

Only In Translation: Applications of Data Into Practice

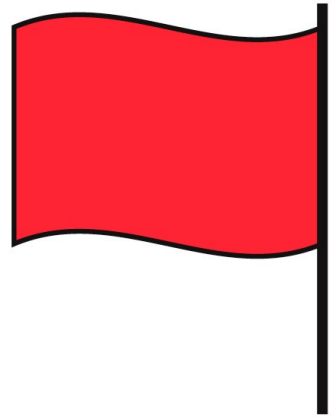
Julia L. Hecht, MD, FAAP
NM EHDI Chapter Champion

Overview

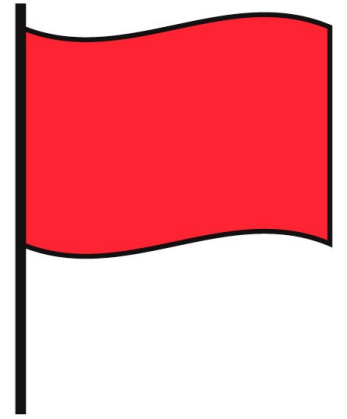
- Introductions
- Studies of Deaf Children - categories for review
- Red Flags for Applying to Clinical Practice
 - Deaf as inferior / flawed
 - Conflicts of Interest in Researchers
 - Poor Study Design
 - Obscuring Poor Outcomes (unethical)
- Summary

Introductions

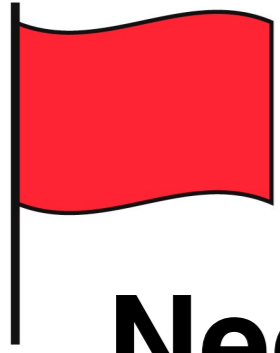
- Presenter
- Audience



Red Flag Categories

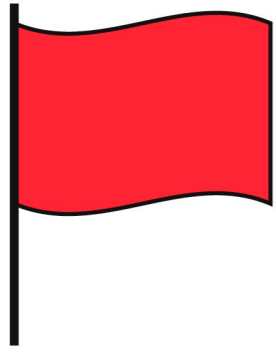


- ❑ Studies showing Deaf individuals to have negative personality traits: immature, less empathy, etc
- ❑ Studies concluding exposure to sign language is bad for deaf children
- ❑ Cochlear Implant Outcomes (CDaCI)



Beware Studies That Show: Negative Labels & Character Flaws

- **Historically:** Deaf people described as **socially immature, morally deficient, low empathy, impulsive, rigid** (Altshuler, Deming, Vollenweider, Rainer, & Tendler, 1976; Chess & Fernandez, 1980; Nass, 1964; Levine, 1960; Lewis, 1968)
- **Present:** More accurate
 - Language Deprivation Syndrome, Information Deprivation Syndrome, and trauma (Hall, 2017 Tate, 2012)
- **Present:** Paucity of positive descriptions of Deaf people
- **Present:** Historical inaccuracies recycled
 - **2017 - immaturity, low executive function** (Marsharck)
 - **2015 - low empathy** (Netten)

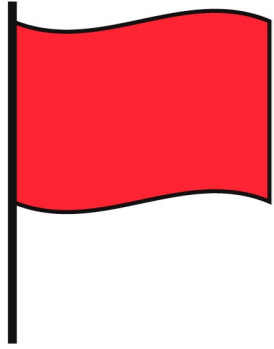


Beware Studies That Show: Sign Language is Harmful



LOOK FOR:

- ▀ Conflict of Interest
- ▀ Poor Study Design
- ▀ Ethical Concerns



Beware Studies That Show: Sign Language is Harmful

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™

Professional Resources | Professional Education | Advocacy & Policy | shopAAP | About the AAP

AAP.org > English > About the AAP > AAP Press Room > Use of Sign Language After Cochlear Implant M

print email share

Use of Sign Language After Cochlear Implant May Slow Verbal Development

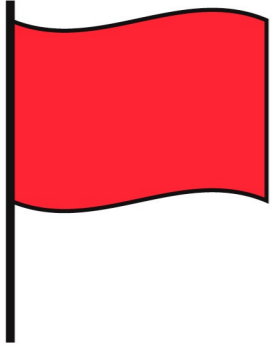
6/12/2017

A study in the July 2017 Pediatrics examines the impact that exposure to early sign language had on children who received cochlear implants. The study, "Early Sign Language Exposure and Cochlear Implantation Benefits," used data from a nationwide database to document verbal skills in children with cochlear implants who differed in the amount and duration of early sign language exposure provided in their homes or in intervention programs. Researchers found over 70 percent of children without sign language exposure achieved spoken language similar to their age-mates with normal hearing, compared to only 39 percent of those exposed to

Geers et al, 2017, Pediatrics

Beware Studies That Show:

