

Healthcare experiences of adults
deaf since childhood:
Implications for people who work
with deaf children

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Take Home Messages

- Childhood healthcare experiences influence adult perspectives
- Adults report limited access to health information
- Adults report limited access to healthcare communication
- Disparities exist in research and health

Acknowledgements

- AHRQ
- CDC/ATPM
- CDC PRC
- Bayer Institute for Health Care Communication
- colleagues and collaborative partners

Outline

- Describe the population(s)
- Research on healthcare and health
- Implications

Why health & healthcare?

- Evidence of health disparities
- Frequently overlooked group
- “Rubella bulge”

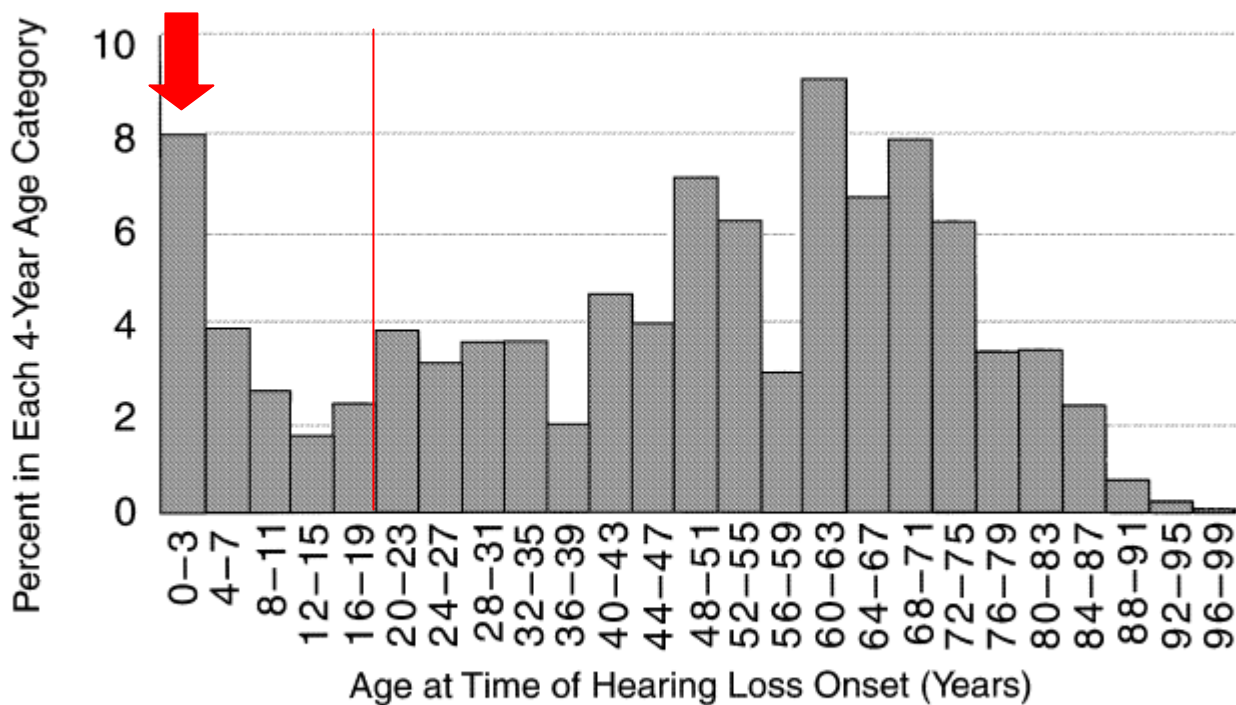
Research is limited

- Prelingually deafened adults
- Prevocationally deafened adults
- Research conducted in ASL

Age at Onset for Deaf Adults

- Before age 3 yrs 6.6%
- Age 3-19 years 10.0%
- Before 19 (but unknown) 0.5%
- Older than 19 years 82.9%

Figure 1: Percent Distribution of Age at Onset of Deafness for Deaf Adults



Note: Responses regarding deaf adults ($n = 2,449$) when asked at what age they began to develop serious trouble hearing or deafness

Research in ASL

- US Census does not measure ASL use
- Different definitions for “deaf”
- Signed communication is not all ASL

