

DEAFplus Individuals and the Importance of DEAF Identity

ROBERT C. NUTT, MD, MPH

DEVELOPMENTAL & BEHAVIORAL PEDIATRICS OF THE CAROLINAS

ATRIUM HEALTH | LEVINE CHILDREN'S NETWORK

DEAFPLUS INTERNATIONAL CONFERENCE

UNLOCKING THE POTENTIALS OF DEAF PEOPLE WITH SPECIAL NEEDS

MARCH 28 - 29, 2019 | LINZ, AUSTRIA



Abstract

There is much to be gained from celebrating diversity on a personal and societal level. Deaf individuals with multiple conditions should see themselves as part of the greater Deaf Community. In order to be healthy, productive members of our diverse societies, DEAFplus individuals need effective communication and a healthy Deaf Identity – both in others' eyes and their own. Limited access to visual communication, including sign language, isolates DEAFplus individuals in oral-aural dependent environments. One's inability to communicate effectively is frequently an underlying reason for challenging behavior in this vulnerable population. Such behaviors and the inability to communicate further restricts the DEAFplus individual's engagement with their community. Regardless of communication modalities used by the individual, self-esteem is closely linked how one perceives their deafness. The importance of role models is recognized as critical in fostering one's healthy Deaf Identity, and Deaf role models are necessary to empower DEAFplus individuals. Dr. Nutt will draw from personal experience and published research to discuss how fostering an individual's Deaf Identity is crucial to meaningful inclusion of DEAFplus individuals.

Disclosures

- Dr. Nutt has no financial conflicts of interest

Personal Disclosures

- physician by training and employment
- Dr. Nutt's primary language (L1) is spoken English; he has used assistive listening technology since 6 years of age.
- Dr. Nutt is fluent in American Sign Language
- Dr. Nutt regularly uses interpreting services

Multiple-disabilities

Deaf plus

DEAFplus

Deaf +

deaf PLUS

A deaf or hard of hearing with other conditions

A deaf or hard of hearing with special needs

deaf-plus

Deaf PLUS

DEAFplus

Approximately 40% of children identified as deaf/hard of hearing also have other conditions (Gallaudet Research Institute, 2005).

Individuals with multiple issues are more likely to have vision or hearing loss than their typically developing peers.

The term "DEAFplus" is a reference to the individual's hearing status combined with one or more additional conditions.

The conditions impacting children identified as DEAFplus are many and varied.



Modified from: <https://www.google.com/url?sa=i&source=images&cd=&cad=rja&uact=8&ved=2ahUKEwjimY7B-dLeAhUohOAKHQVwDqwQJR6BAGBEAU&url=http%3A%2F%2Fwww.knitley.net%2Fwigs-of-the-triad%2F&psig=AOvVaw2Y1KSZg1lhHFQVWHQJCL6k&ust=1542252709020634>

Specific Challenges of Special Needs in Deaf Individuals

ADHD

- Inattention, Learning/Social challenges due to deficit in executive functioning or with psychosocial aspects of deafness

