Can parents give their child all the options?

Presenters:

Andrea Marwah

- Parent
- Advocate
- IDEA trainer/consultant
- ADA commissioner
- IL Early Intervention Trainer
- President IL Hands & Voices

Alejandra Ullauri

- Pediatric audiologist
- Board certified in CIs
- Board member Illinois Hands & Voices
- Board member Child's Voice

Samantha

16 y/o

Profoundly deaf

Late diagnosis at age 2

EVAS

Known progressive loss

Lost all hearing by age 7

Bilateral CI’s

ASL college level classes

Her goal is to go to college after graduation

Our Journey

- Entered EI at age 15 months
- Diagnosed with sensorineural hearing loss at 23 months
- Received Hearing Aids at 24 months
- Started AVT at Child's Voice School at 24 months
- Mainstreamed to neighborhood school at age 6
- Received 1st CI at age 6 years
- Received 2nd CI at age 7 years
- Currently a sophomore with a 3.8 GPA
- 20 minutes every other week with HI teacher to discuss college and self advocacy, no other special education

Comments from Deaf Adults and biased professionals

- 1st AG Bell conference – deaf community with dolls, hands and mouths taped in protest.
- Deaf adult seeing me use ASL (really baby sign) and comes to talk until CI is noticed then rudely walks away.
- Why doesn't she sign? She is deaf and should sign!
- Why did you make such a big decision without her input?
- Why do you use the term "hearing loss", why are you afraid of the term "deaf"?
- You should have waited for her to make the decision to get a Cochlear Implant.

Comments from Deaf Adults and unbiased professionals

- She's beautiful
- You are a great mother/parent, doing what your child needs. Listen to your heart and gut.
- Technology has come a long way, she will be just fine.
- You can do this, she will go places you never imagined.
- My deaf mentor Karen Putz was such a positive influence on us..

Our role as professionals

We have a duty to provide families with information that is:

- Current
- Evidence based
- Scientific and not anecdotal

Our profession

- We are in a field that is rapidly evolving
  - Patients' candidacy criteria
  - Diagnostic/Clinical protocols
  - Technology
  - Habilitation strategies

Every day we know a little more!

What we know TODAY


Diagnostic technology & clinical protocols have evolved

Neonatal Hearing Screeing (NHS)

- **1971: First** Joint Statement on Neonatal Screening of Hearing Impairment
- **1973:** No satisfactory technique for screening
- **1982:** At-risk babies before 6 months of age using BOA or ABR
- **1990:** At-risk babies at birth / ABR
- **1994: Universality is introduced**! ABR + OAE
- **2000:** JCIH endorses EHDI / 1,3,6 rule
- **2007: Different screening protocols**
- **2013:** Supplement of 2007 statement / Guidelines for EHDI /12 goals

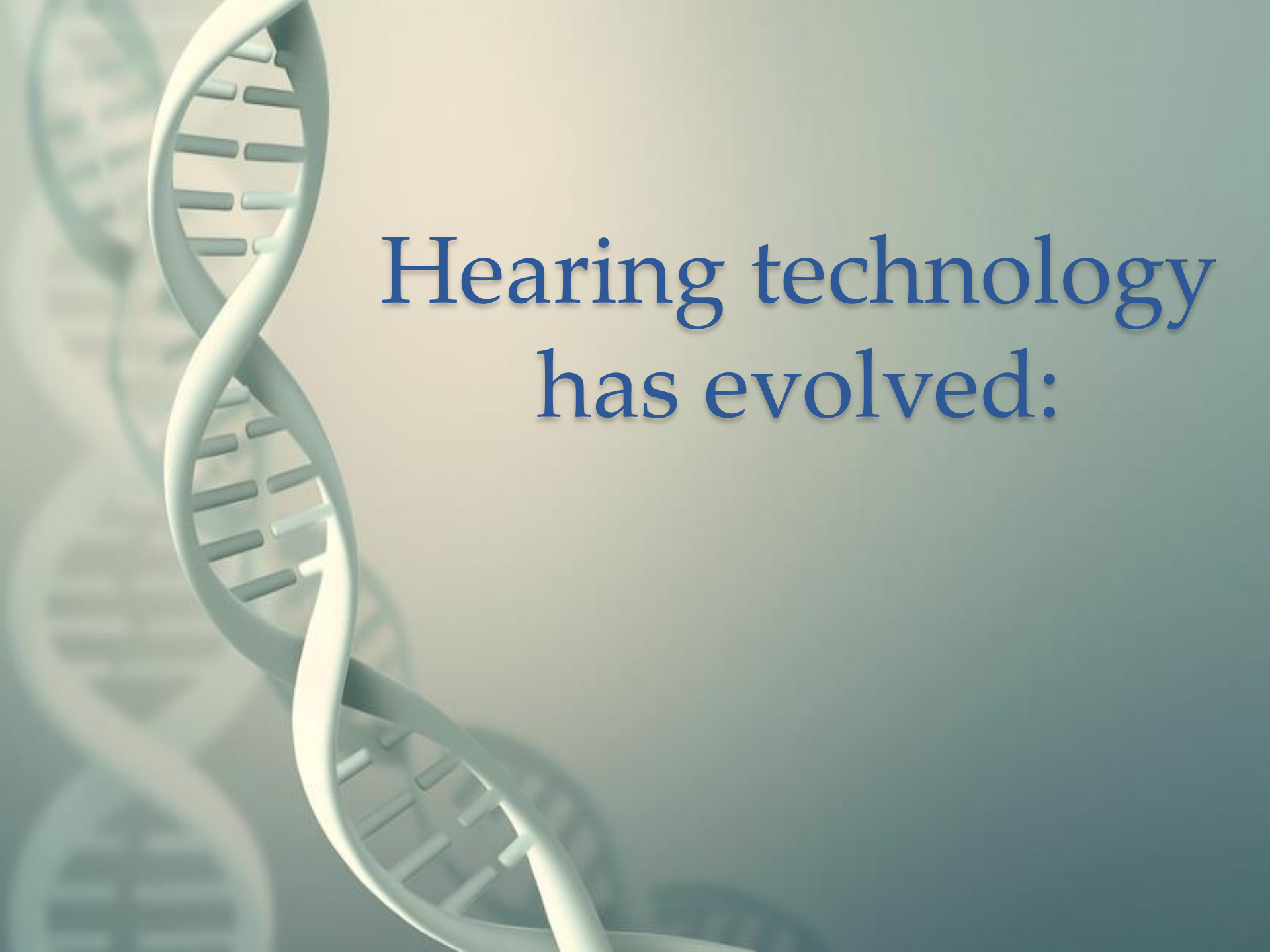
Neonatal Hearing Screening (NHS)

