The Art of Raising a Resilient Deaf Child

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Michael A. Harvey, Ph.D.
508-872-9442
mharvey2000@comcast.net
My background
What Is Resilience?

Resilience is

- the process of adapting well in the face of adversity, trauma, tragedy, stress, etc;
- It is **not** a trait that people either have or do not have. It involves behaviors, thoughts, and actions that can be learned and developed in anyone.
- It involves mastering various coping tasks.
Agenda

Reconciling one’s identity crisis
School
Socialization and dating
Putting one’s HL in “its place”
Preparing for unfairness and rejection
Roots and wings: receiving family support for gaining autonomy
Finding benefits in adversity; making lemonade from lemons
Communication (last but most imp)
Reconciling one’s identity crisis

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Reconciling one’s identity crisis:
Adolescence:

No longer who I was *(a child)* but not yet who I will be *(an adult)*

Identity vs. Role Confusion: "Who am I?” *(a la Erik Erikson)*
Raising teenagers is like trying to nail jello to a tree.
Deaf verses Deaf

Deaf: audiologic hearing loss.

Hearing impaired, decibel loss, hearing aids, cochlear implants -- Oriented toward hearing.

Deaf: cultural, linguistic minority.

Deaf Community, ASL -- Oriented toward Deaf.

Is deafness a deficit to be corrected or a difference to be accepted?
Between two worlds:
The story of Jill
“Hearing people view me as too deaf. Deaf people view me as too hearing. I wish I was one or the other. I don't fit in either world.”

Hard-of-hearing woman
“Hearing people often think I am hearing because my speech is good; deaf people often think I am hearing because my signs are bad...we are caught between incomprehensible speech on the one hand and incomprehensible signs on the other. If only those hearies would talk more clearly! If only those deafies would sign more slowly!”

Holly Elliott
Progressive Hearing Loss

"I'm continually grieving and re-grieving because anytime I start to feel better, my hearing gets worse, and down I go again! It's been a terrifying emotional roller coaster."
What’s the loss?

Access to Information & control

Access to information: Ramsdell's Tri-level Psychological Functions of Normal Hearing

- The symbolic or language level: understanding language
- The signal or warning level: direct signals of events
- The primitive level: auditory background or "rumble" of daily living.
Level of Control:

E.g. of George: He expects to understand 90% of conversation, but only understands 60%.

Four possible solutions:

- Insist on 90% even though impossible
- Avoid the situation
- Advocate for reasonable accommodations
- Accept reduced percentage
George’s Homework

- frustration
- understand
- confidence
Combatting global helplessness

Aka “All or none thinking”

Cannot control: Discrimination. Not understanding many persons' speech, particularly group conversations.

Can control: hearing aids, choosing to be assertive and educate certain people.

Cannot control: some people aren't interested in being educated.

Can control: advocacy efforts.
God grant me the serenity
to accept the things I cannot change;
courage to change the things I can;
and wisdom to know the difference.

Reinhold Niebuhr
Reconciling one’s identity crisis

“What would you like to be called?”

Reconciling one’s identity crisis

"Don't call me a teenager. From now on, I want to be referred to as a pre-adult."
Providing emotional containment for

Celebrating one’s Deaf status or
Grieving one’s deaf status or
Celebrating one’s HOH status or
Grieving one’s HOH status
Etc.
Adolescence begins when children stop asking questions, because they know all the answers.

Adolescence = resistance
We often think we’re collaborating with an adolescent when we’re not.
Paul shouted, “I don’t need hearing aids! And tell my mom I don’t need to be dragged in here for counseling.”

“Why don’t you need hearing aids?” I asked.

“They don’t help me understand anything better.”

“How much do you think you understand at school without them?”

“It doesn’t matter,” Paul replied. “School’s boring. I’m gonna be a fisherman like my dad. You don’t need hearing aids to fish.”
My proposal to Paul:

“You’ll wear your hearing aids every day at school for the next month. Every morning before you wake up, your father will remove your HA battery or leave it in, according to a coin flip. He’ll then give the HA to your mother who will give it to you. Neither you, your mother nor your teachers at school will know if the batteries are in or not.