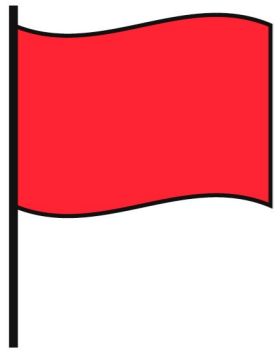
Sign Language is Harmful



Conflicts of Interest

- Financial Ties to Industry
 - Cochlear implant companies
 - Hearing aid companies
- Funding from Oberkötter Foundation
 - Ideologically driven - exclusive oralism
 - Prohibition of Sign Language


Beware Studies That Show: Sign Language is Harmful



Conflicts of Interest

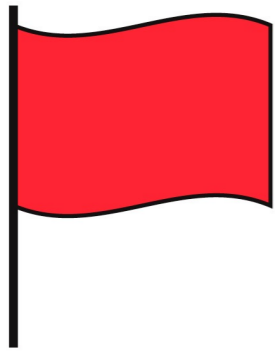
Laurie Eisenberg, PhD,
USC / Caruso Family Center

- Lead Investigator of Geers et al, 2017 and Child Development after CI (CDaCI)
- Funded by **Advanced Bionics (stated)**
- Funded by **Oberkötter Foundation** which promotes exclusive oralism and the **prohibition of sign language (hidden)**

 Secure | <https://oberkotterfoundation.org/grants-awarded/>

University of Southern California: *USC Caruso Family Center for Childhood Communication (2-year grant totaling \$270,780). Funding will support expanding access*

Beware Studies That Show: Sign Language is Harmful



Conflicts of Interest

Karl White, PhD,
Utah State University

- Authored “Opportunities and Shared Decision-Making to Help Children Who Are Deaf to Communicate” **Pediatrics, 2017** commentary to Geers
- No financial conflict (**stated**)
- Hearing parent of hearing children??? (**stated**)
- \$2.53 million from **Oberkotter Foundation** which promotes exclusive oralism and the **prohibition of sign language (hidden)**



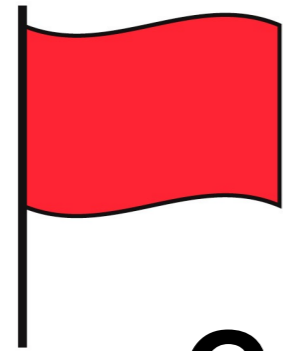
**Listening and Spoken Language Emphasis for Deaf Educators,
Speech-Language Pathologists and Audiologists**

Researchers: White, KR; Munoz, K; and Nelson, L

Funding: Oberkotter Foundation, \$2.53 million, January 2007 to May 2015

Beware Studies That Show:

Sign Language is Harmful



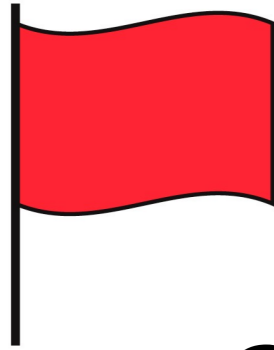
Poor Study Design

Geers, 2017, Pediatrics

- Selection Bias
 - The outcome (data) of the subjects were known prior to the determination of selection / exclusion criteria and the **grouping of data into “subject groups”**
- Children with rich exposure to ASL excluded
- Children with poor or no access to language studied as “exposed to sign”
- Failure to control for other variables that affect outcome

Beware Studies That Show:

