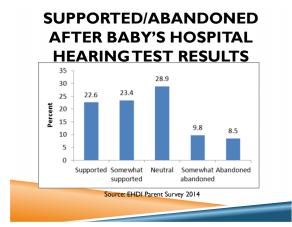
Realize the Journey to a diagnosis can sometimes seem long, with confusion along the way.



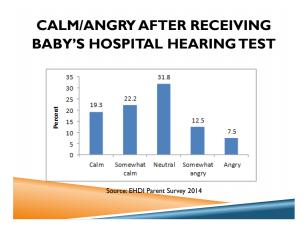
LEVEL OF WORRY AFTER RECEIVING BABY'S HOSPITAL HEARING TEST













DID YOU KNOW WHAT TO DO NEXT?



PARENT PERSPECTIVES

- "My baby was screened 7 times in the hospital... I finally said, 'Enough!'"
- "...we were on pins and needles. What if something was wrong? What does it mean? With all of the nerves, worries, and fears that new parents have, this was not something that we planned for."
- "My daughter was diagnosed shortly after birth, and has had hearing aids and language support from the get-go..."



MICHIGAN 2010-2013 LOST TO FOLLOW-UP (LTF)/LOST TO DOCUMENTATION (LTD)

Birth Year	Referred	LTF/	LTD
2010	1531	833	54%
2011	1557	822	53%
2012	1173	569	49%
2013	1182	491	42%

Data Source: MI EHDI Data, 2010-2013.

PROGRESS IN IDENTIFYING INFANTS WITH HEARING LOSS-UNITED STATES, 2006-2012

Reasons Lost to Follow-Up/Lost to are as follows:

The parents/family were contacted but unresponsive.

Unable to contact.

Unknown.

*Excludes infant died, parents refused, or parents moved out of state.

HOW CAN EARLY ON HELP?

Action Items

Did baby pass newborn hearing screen?

- Encourage family to go for diagnostic test.....too many hearing screens!
- Do you know where the closest PEDIATRIC diagnostic center is
- located?





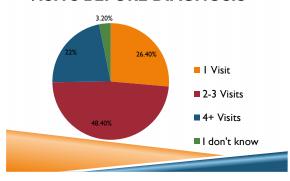
MICHIGAN 2010-2013 DIAGNOSING NO LATER THAN 3 MONTHS

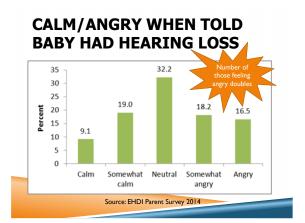
Birth Year	# Babies with Hearing Loss	< 3 Months	3-6 Months	> 6 Months
2010	144	58%	24%	17%
2011	166	52%	30%	19%
2012	162	54%	23%	23%
2013	156	56%	22%	22%
Date	Source: MI EHDI Da	- 2010 2012		

DIAGNOSTIC EVALUATION

- ► Gives specific information about hearing status, not just pass/refer
- Should be done by an audiologist experienced with working with <u>children</u>.
- ► Should be a battery of tests: ABR, OAE, Tympanograms, Acoustic Reflexes, Behavioral
- Best practice facilities have to work hard to be recognized as best practice facilities.

NUMBER OF HEARING TEST VISITS BEFORE DIAGNOSIS





LATE ID OF HEARING LOSS

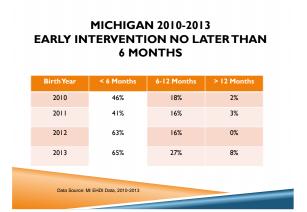
- Late identification of hearing loss or lack of early intervention services can negatively impact speech and language development, academic achievement and social-emotional development.
- The most critical time for stimulating the hearing centers in the brain is during the first few months of life.

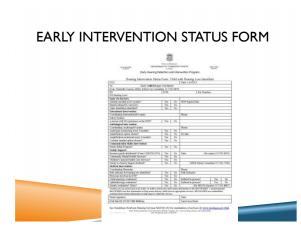


WHAT IS ANOTHER NAME FOR SUPERMAN?