Anxiety

- Heightened vigilance, social burden of visible difference

Physical Disabilities

- Challenges of communication: Dysarthria, Motor tone, Spasticity

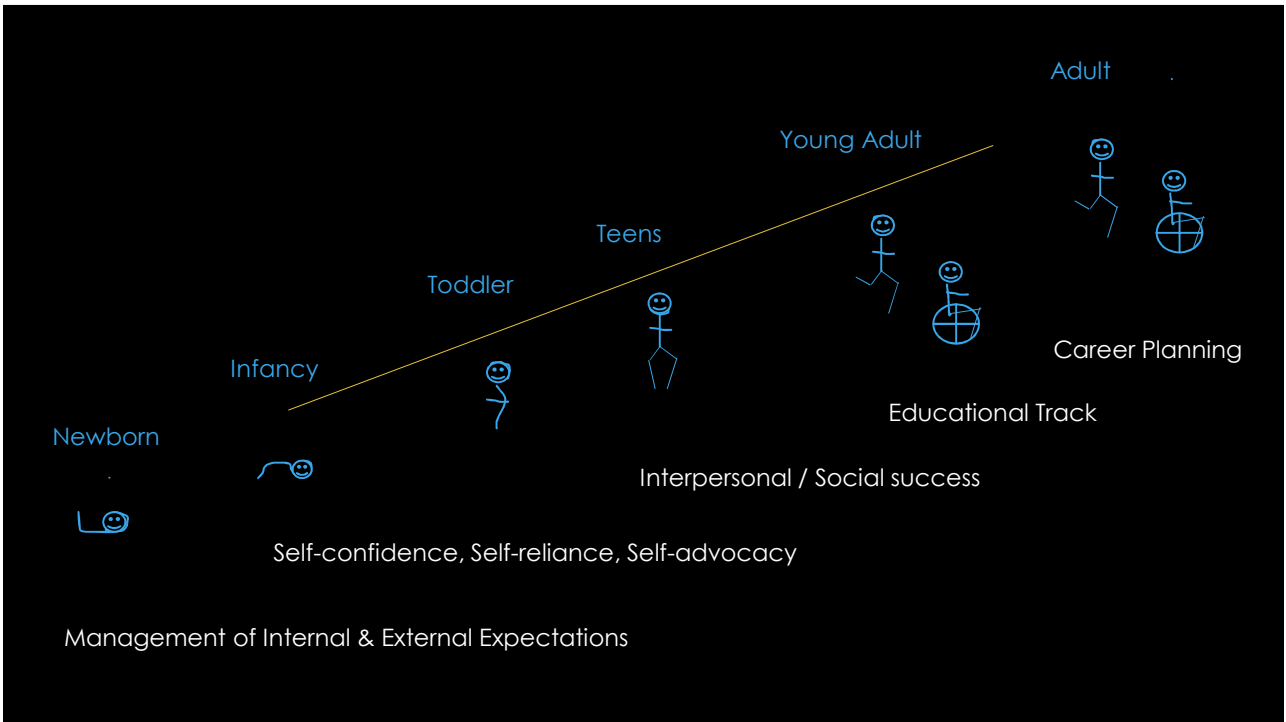
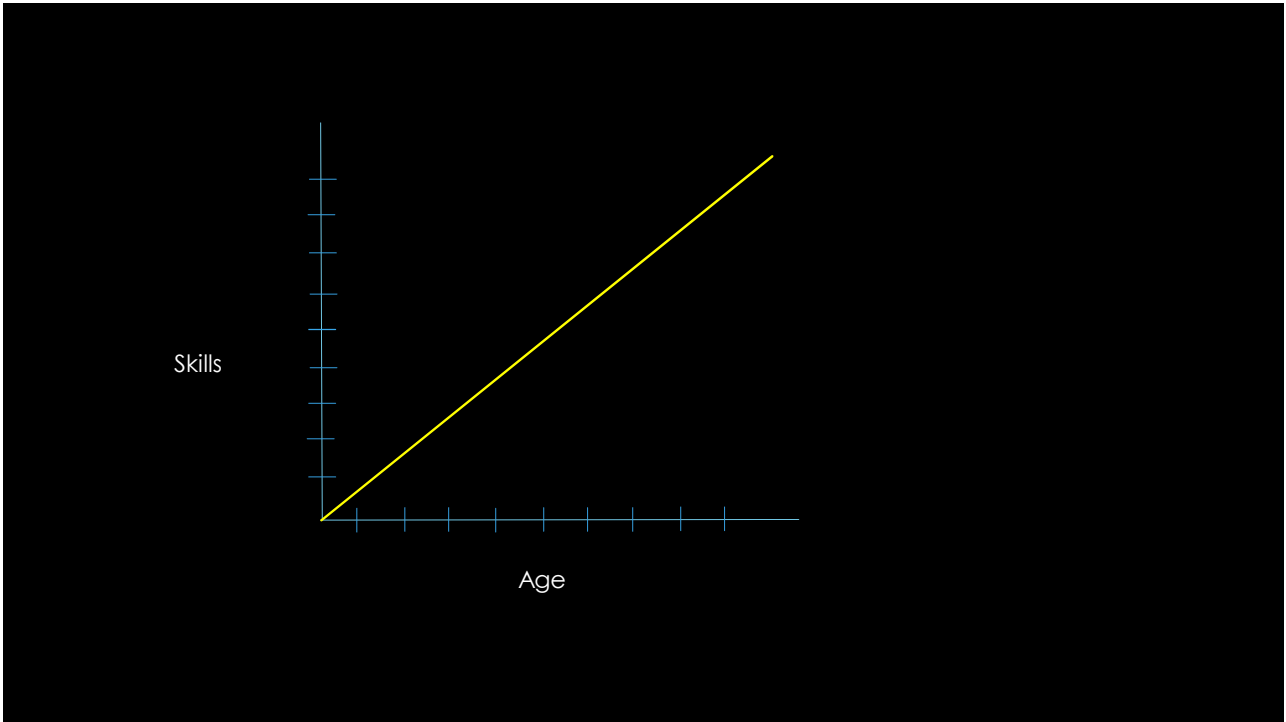
Intellectual Disabilities