Adult ASL users

- Most ASL users became deaf as children
- Many adults deaf since childhood use ASL

The math

- US deaf 3.8M – 4.8M
- Prevocational deaf (18%) 684K – 864K
- Prelingual deaf (8%) 304K – 384K

- ASL users 350K – 500K

Demographics

	General pop. adults	Prelingual deaf adults
Age	44.0 ± 0.2	44.5 ± 1.5
White	85.1 ± 0.6	91.0 ± 2.4
Married (not separated)	66.1 ± 0.4	49.8 ± 4.3

Demographics

- Less education
- Lower income
- Downwardly mobile?

Health

- General population 0.85 ± 0
- Prelingual deaf adults 0.68 ± 0.2

HP2000 YHL measure (1=good health)

Healthcare services

- Less likely to have seen a physician
- Fewer physician visits

- Similar to other groups with difficulties with healthcare communication

Healthcare services

Accessible facilities record more visits with deaf adults and their families

- NTID/RIT
- URMC
- Folsom Family Medicine
- Baltimore

Health Insurance

Health Risk Behaviors

Smoking

Less likely to be current smokers

Prelingual deaf AOR= 0.48 (0.23, 0.99)

Postlingual deaf AOR= 1.07 (0.86, 1.33)

Health Risk Behaviors

- Seatbelts ?
- Helmets ?
- Alcohol ?
- Drugs ?
- Sex ?
- Impaired driving ?
- Combinations ?

Health Disparities

Retinitis Pigmentosa

120-240 times higher

- Prevalence (general population) = 1/4000
- Prevalence (childhood deafness) = 3-6%

Usher Syndrome

Health Disparities

Prolonged QT Syndrome

15 times higher

- Prevalence (general population) = 1/5000
- Prevalence (childhood deafness) = 3/1000
Jervell and Lange-Nielsen syndrome

Health Disparities

Diabetes

- Prevalence (general population) = ~7%
- Prevalence (childhood deafness) = ?

Congenital rubella syndrome

Mitochondrial inheritance

Lifestyle issues

Healthcare Communication

Frustration

- Face masks
- Automated telephone systems
- Limited email and internet access
- Writing
- Interpreter services
- Direct communication
- Low satisfaction

Healthcare Communication

Self advocacy

- Patients/families: often reluctant to request interpreter services
- Physicians: patients often do not request interpreter services

Learned behavior

Healthcare relationships

Trust

- Communication
- Life experience issue
- Implications for self advocacy

Health Information

Family Health History

- Little information
- Often don't know it is important
- Embarrassing
- “adoption model”
- Implications with genomics

Health Knowledge

HIV

- >70% said deaf people could not get HIV
- >50% did not know the meaning of “HIV positive”

From Goldstein MF, Eckhardt EA, Joyner P, National Development and Research Institutes, NYC presented at APHA November 2004.

Health Information

Cardiovascular Health

- 40% could not identify signs of heart attack
- >60% could not identify signs of a stroke

From Margellos H, Hedding T, Kaufman G, Perlman T, Miller L, and Rodgers R, Sinai Health System, Chicago, presented at APHA November 2004.

Health Information

- Desire for information about children's health and development
- Public health messages
- Basic health information (general, individual and family)

Health Literacy

- Associated with health outcomes
- No tools for use with adults deaf since childhood

Health Literacy

- Rapid Estimate of Addult Literacy in Medicine
- Modified REALM
- 61 deaf adults, 48 had a college degree
- 57 completed m-REALM
- 38 scored in the HS grade level (highest)

Promising Future

- Physicians with childhood onset deafness
- Agency for Healthcare Research & Quality
- CDC
- National Center for Deaf Health Research

What to do

Healthcare

- Facilitate access to healthcare communication
- Foster a positive relationship between a deaf child and his/her clinicians

What to do

Health Knowledge

- Facilitate access to health information
- Teach children family health history
- Directed teaching

What to do

Foster Self Advocacy

- Nurture self advocacy skills (self/families)
- Access to adult deaf role models

What to do

Advocate

- Encourage the realization of Healthy People 2010 goals on disparities in research and health for people with disabilities

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