Sign Language is Harmful



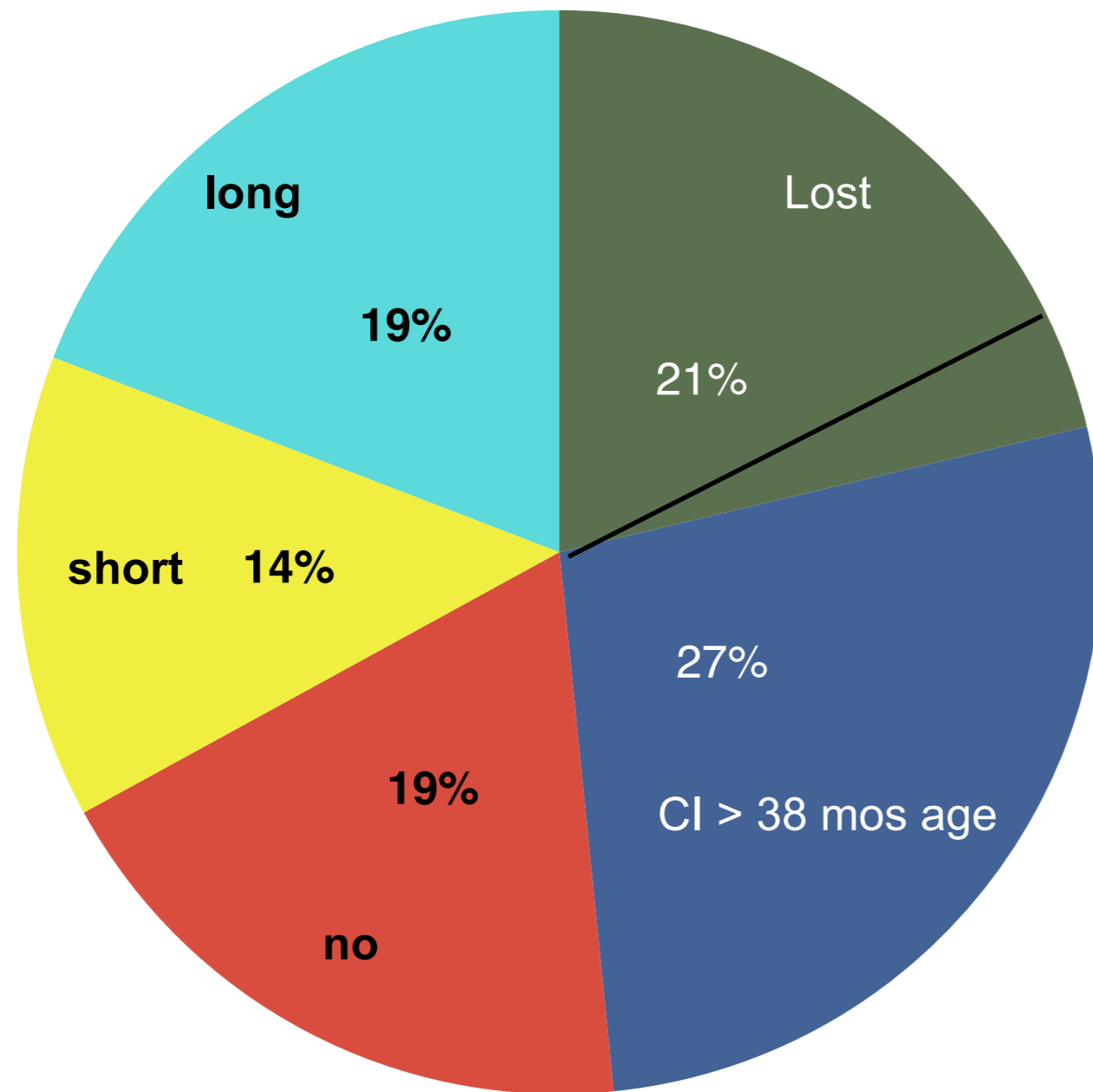
Ethical Concern

Geers, 2017, Pediatrics

- 30 children from CDaCI study received NO linguistic benefit from the CI
- These 30 children left the CDaCI study - not included in Geers
- Late exposure to sign language / any language with consequent cognitive stunting (brain damage)
- This is obscured by calling them “LOST”
- Revealed in Barnard, 2015

Geers et al, 2017 - Subject Population

As a percent of CDaCI Deaf Subjects (N=188)