- A. The Red Redeemer
- B. The Masked Avenger
- C. The Caped Crusader
- D. The Man of Steel







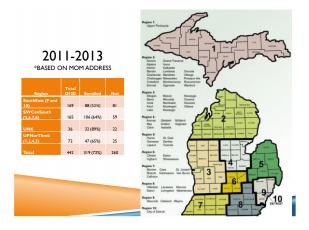


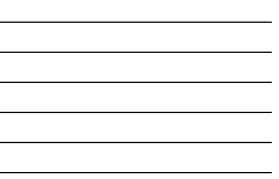
EARLY ON DATA SHARING

Year	# HL	Pre- Sharing # Enrolled	Pre- Sharing % Enrolled	Post- SharingE nrolled Updated 4/2015	Post- Sharing% Enrolled
2011	156	63	40%	103	66%
2012	152	32	21%	91	60%
2013	151	75	50%	82	54%

Aggregate Data Sharing Protocol developed and agreed upon in January 2015.

- After 2013 completed, went back and evaluated 2011 and 2012.
- Updated numbers for 2013 in April 2015.





DIAGNOSIS: NOW WHAT

- Refer to specialists
- Genetics − sometimes syndromes can be discovered later
- Start Educational Planning
- ► It is about **COMMUNICATION**
 - Communication decision can be a flexible process. As a parent learns what works for the child, decisions can change.
 - "Goodness of fit" Families consider family goals, resources, risks, culture, degree of loss, and available information.

PROFESSIONALS	PARENTS
EXPERTS.	NEWBIES.
Familiar with VOCABULARY.	Audiogram? Impaired? Disabled? CSHCS? Vestibular? ASL? Decibels? Banana? Receptive? Early On? Hertz? Transition? Expressive? Speech Discrimination? Inner Ear? Hair Cells? IFSP? AVT? Sound Threshold? OAE? Connexin? Cue? Ear Mold? Tymp? SEE? AABR? Bilateral? D/d? Sensorineural? HA? SPL? SLP? Cerumen? Total Communication? LSLS? Deafblind? HOH? CI? Who? Where? Why? How? When?
Go home at end of day and put it aside	Live it and Breathe It Instantly and Constantly
PAID.	NOT PAID. Financial and emotional tolls. Stress.

INFORMATION RECEIVED AT DIAGNOSIS

	92%	7%	2%
			2/0
cess	83%	15%	2%
	70%	17%	12%
Parent support programs – meeting other parents			
Insurance coverage for tests and hearing aids			
Causes of hearing loss			
Parents	58%	32%	9%
may not	48%	39%	3%
get this	22%	50%	26%
imo.			
1	ther parents ring aids Parents may not	Parents Parents 70% 66% 63% 88% may not get this 22%	Parents may not get this 220% 63% 32% 58% 32% 22% 50% 58% 32% 22% 50% 50% 50% 50% 50% 50% 50% 50% 50%

PARENT PERSPECTIVES

SUMMING IT UP

- Many did not understand the next steps in the process to get a diagnosis.
- Many had to make multiple trips to a specialist.
- Once hearing loss was confirmed, the number of parents who feel angry doubles.
- Now there's a lot for them to learn.
- But many do not get ALL the information they should get.

By and large, parents may not KNOW anything and they don't KNOW what to ask.



GRIEF.

"The days that followed my son's identification of hearing loss were filled with the echo of my cries along with his. I remember feeling like something was wrong with me - or with everyone else. No one seemed to think it was a big deal. They would say, "Well, at least he's healthy."

"Yes, YES - I know I should be grateful for that, but why wasn't anyone else upset that my son couldn't hear! Certainly, I grew to learn how much he could hear. But at the time "mild-moderate" had no meaning to me. There was no history of hearing loss in either sides of the family. I had a healthy pregnancy. The "Why?" haunted me for a couple of years."

HOW PARENTS DESCRIBE IT

- Felt out of CONTROL.
- Wanted to know what I was doing was RIGHT.
- The tests, and what I knew about my child, seemed to CONFLICT.
- ▶ What did I do WRONG?
- I'm Deaf/Hard of Hearing. What's the big deal?
- WEIGHT on my shoulders.
- Aids will "fix" it, right?
- Nobody UNDERSTOOD.