- NHS: 97% of infants born in the US are screened each year (CDC, 2014):
  - 1990: Hawaii passes the first legislation requiring NHS for babies
  - 1993: NIH recommends that all babies get screened at birth
  - 2018: 43 states have regulations or status related to NHS
  - Only 28 of 43 states require NHS for ALL babies

Diagnostic equipment

Objective testing:

- Tympanometry
- Acoustic Reflexes
- Automatic ABR
- Diagnostic ABR
- ANSD ABR protocol
- ASSR
- OAEs (DPs an TE)
- OAEs protocols and pass or fail criteria
- Vestibular assessment (VEMPs)
- Real Ear Measurements (REM)


Hearing technology
has evolved:

Hearing Aids (HA)

- 1953: Analogue HA, Transitor, BodyWorn BWHA
- 1970: Digitally programmable HA
- 1996: Digital HA
- 2006: Binaural amplification, connectivity
- 2014: Wireless connectivity to smartphones, internet connection, accessories

1953 61 years 2014

Connectivity

Cochlear Implants (CI)

Historical Expansion of FDA Guidelines

ACI Alliance Presentation by Donna Sorkin Executive Director

Criteria	1985	1990	1998	2000	2014
AGE of implantation	Adults 18 yrs +	Adults & Children 2 yrs +	Adults & Children 18 mos +	Adults & Children 12 mos +	Adults only for Hybrid
ONSET of hearing loss	Post linguistic	Post linguistic adults/ Pre & Post Linguistic Children	Adults & Children Pre & Post Linguistic	Adults & Children Pre & Post Linguistic	Adults & Children Pre- and Post- Linguistic
DEGREE of hearing loss	Profound	Profound	S/P Adults Profound Children	S/P Patients 2 yrs+ Prof Child<2 yrs	Nucleus Hybrid: Normal to Moderate in low freq; S/P mid to high frequencies

2017

Children can receive a CI as early as 6 mths of age (Ching et al., 2017)

Adults Only — **Babies 6 Months Old**

1985 — **32 years** — **2017**

Cochlear Implants (CI)

DELAYED COMPLICATIONS AFTER CI (>3 DAYS AFTER SURGERY):

22 842 patients, ages 0.2 to 94.9 years, follow-up 1 mth to 17yrs.

Delayed complications 5.7%:

1. Vestibular complications 3.9%
2. Device failure 3.4% (including accidents)
3. Taste problems 2.8%
4. Less common: cholesteatoma 0.5% and facial nerve palsy 0.6%.

CONCLUSIONS:

- **Cochlear implantation continues to be a reliable and safe procedure**
- **Patients should receive lifetime follow-up.**

(Terry et al.,2015)

Hearing Technology

- Wireless Cross Aids
- BAHA systems
  - Conductive/Mixed losses
  - Single sided deafness
  - Attract System & Abutment System
- Aural Rehabilitation Apps
- Accessories designed to enhance communication
  - Remote microphones
  - Phone clips
  - Apps

Scientific Knowledge has evolved:

Outcomes

- **2014**: **Early** diagnosis & timely intervention can result in **age appropriate** language, cognitive, & social skills in children with HL (JCIH)
- **2017**: The benefit of **early** intervention (Ching et al.)
  - Children who received amplification by 24 months of age had poorer language outcomes than those who received amplification by 3 months of age.
  - Children who receive CI by 2 years of age had poorer language than those implanted by 6 month of age
- **2017**: Children without **early** sign language exposure achieved better speech recognition skills & exhibited a significant advantage in spoken language & reading in elementary grades over children exposed to sign language. (Geer, et al.)
- **2018**: Auditory Verbal intervention is associated with improved outcomes for children (Percy-Smith et al.)