- True ID vs. *de facto* auditory or nonverbal learning disability

Autism Spectrum Disorder

- Diagnostic accuracy: language, social, behavioral features of ASD vs Deafness

**Supporting DEAFplus
individuals throughout
the Lifespan**



Our work is challenging

*The figurative distance between
Deaf / Hard of Hearing children and
educational/vocational and social learning
that needs to be overcome is great.*

Reflections from a Deaf Developmental & Behavioral Pediatrician

Identification of Developmental & Behavioral Conditions in Individuals who are Deaf or Hard of Hearing

- **Diagnostic accuracy:** Diagnosis of conditions – such as ID or ASD – is challenged by common features of deaf child development that presents with subtle differentiating features of language, socialization, and behavior.
- **Misdiagnosis:** Both over and under-diagnosis are more common than in an equivalent hearing population (Austen, Grey, and Carney, 2007 re: ASD)
- **Specialists:** Scarcity of professionals who have experience of working with deaf people who have other special needs.
- **Transitioning:** autonomy is not something that should be assumed or mis-approximated. This goes for residential placement, employment, access to health care (or knowledgeable medical professionals).

Barriers to Educational Access for Deaf Individuals with other Special Needs

Barriers to success are closely linked to Barriers to access

- Limited Resources (funding, space, equipment)
- Limited Assessment Tools (existing tools adapted without validity)
- Scarcity of specialized EC providers (SLT, OT, PT, Teacher of the Deaf) skills in optimal assessment and management of coexisting conditions.
- Lack of Responsiveness
- Limited research informing best practice
- Implicit bias (system designed for student to fit, rather than v.v.)

Best Practice based on Research?

- There is a paucity of research (and data) upon which Educational Policies relating to the integrated education of Deaf and Hard of Hearing students are based
- Developmental and behavior concerns arise from the Gap between educational system-based practice and student performance within a system attempting to provide access through reasonable accommodations
- Patients in my office have concerns raised by any or all of their primary care providers, early intervention providers, and educators
- Diagnoses made by DBP inform recommendations for improvement in educational modeling around the individual's developmental and behavioral profile (i.e. IEP, Section 504 Plan, and/or Behavior Intervention Plan)

Tricks from Clinical Encounters with a DBP

- Behavior as Language
- Language-rich Environment
- Narration of Life
- Emotional Vocabulary
- Impact of electronics on language development
- Play as conduit for developmentally meaningful interaction
- Development of Adaptive/Life Skills
- Developmental of Social Skills (relations with peers)

Deaf Identity for D/HH Individuals

Acquisition of Individual Identity

Modern Physical Anthropology

"nature" – biology
(inherited)

"nurture" – culture
(learned)

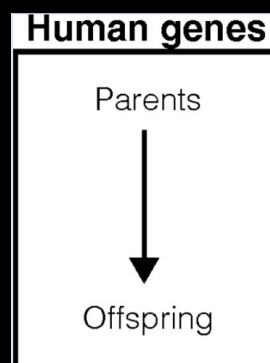
Formation of Identity

- identity is a socially constructed process, which is expanded upon by relating past and present experiences into one's identity.
- Identity is being shaped by the narratives or stories that we tell others.