SO WHAT CAN BE DONE?

- Empathy
- Patience
- Get families ALL the information so they can make informed decisions.
- Support from a FULL RANGE of perspectives

THE FAMILY'S PROCESS

- ACTION
- ADVOCACY



Noel Matkin, 2009 H&V National Leadership Conference

FACTORS AFFECTING EMOTIONAL RESPONSE

- Birth Order of Children.
- Birth Experience.
- Screening and Diagnosis Experiences.
- Other current health issues of child.
- Religion/Beliefs.
- Parents' experiences with previous medical situations in their family.
- Family history with hearing loss and deafness.
- Degree of child's deafness.
- Personality.

EARLY ON ELIGIBILITY

Eligibility requirements related to Hearing loss are:

Established Condition – Hearing Deficiency

 Bilateral or unilateral hearing loss of greater than or equal to 25 dB at a minimum of 2 frequencies between 500 and 4000 Hz.



SUPPLEMENT TO JCIH 2007 POSITION STATEMENT: PRINCIPLES AND GUIDELINES TO EI AFTER CONFIRMATION THAT A CHILD IS D/HH

Goal 7

All children who are identified with HL of any degree, including those with unilateral or slight hearing loss, those with auditory neuropathy, and those with progressive or fluctuating hearing loss, receive appropriate monitoring and immediate follow-up intervention services where appropriate.

IMPACT OF SERVICES EARLY

- Approximately 2.5 million, or 5.4%, of all school-age children, have mild or unilateral hearing loss.
- Over one-third of these children are projected to fail at least one grade and/or will require additional educational support, costing the educational system over \$5.5 billion.
- Children with mild or unilateral hearing loss can benefit from early intervention services. Left undetected, mild or unilateral hearing loss can result in delayed speech and language acquisition, social-emotional or behavioral problems, and lags in academic achievement.



WHY ARE BABIES NOT ENROLLED?

- Parents going through grieving process and not ready?
- Are parents not understanding what Early ON can provide?
- Early On providers not starting services due to lack of understanding of importance?
- Are parents aware of Early On?
 - Nearly 40% of children identified with hearing loss and their families are not referred to the Part C early intervention system and may not be aware of the broad array of services and funding available to them.
- ► Need to investigate to find out WHY.

WHAT IS SUPERMAN'S ONLY WEAKNESS?

- A. Samsonite
- B. Cosmonite
- C. Kryptonite
- D. Plutonite



THE GOAL

- Strong Family
- ▶ Effective Education
- WASK:

Well Adjusted Successful Kid

A result of good decisions

Source: Hands & Voices Headquarters

WHY DO FAMILIES NEED SUPPORT

- ▶ 95% of all children who are deaf or hard of hearing are born into hearing families (Mitchell & Karchmer 2004)
- ▶ 90% of these families have no background in deafness or connections to the deaf community (Center for Demographic Studies 1984)
- "The key to a successful integration of hearing loss into a family is the degree to which parents are able to integrate hearing loss into their lives" (D. Luterman, 2006)

RESEARCH SUPPORTS PARENT-PARENT SUPPORT

- Parents reporting social networks with other parents of children who are deaf were associated with less isolation, greater acceptance of their child, and improved interactional **responsivity**. (Hintermaier, M., 2000)
- In a nationwide survey, 97% of parents of deaf or hard of hearing children stated that they preferred to get support & information from another parent of a child who is D/HH. (Wood Jackson, C., 2009)



MICHIGAN HANDS & VOICES GUIDE BY YOUR SIDE PROGRAM

17 Parent Guides around the state

Will come meet with family in home or wherever the family is comfortable, as many times as needed.

Represent many different experiences with deafness:

- From Profound all the way through Mild.
- Bilateral and Unilateral.
- ASL, Oral, Total Communication, Cued speech, .
- Auditory Neuropathy, Microtia/Atresia, Syndromes.
- .
- Identified as newborn, late, and adopted. Michigan School for the Deaf, in-school programs, mainstreamed, etc. .

GUIDE BY

YOUR SIDE

WHO IS GUIDE BY YOUR SIDE (GBYS) FOR?