Every day, you and your teachers will estimate what percentage of classroom conversation you’re able to understand. At the end of the month, we’ll correlate when your HA were working with your and your teacher’s estimations of how much you understood.”
Paul’s data

% understood

- Self
- Teacher

Rater

On
Off
Reconciling one’s identity crisis

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“My son was actually in an environment with his peers--other deaf students!!! Communication was very natural, as it no longer was necessary to facilitate through an interpreter. He had as role models Deaf adults who had achieved master's degrees in education, and the hearing faculty and staff were all fluent signers. He was able to play sports without coaches being unaware of his communication needs and therefore, leaving him on the bench. He was able to participate in the signing choir, theater productions, and mentor some of the younger students at the elementary level. My son is comfortable with his deafness, and with his identity as a Deaf individual.
<table>
<thead>
<tr>
<th>Deaf student, college freshman</th>
<th>15-year old, hard-of-hearing mainstream student</th>
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<td>“I’m so grateful I went to an inclusion, mainstream program with other hearing kids. I got the breath of experience, academic stimulation and great friends in the neighborhood that I would never have gotten in a deaf school away from my home.”</td>
<td>“I couldn’t tell my parents that going to school was like drowning in ice water.”</td>
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Potential positive and negative effects of mainstreaming or inclusion

Positives:

- Proximity to one’s home & neighborhood
- More spontaneous social opportunities between home and school
- Easier after-school logistics
- Often higher level academics than in self-contained settings
- More variety of information and peers
Negatives

• More difficult to connect with other larger deaf/hoh peer network and deaf/hoh adults
• Teacher communication often one step removed via interpreter
• Varying degrees of competency with interpreters
• Difficulty communicating with hearing peers in unstructured time (e.g., recess, hallway, cafeteria)
• Reduced opportunity for incidental learning
• Difficulty participating in classroom discussions
• Varying levels of deaf/HL awareness and sensitivity among teachers and staff
Without adequate accommodations and supports, mainstreaming a deaf student is the most restrictive environment.
"Interpreter Isn't Enough!"
by Leah Hager Cohen

An interpreter doesn’t solve isolation from peers

“It's a few minutes before the class will start. Everyone's sharpening pencils and it's all 'What did you put for the last answer on the algebra?' and 'If we want to stay for the game, Toni says she can give us a ride.' All of the eleventh-graders are speaking or listening, directly or indirectly. Except for one student, sitting down front. She is neither speaking or listening; she is not involved; she is deaf.”
9-year old pupil with profound hearing loss

“Hearing classmates are not nice and I don’t feel right. It would be better if I had my deaf friend with me. The teacher said she had to separate us. I was angry inside.”
“There was one student who knew sign language. I talked to him . . . and that had been good, you know, he's in my lab. One time the teacher was lecturing and the interpreter was gone, but I had forgotten something. So, after the lecture I asked that student, "Well, what does this mean? What work should I do here?" So he explained to me in sign language, and I thought that was really nice and he really helped me.”
Deaf college student

“Mainstreaming and isolation are “best friends.” I grew up in the mainstreamed environment, and I never knew how much I had missed in speaking of social and emotional aspects until I visited Texas School for the Deaf during the homecoming celebration. Now, I knew what I had missed.”
How can we maximize the positives and minimize the negatives of mainstreaming???
The three most important words

Communication

Communication

Communication
15-year old, hard of hearing student

“If you inform the hearing students from the beginning and let them know what kinds of things that you need to make communication clear, everything goes smoothly. If you don't inform them they just won't know. So, you just need to say, "Look, I'm hard of hearing. Could you speak a little louder?" Then they know. I've found when I came here that if you inform them first that you're hard of hearing . . . That really helps.”
Don’t assume that including an interpreter makes a mainstream situation accessible. It ain’t that simple

Tips for utilizing interpreters

American Sign Language verses English-based SL

Know that deaf student is always a couple of sentences behind.
English: I want to eat ice cream now