Hadjikakou K, Nikolaraizi M. The role of educational experiences in the development of deaf identity, *Journal of Deaf Studies and Deaf Education*, 2006, vol. 11 (pg. 477-492).

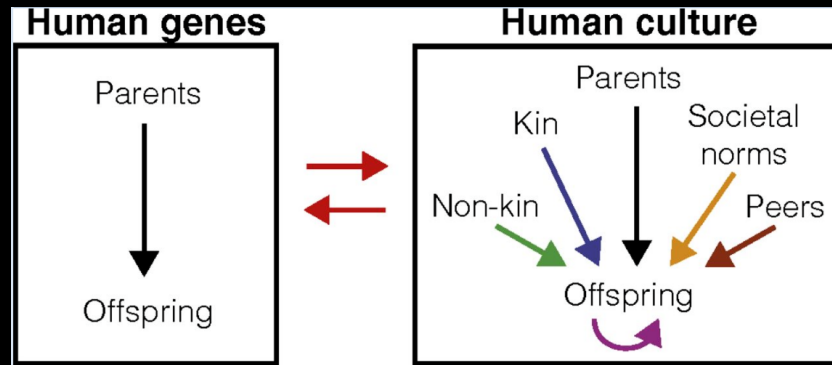
Sikes P, Gale T *Narrative approaches to education research*, 2006.

Vertical Acquisition of Cultural Identity



N Creanza, O Kolodny, MW Feldman. Cultural evolutionary theory: How culture evolves and why it matters. *Proceedings of the National Academy of Sciences, Early Edition*. www.pnas.org/cgi/doi/10.1073/pnas.1620732114

Vertical Acquisition of Cultural Identity



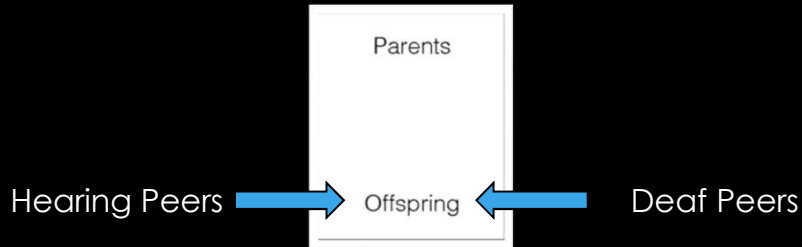
N Creanza, O Kolodny, MW Feldman. Cultural evolutionary theory: How culture evolves and why it matters. *Proceedings of the National Academy of Sciences, Early Edition*. www.pnas.org/cgi/doi/10.1073/pnas.1620732114

Avoiding Erosion of Deaf Identity

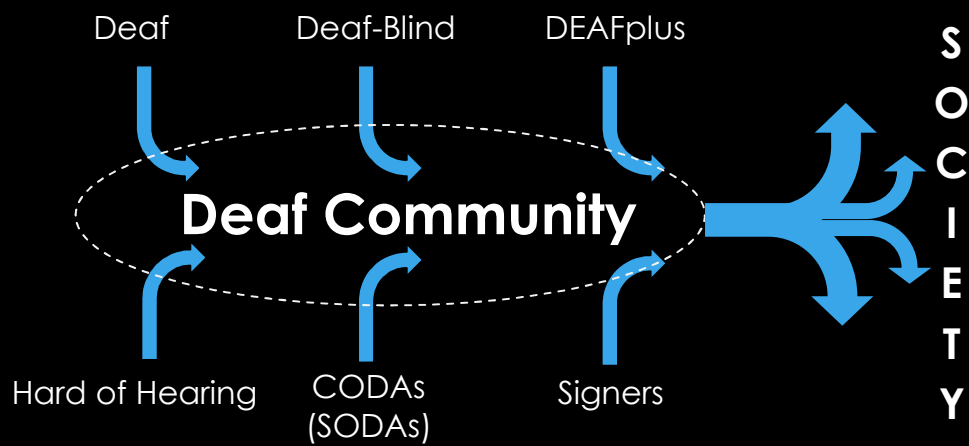
... if Deaf persons were to believe that they are disabled, it is because they experience contempt and shame before others (hearing) in the public space especially at school, and therefore their dignity is compromised.