- Families of newborns and children recently identified.
- Families who need guidance in the journey: how to make sure their child's needs are met, a need to build confidence, need another family as a model
- Families who have recently moved to Michigan.
- Families going through a transition period with their child
 Part C to Part B
 - Starting kindergarten
 - > Just now realizing the impact on the child or the family
- NEW! Now seeing families of older children too!

GBYS PARENT GUIDES

- Are paid.
- Are <u>not</u> advocates for IEP meetings.
- Follow the GBYS 8 Guiding Principles.
- Are formally trained biannually, attend conferences, and are encouraged to undertake additional training on their own.
- Are assessed annually to encourage growth.
- Collaborate with medical and educational professionals.
 - Clarify recommendations.
 - Ensure referrals.
 - Help family understand the available services.

GBYS PROCESS

- MATCH: The GBYS Coordinator matches a family to a Parent Guide based on geography, degree of deafness, stated interests or concerns, cause of hearing loss, and more.
- IN PERSON: Guide meets with family in person at their home or wherever they feel most comfortable.
- AGENDA: Family dictates agenda: Emotional, Resources, Advocating, Navigating Systems, etc.
- CHECK: Guide has checklist to ensure all resources are being utilized. Makes referrals as needed.
 - Awareness of communication modes and information about them given in unbiased manner
 - Early On, CSHCS, Opthamology, Genetics, etc.
- MORE: Family may meet as many times as they want with Guide.

GBYS BENEFITS

- Empowers families
- Promotes self efficacy and hinders isolation by exploring our common bond, experiences, challenges, and wisdom.
- Combines an experienced parent's insight with knowledge of early intervention and educational systems.
- Helps families understand what they are feeling, not make the feeling go away
- Helps professionals when parents know what to ask and how to ask it.



GUIDE BY YOUR SIDE

"I had so many questions about day to day life, and she had so many examples." - Parent



"Only another parent 'gets it.""

It's a great first step into this community of families who all can relate to one another. It's the door that opens into Hands & Voices and a lifetime of support for our kids. -Coordinator

WHAT IS THE NAME OF BATMAN'S SECRET IDENTITY?

- A. Bruce Devon
- B. Bruce Wayne
- C. Bruce Davis
- D. Devon Bruce



WHAT ARE THE BURNING ISSUES WE HEAR IN OUR STATE?

- School programs for HI closing.
- I did not know there was state school for the deaf/HI program near me.
- How do I know my child is getting the right amount of therapy?
- There is no Teacher Consultant in my county!
- How can I make sure my child is safe?
- My child needs friends like her.
- Help! They tell me my child cannot receive special education services!
- My child's SLP has never worked with students with hearing loss.

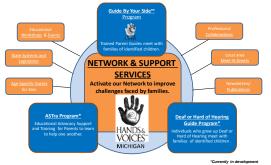
MICHIGAN HANDS & VOICES

- We are a parent-driven, parent/professional collaborative group that supports families without bias about communication modes and methods.
- We believe that there is no one communication choice that will work for all children who are deaf or hard of hearing.
- We think families need access to good information that's free from a sponsoring agenda or ideology.
- We believe our children have a fundamental human right to communication, regardless of their mode or method of communication.
- We believe Parent-to-Parent Support is a cornerstone for families finding their way, "...when you come to a place where the streets are not marked." – Dr. Seuss
- We promote the life experiences and talents of adults who are Deaf and Hard of Hearing to help families ensure success for their children who are d/hh.
- We get meaningfully involved in EHDI programs, educational advocacy, and other systems to improve them from an end-user perspective. – through highly trained, knowledgeable parents
- We exist to help our children/students reach their highest potential.

"What works for your child is what makes the choice right." ©













www.mihandsandvoices.org/join.html

HOW DID SPIDERMAN GET HIS SUPERPOWERS?

- A. He was bombarded by cosmic rays.
- B. He was born with his powers.
- C. He was caught in a chemical explosion.
- D. He was bitten by a radioactive spider.



PARENT PERSPECTIVES

SUMMING IT UP

- Even if the journey to diagnosis was not particularly long, it may have been traumatic.
- It is a surprise to the majority.
- ► Grief.
- Parents need ALL INFORMATION, and to hear from a FULL RANGE of perspectives in order to move forward.