Early AGE & Neuroplasticity

Neuroplasticity

The brain's ability to modify, change, and adapt both structures and function throughout life and **in response to experience**

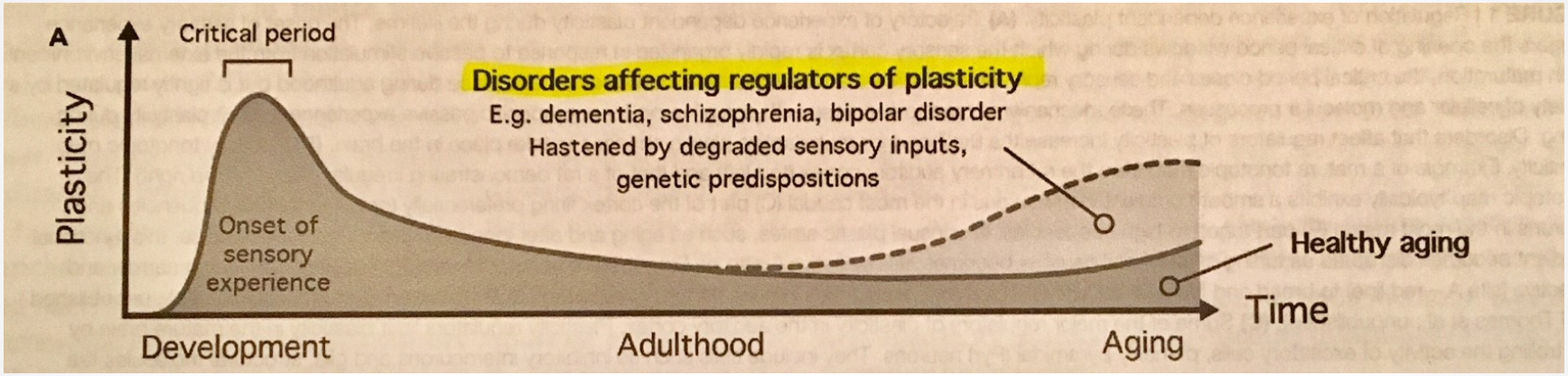
- **Age:** Experience-dependent cortical plasticity
- **Critical period (CP):** Time period early in life when important structural and functional changes tend to occur
- **Sensory experience:** key for normal neural development

The quality and quantity matter:

Enrich sensory environment can prolong CP plasticity

(Greifzu et al., 2014)

Neuroplasticity



Research: Plasticity inhibitors & molecular brakes. Findings could lead to develop methods to promote neuroplasticity in situations of learning or recovery.

Voss et al., 2017

Cross-Modal Plasticity

- The ability for an intact sensory modality to recruit cortical regions from a deprived sensory modality
- Auditory deprivation leads to Cross-Modal plasticity or brain-reorganization
- Brain changes may have a significant impact on variability of clinical outcomes in patients with hearing loss.

(Sharma & Glick, 2016)

Myelination & Critical Periods

The auditory system processes a complex spectrum of acoustic information: pitch, intensity, and timing, and it needs myelin.

Myelin is:

- Crucial for the conduction velocity & coordinated communication between neurons.
- Vital to auditory functions such as sound localization
  - Sound localization is crucial for speech understating in noise.
- Dynamic and influenced by multiple forms of experience

(Long et al., 2018)

Myelination & Critical Periods

Auditory deprivation:

- Alters myelin along the auditory pathways
- Is associated with myelin deficits in the auditory cortex
- Decreases myelin development, and maintenance.

Auditory experience is needed to sustain myelin along the auditory pathways

(Long et al., 2018)

Myelination & Critical Periods

Under Research:

- Auditory enrichment may also promote Myelination in the brain.
- While insufficient auditory experience may diminish levels of myelin, certain forms of auditory exposure may promote and maintain myelin in the developing and aging brain.

Experience & Critical Periods

- Maturation of efficient processing of spectro-temporal acoustic cues is critical for perception of complex sounds
- Interactive participation in an acoustic experience may be a more effective for temporal sensitivity than passive listening
- Attention-driven auditory plasticity may result in an increased number of neurons recruited for processing
- Active engagement with linguistic-like acoustic cues early in life (4-7 months) has a good chance of impacting experience-dependent neuroplasticity

Active Auditory Experience

(Musacchia et al., 2017)

Summary

- Share current, scientific- evidence-based information
- Keep a perspective of time when sharing anecdotal experiences
- Teach parents about neuroplasticity, cross-modal plasticity & critical periods

AGE seems to be a key factor!

Current research:

- Extending critical periods of plasticity
- Understanding plasticity inhibitors
- Promoting myelin development

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