ASL: Now eat ice cream I want
"Class begins. She pays attention for a while. Sometimes when the teacher asks a question, she signs a response, which I interpret into spoken English -- always a little late, just a few seconds after the other students. Sometimes the students all talk at once; their voices overlap and I have to choose one thread to follow, or compress them all in a quick synopsis, inserting who said which thing to whom and in what tone of voice.”
Tips for utilizing interpreters

- Talk directly to deaf student, NOT “tell him/her that…”
- Talk sequentially. Ball technique.
- Ask “Am I being clear?”, not “Do you understand me?”
- Schedule interpreter breaks and “eye breaks”
- Respect student’s need for intermittent invisibility
- Signer verses interpreter: appropriate screening via Massachusetts Commission for the Deaf and Hard-of-hearing (MCDHH) at 617 740 1600.
- Pre and post class meetings, particularly at the outset.
"Her teachers ask me how I think she's doing. I tell them that I cannot say; as the interpreter, I'm not permitted to give an opinion. I say, 'Maybe you would like to ask her? I'd be glad to interpret if you'd like me to ask her yourself.' They do not take me up in it."
Relevant student characteristics for successful mainstreaming/inclusion

- Low degree of HL
- High level of frustration tolerance
- Ability to utilize interpretation
- Hearing or deaf identity
- Ability to navigate hearing world
- High level of incidental learning
- High verbal IQ
- Early intervention
Common Accommodations for Deaf/HOH Students in Mainstream/Inclusion Settings

• Interpreting (ASL, Sign English, oral)
• Preferential seating
• Small # students
• Note-taking
• Teacher of Deaf to supplement mainstream
• Weekly lesson plan summaries
• Homework written on blackboard
• Academic monitoring of progress
• Assistive Listening Devices (e.g., FM system)
• Acoustic modifications
• Consultant re using Assistive Listening Devices (ALD’s)
• Program consultant
• In-service training for school personnel
• Audiological monitoring
• Equipment monitoring
• Speech therapy and auditory training
Common Accommodations cont

- Peer group of deaf/hoh students at or slightly above level of functioning
- Counseling
- Group therapy
- Peer mentor
- Disabilities awareness module
- Out of school contact with deaf/hh peers and adults
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“Blindness separates you from things. Deafness separates you from people.”

Helen Keller
People need people: the importance of connection

Barbara Streisand
Artwork by Nick Curtin, a 15-year old deaf boy.

“The two towers are weeping and hugging as they collapse.”
The importance of relationships
Finding the right balance

Similar others

Dissimilar others
Common Social Challenges

- Dominating conversations. Best way to avoid not understanding is to talk more
- Beginning and entering conversations
- Finding commonalities
- Helping hearing peers feel comfortable, ie showing/explaining HA, teaching some SL
- Reducing bothersome acoustic habits
- Defining friendship: deep talk, surface talk
- Approp fliriting & distinguish from harrassment
HL Social Networking Websites

http://www.healthfulchat.org/hearing-impaired-chat-room.html

http://www.hear4life.org/

http://www.deaflinx.com/DeafCommunity/chat.html

http://www.hearingexchange.com/chat/chat2.htm

http://www.hearingloss.org/content/message-boards/chat-rooms

http://www.saywhatclub.com/
We know your column isn’t a dating service, but can you give us some dating tips for our hard-of-hearing daughter?

Worried parents
Boulder, CO
First hoh dating task:

Introducing one’s HL in non-apologetic manner

Identify one’s HL and needs while preserving self-esteem
How to inform a date about your HL

One way:

He talked a lot in order to avoid not understanding what his date was saying. Other times, he tried to “pass” by saying “Oh yeah” or by nodding his head.” Finally, when pressed, he admitted, “I can’t hear well, I’m sorry (looks down)

A better way:

She told her date, “I just wanna tell you that I have a hearing loss in both ears. See my hearing aids? I do very well in small groups with little background noise, but have trouble in other noisy places with dark lighting. I hope that’s not a problem for you, because it’s not for me.”
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Task: Putting one’s HL in “its place”
Reducing spread

**Spread:** how much a disabled person views that disability as impeding, not some aspects but all aspects of his/her functioning and being

“I’ve learned ways to cope with my HL in order to be successful”

“Because of my HL, there’s no way I’m gonna make it in this hearing world.”
“Shifting gears is a process by which we choose change. Now that may seem crazy because we sure didn't 'choose' hearing loss. But we can choose how we manage it. “

Holly Elliot
Two examples of high degree of spread

5-year old

6-year old
Lost in the Fog

An example of low degree of spread

©Paul Smith
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“We need to nurture ourselves the way we might nurture and care for our best friend.”