Michigan Hands & Voices[™], and its Guide By Your Side[™] program can help in the beginning and beyond.























after only 4 weeks activated. First word spoken after only 2 months after cochlear activated, and of all words it was "Peppa"

First response to sound after Cochlear Implant,



EARLY ON REFERRAL...NOW WHAT?

Early On Service Providers have a key role to play in

- Reducing loss to follow up
- Ensuring that a child receives appropriate early intervention services

FACTS ABOUT PEDIATRIC HEARING LOSS

- 92% of children with permanent hearing loss are born to two hearing parents.
- According to 2005 data, when parents were clearly instructed on communication choice, 85% chose spoken language options, compared to 15% who chose sign language options (Brown, 2006)
- Even mild hearing loss can interfere with spoken language and education performance. Children with unilateral hearing loss are TEN times more likely to be held back at least one grade. (Cho Lieu, 2004)

THIS SUPERHERO'S SUPERTOOLS INCLUDED BULLET-PROOF BRACELETS AND A MAGIC LASSO. WHO IS SHE?

- A. Wonder Woman
- B. Super Girl
- C. Catwoman
- D. Elastigirl



GETTING STARTED WITH A FAMILY

Service Coordination:WHO?

- Service Provider(s)
 - Specialized Skills needed
 - Audiologist
 - Special Education Teacher with DHH certification?
 - Speech-Language Pathologist?
 - Listening and Spoken Language Specialist?

COMMUNICATION CHOICE

- Parents should be provided non-biased information on all communication options.
- Choices in Deafness, 3rd edition: This book was written in 2007. It is a very relevant text and still a good choice for families.
- ncbegin.org: This is the website for the North Carolina nonprofit Beginnings for parents of Children who are Deaf or Hard of Hearing.
- Parent Notebook: Michigan Guide By Your Side. VERY comprehensive resource.
- REMEMBER: Parents of a newly identified young child with hearing loss are facing an enormous decision about their child's communication choice that few other parents ever have to face.

PARENT SUPPORT

 If the child's family has not yet been referred to Guide By Your Side yet it is our job to make that referral as soon as possible.

- You can submit online at mihandsandvoices.org
- mihandsandvoices@gmail.com
- (248) 845 8762
- The GBYS program has grown tremendously in the past few years and they will find a guide suitable for a family.

UNILATERAL HEARING LOSS

- Part C vs. MMSE
- General Early Interventionist?
- Role of SLP or HITC?
- Needs CLOSE monitoring of language milestones
- Consideration for technology
- Parent education and training

MILD TO MODERATE HEARING LOSS

- Part C vs MMSE
- Usually receive amplification early
- Usually do well with amplification
- Full time technology use
- Appropriate Audiology and medical Follow Up
- Parent education and coaching
 - Best Practices in Early Intervention
 - Supporting the child's chosen communication mode in the home setting

SEVERE TO PROFOUND HEARING LOSS

- Part C vs MMSE
- Usually amplified early
- Hearing aids may not give adequate benefit
- Promote full time technology use, regardless of benefit
- Appropriate Audiology and medical follow up
- Parent education and coaching
 - Best Practices in Early Intervention
 - ASL or TC: aggressive training in ASL and optimally a provider who is an ASL user
 - LSLS: There are 11 LSLS certified professionals in Michigan; great need to build capacity for Early On Providers to have enough skills in this area to work WITH the medical providers as a team to follow through with auditory therapy goals in the natural environment.

IN THE MOVIE ANCHORMAN, RON BURGUNDY SAYS THAT WHAT SUPERHERO WAS DENIED A BANK LOAN?

- A. The Phantom
- B. The Flash
- C. The Punisher
- D. The Human Torch



LISTENING AND SPOKEN WHAT?

- 10 Principles of LSLS Auditory-Verbal Therapy/Education (listeningandspokenlanguage.org, the website of the AG Bell Association for the Deaf and Hard of Hearing)
- Overwhelming theme when you read through the principles:
 Early diagnosis with maximized use of technology
 - Early diagnosis with maximit
 Guide and Coach Parents
 - Parents are primary facilitators for their child
 - Create environments that support spoken language through daily activities
 - Integrate listening and spoken language into all aspect's of child's life
 - Promote education in regular schools with peers who have typical hearing with appropriate support from early childhood on.