Taylor C. , Sources of the self: Making of the modern identity , 1992 London, UKCambridge University Press; p51
(in McIlroy G, Storbeck C. Development of Deaf Identity: An Ethnographic Study. *The Journal of Deaf Studies and Deaf Education*, Volume 16, Issue 4, Fall 2011, Pages 494–511)

Horizontal Acquisition of Deaf Identity



McIlroy G, Storbeck C. Development of Deaf Identity: An Ethnographic Study. *The Journal of Deaf Studies and Deaf Education*, Volume 16, Issue 4, Fall 2011, Pages 494-511



Fostering a Healthy Deaf Identity

Importance of Peer Relationships in Children Receiving EC Services

Presidential Address

Social Consequences of Pediatric Conditions: Fertile Area for Future Investigation and Intervention?!

Annette M. La Greca²
University of Miami

Received September 19, 1989; Accepted September 19, 1989

Very little systematic research has examined the peer relations and social functioning of youngsters with chronic illness. In order to stimulate empirical and clinical interest in this potentially important area of pediatric psychology, the present paper discusses several pertinent issues. These include (a) the role of peers in disease adaptation and treatment management, (b) specific aspects of diseases or treatments that are likely to have implications for youngsters' social functioning, (c) guidelines for further investigation in this area, and (d) suggestions for incorporating peer/social issues into educational programs and intervention efforts for youngsters with chronic disease. Throughout the discussion, the complex interplay between peer relations and adaptation to chronic illness is highlighted.

KEY WORDS: peer relations; psychosocial adjustment; youngsters with chronic illness; developmental issues; social skills.

I am suggesting that by neglecting to consider youngsters' peer status and daily social milieu, we are missing significant pieces of the overall adaptation picture. Many of the daily stressors associated with pediatric conditions, and that affect the youngster and family, develop in the context of coping with peer pressure and social consequences of pediatric illness.

Presidential Address at the annual meeting of the American Psychological Association (August 12, 1988, Atlanta, GA)

Importance of Deaf Mentors & Role Models

The Deaf Mentor Experimental Project

- investigated the efficacy of deaf mentor services to young deaf children and their families.
- The children who received deaf mentor services were compared to matched children whose families received only parent adviser services.
- Children receiving early bilingual-bicultural programming made greater language gains, had considerably larger vocabularies, and scored higher on measures of communication, language, and English syntax than the matched children.



Watkins, S. & Pittman, P. & Walden, B. (1998). The Deaf Mentor Experimental Project for Young Children Who Are Deaf and Their Families. *American Annals of the Deaf* 143(1), 29-34. Gallaudet University Press.

Importance of Effective Communication

Providing deaf and hard of hearing individuals a foundation for expressive language is an essential skill for inclusion and self-empowerment

- Developmental delay
- Maladaptive behavior-as-language
- Social isolation
- Unemployment
- Mental health disorders

Preparation for and Inclusion of DEAFplus individuals to find pride of being productive members of society



Identifying unmet needs of DEAFplus individuals

- Start early!
- Accurate assessment and individualized management planning
- Make timely adjustments
- Transitioning is a process, not an event
- Infrastructure/Network for checking in
- Be mindful of bio-psycho-social-spiritual elements throughout the Lifespan

Unlocking potential of DEAFplus individuals

- Early intervention (**language**, behavior; self-regulation)
- Fostering a **healthy Deaf Identity**
- Socialization (peers, **deaf mentors**/role models)
- Evaluate **abilities** for educational and employment opportunities
- Foster **self-advocacy** and sense of **empowerment** ("Deaf can!")
- Awareness and sensitivity training at-large (**acceptance**, diversity)



Added Complexity of Condition... Added Complexity of Accommodation

The figurative distance between Deaf / Hard of Hearing children and educational and social learning that needs to be overcome is great...

but for or children who are Deaf / Hard of Hearing with additional developmental or behavioral conditions, that distance is even greater.

Thank you!



robert.nutt@atriumhealth.org