Oprah
“It is a rare deaf person who has not as a child been ostracized, ridiculed, and denigrated by non-disabled children. Such memories are painfully poignant.”

Allen Sussman
An important task: Managing anger

“Kid Pretends to be Deaf”

Scott BU Med students story
Ordinary evil doesn’t make the news
Bullying

Dealing with bullying

Overt aggression

The Bully, the Bullied, and the Bystander: From Preschool to High School
Barbara Coloroso

Covert aggression

Odd Girl Out: The Hidden Culture of Aggression in Girls
Rachel Simmons

A new twist

How to Stop Bullying on Facebook
Bowman
http://www.ehow.com/how_4966768_stop-bullying-facebook.html
Other resources on bullying cont

“Braving the Bullies: What Speech-Language Pathologists Can Do” by Nancy McKinley from The ASHA Leader

“Good friends are hard to find: Help your child find, make and keep friends” by Fred Frankel.
Preparing for unfairness and rejection

“Their words mean more about them than about you.”
Anticipatory Coping

The Skin We’re In
by Janey Ward
If “deaf” is a dirty word or hearing aids are something to be covered up or hidden, why wouldn’t your child think that this is a shameful part of himself? Instead, teach age-appropriate, simple, neutral language to help your child self-advocate and explain his hearing loss to peers. A simple, “These are my cochlear implants. They help me hear just like glasses help people to see,” is usually sufficient to stop peers’ stares.
Other common precipitants of anger/rage

- Mental health profession mis-dx and minimalizing HL
- Constantly needing to assert oneself in a society that ignores issues of hearing loss.
- "Try Harder and you can hear/lipread/understand communication. If you don't succeed, means you didn't try hard enough." (Blame victim)
- "I know what's best for you...It's the hearing way or the wrong way." ie putting down a deaf person's decision to affiliate with Deaf culture and exclusively use sign language.
- Ignore the deaf person and maybe s/he will go away
- Forcing deaf children to undergo speech training when it becomes traumatic for them.
Distinguishing inappropriate school accommodations from ADD or bipolar disorder

Rapid cycling bipolar disorder study

Fear gets expressed as anger, especially with boys

Beware of the student who has perfect speech (airplane ticket story)

Higher risk for emotional disorders, including social difficulties, depression and anxiety
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Roots and wings: Receiving family support for gaining autonomy:

A tale of triumph
The story of Carol
The hearing sibling:
Pam’s letter
Imaginary dialogue and Resilience
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1. “I call them as they are.”
2. “I call them as I see them.”
3. “They are as I see them.”
If you don't like something change it; if you can't change it, change the way you think about it.

Mary Engelbreit

“They are as I see them.”
“Shifting gears is a process by which we choose change. Now that may seem crazy because we sure didn't 'choose' hearing loss. But we can choose how we manage it.”

Holly Elliot
Adopting an evolved self-image

Christopher Reeve
Finding potential benefits in adversity

Crisis = Danger and Opportunity
“If hearing loss is a teacher and I’m the student, what *lesson* or opportunity does it offer me?”
Wisdom is from Enlightenment & Endarkenment
Developing mentor relationships
“Childhood's logic never asks to be proved (all conclusions are absolute). I didn't question why Mrs. Flowers had singled me out for attention... All I cared about was that she had made tea cookies for me and read to me from her favorite book. It was enough to prove that she liked me."
Principle of healing:

Pain has a size and shape, a beginning and end. It takes over only when not allowed its voice.
Fundamental Psychological Needs

- Frame of reference
- Safety
- Intimacy/Trust
- Independence
- Cultural Affiliation
- Esteem
- Power
- Existential Meaning
- Spiritual
Frame of reference

"My hearing loss

• destroyed what might have been.