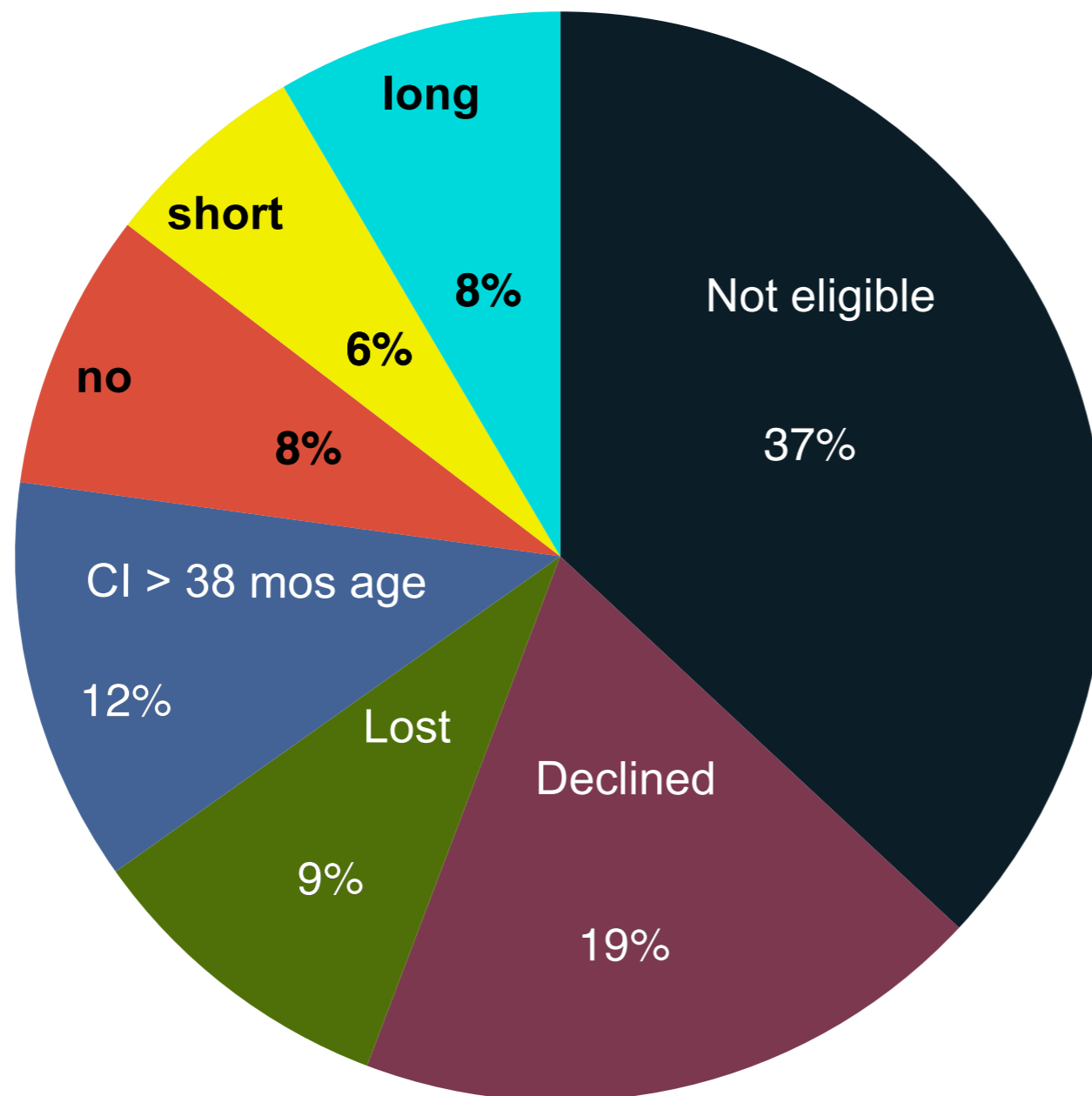


**Post Hoc Data
Outcomes known in
advance
(Declined: N=0)
No consent req'd
No ling benefit from CI:
N=30
Obscured in lost group**

■ No follow up ■ CI > 38 mos ■ No "sign" ■ Short term "sign" ■ Long term "sign"

CDaCI with Geers Subject Population

Geers groups as a percent of children screened in 6 Centers participating in CDaCI study (N=425)



**CDaCI
Prospective Study
Requires Consent
19% Declined**

■ Ineligible ■ Declined ■ No follow up ■ CI > 38 mos ■ No "sign" ■ Short term "sign" ■ Long term "sign"

Summary

**** Be aware when looking at studies and data****

Red Flags

- ❑ Deaf people labeled as inferior or flawed
- ❑ Sign language is harmful to deaf children
- ❑ No discussion of technology failure and children who don't benefit
- ❑ Hidden ideological agendas and financing

References

Barnard J, Fisher L, Niparko J, et al. A Prospective Longitudinal Study of U.S. Children Unable to Achieve Open-Set Speech Recognition 5 Years After Cochlear Implantation. *Otology & Neurotology*. July 2015;36(6):985-992.

Facts on Trauma and Deaf Children

<http://www.pluk.org/centraldirectory/Deaf/Facts%20on%20Trauma%20and%20Deaf%20Children.pdf>

Fink, NE, Wang, N-Y, Visaya, J, Niparko, JK, Quittner, A, Eisenberg, LS, Tobey, EA, Childhood Development after Cochlear Implantation (CDaCI) Study: Design and Baseline Characteristics. *Cochlear Implants International*. 2007;8(2), 92-116

Geers, AE, Mitchell CM, Warner-Czyz, A, et al. Early Sign Language Exposure and Cochlear Implantation Benefits, *Pediatrics*. 2017;140(1)e20163489

Hall, WC, Levin LL, Anderson, ML, Language Deprivation Syndrome: A possible neurodevelopmental disorder with socio-cultural origins. *Soc Psychiatry Psychiatr Epidemiol*. 2017 Jun;52(6):761-776. doi: 10.1007/s00127-017-1351-7. Epub 2017 Feb 16.

Tate, C., 2012 Trauma in the Deaf Community

https://dbhdd.georgia.gov/sites/dbhdd.georgia.gov/files/related_files/site_page/Deaf%20and%20Trauma%20Paper_1.pdf

White, KR, Cooper LZ. Opportunities and Shared Decision Making to Help Children Who are Deaf to Communicate, *Pediatrics*. 2017;140(1) e20171287