ROUTINES BASED INTERVENTION

Children learn through "repeated interactions dispersed over time. They do not learn in lessons or sessions in which the 'trials' are massed or the practice is concentrated, with little or no carryover to other situations."

Robin McWilliam, 2010

ASSEMBLING THE TEAM

Child and Family

- We all work FOR them
- Early On
- Medical/Clinical Services
- Daycare/Education Setting
- Parent Family Support Services

INITIAL STRATEGIES

- Full time technology use
- Create a Listening Environment
- Adult Modeling of Speech
- Learning to Listen Sounds
- Conditioned Play
- > All the tools in our Early Interventionist Tool Box are still applicable
 - Hanen Approach
 - Communication Temptations
 - Language Modeling
 - Sabotage
 - Parent Coaching/RBI/Family Centered/...

PARENT COACHING THROUGH AN "AUDITORY LENS"

- Early On Providers need to learn more about auditory learning techniques in order to incorporate many of the aspects of LSL/AV therapy the child is getting in the medical setting into the home:
 - Sound Awareness
 - Phoneme Level (Speech Babble)
 - Discourse Level (Auditory Processing of Speech)
 Auditory Sandwich Technique

 - Repetition Repetition
 - Model Turn Taking
 - Reduce Background Noise and then add in slowly
 - Start with slightly slower rate of speech...increase to normal
 - Start with natural occurring gesture and context...reduce visual context

Parent Coaching through an "Auditory Lens" cont'd

- Don't talk louder, get closer! 6 inches from child's technology
- Parentese: higher pitch, elongated vowels, exaggerated facial expression, short and simple sentences increase the audibility of speech for all young children and especially those with hearing loss!
- WAIT: increased wait time, then reduce it...OWL from Hanen.
- Emphasize specific sounds, prolong s or sh to increase audibility

HOW DO WE BUILD CAPACITY IN THIS AREA?

- Continuing Education/Professional Development
 - AG Bell: national conference every two years
 - MI Chapter AG Bell: Professional conference
 - ► EHDI: Professional Conference in March, 2016
- Partnering with Listening and Spoken Language Specialists
 - I I listed in directory at listeningandspokenlanguage.org
- Building relationships with the medical therapy team where the children in our programs receive services.
- Formal education and training.

BUILDING CAPACITY CONT'D

Sound Support Grant

- University of Michigan Pediatric Audiology and Hearing Rehabilitation Center staff can make visits to Early Intervention and Preschool Programs to educate, provide some training, inservice care providers and build relationships with the educational team.
- Early On Mentoring Program: A new program is being piloted this year.
 - Early On Service Providers are paired with a mentor (either Audiologist or SLP/AVT) from November; 2015 through May, 2016
 - Web based trainings
 - In person and online learning opportunities with mentor and mentee

- Michigan Department of Education Low Incidence Outreach (MDE/LIO) Beth Rice, Educational Consultant

 - She can provide some support for education and training and is looking for creative ways of expanding her outreach in the state

EARLY ON ROLE IN REDUCING LOSS TO FOLLOW UP

- Educate ALL service providers who take babies on 1/3/6 rules and how to assist families in getting appropriate diagnostic work up after failed newborn hearing screening.
 - Premature infants may be in Early On due to low birth weight, feeding or motor concerns. Service Coordinators/Providers are typically Physical or Occupational Therapists, Early Interventionists or Teachers.
 - All of these providers must know when a child needs a diagnostic work up and how to help a family attain it.
- Have an appropriate hearing screening protocol.
 OAE screening vs. Check List vs. Audiology referral.
 Educate ALL service providers on risk factors for genetic hearing loss.
 - Sibling with a hearing loss? encourage parents to get Audiology referral. Even if the child passed the NBHS!
 - Child with a hearing loss on caseload encourage parents to get Audiology referral for siblings.
 Even if the siblings passed their NBHS!

BATMAN PROTECTS WHICH CITY?

- A. Chicago
- B. Metropolis
- C. Gotham City
- D. New York City



QUESTIONS?