• made my life be over, and a new life beginning.

• threw me off balance.

• changed my world."
Safety

"My hearing loss

- meant danger- not hearing someone coming
- made me worry what if someone is breaking in?
- made me fear ridicule and discrimination.
- terrifies me. I feel claustrophobic."
Intimacy/trust

"My hearing loss

• feels like a glass wall.
• makes me tempted to reject others so won't get rejected by them.
• creates a crisis for me of what to do after saying hello.
• thwarts my spontaneity with romance.
• leads other people to minimize it.
• I've come to find out who my friends really are.
Independence

"My hearing loss

• has forced me to redefine independence-dependence issues as *not* all or none.

• lowers my financial earning power.

• has taught me to cherish aloneness and my independence.

• I feel too dependent."
Cultural Affiliation

"My hearing loss

- has created an identity crisis. I feel between the deaf and hearing worlds
- I don't know sign language but I'm deaf.
- The Deaf community rejects me. The hearing community rejects me. Where am I?
- I'm not in either the hearing or Deaf culture; I'm in ALDA."
Esteem

"My hearing loss

- feels demeaning.
- I have sudden feelings of embarrassment and feeling stupid.
- My self concept goes up and down.
- I must control how much of my sense of self is polluted by hearing loss.
- I feel inadequate, without self respect."
Power

"My hearing loss

• has forced me to learn and practice self advocacy.

• tempts to me do violence.

• makes me aware of my ability to control my world. I need to figure out how.

• The Serenity prayer. I don't have to control everything but I can control a great deal.

• I have the power to decide who to educate.
Existential Meaning

"My hearing loss

- has given me greater purpose in life
- has made me appreciate what I have more
- gives more contrast and texture to my life
- makes me acknowledge the Yin and the Yang
Spirituality

"My hearing loss

• has begun spiritual quest for me.
• has expanded my experience of humanness.
• teaches me that humility is okay, that there's a higher power.
• has improved my relationship with God.
• I appreciate group church less; I pray more individually."
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Communication
Dear Mom and Dad,
If you only had known.
Love, Sue
Every day except May 19th
May 19th!!!!!
The three most important words:

- Communication,
- Communication, &
- Communication

“The most dangerous assumption about communication is the assumption that it’s been achieved.” Mark Twain
MOMM! HEY, MOM!

CALVIN, STOP YELLING ACROSS THE HOUSE! IF YOU WANT TO TALK TO ME, WALK OVER TO THE LIVING ROOM, WHERE I AM!

I STEPPED IN DOG SHIT WHERE'S THE HOSE?
I think that it may snow today.
Aoccdrnig to a rscheearch at Cmabrigde Uinervtisy, it deosn't mtttaer in waht oredr the ltteers in a wrod are, the olny iprmoetnt tihng is taht the frist and lsat ltteer be at the rghit pclae. The rset can be a total mses and you can sitll raed it wouthit porbelms. Tihs is bcuseae the huamn mnid deos not raed ervey lteter by istlef, but the wrod as a wlohe.
Need for policies & procedures for COMMUNICATION
Be proactive, not reactive

Be patient, relaxed, non-accusatory and look for the humor

H: don’t yell from other room; HOH: don’t start communication from other room

Instead of asking “Do you understand?” work out way to verify communication. ie hoh spouse to repeat what hrng spouse said.

Agree on ways to distinguish whether hoh spouse is withdrawing verses not understanding. ie Ask.
Agree on finite expectations for H interpreting

Reduce background noise -- e.g., preferential seating in restaurants, request music be turned down

Maximize visual cues – e.g., Move closer with face to face visual contact, keep things away from mouth, reduce background lighting, ensure ample light

Maximize gestures

Context: Help hoh anticipate what you say

Beware of prosody (speed at which you speak)

Vary how you repeat something hoh has missed. Rephrase with different words.
The sculpture poem
Constructing meaning