Dual Sensory Loss or Deaf-Blindness:
Do all names smell so sweet?

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NOTE

ORAL PRESENTATION IS AN UPDATE
NOT ON YOUR MEMORY STICK
Can find it at the Forum Website
My Practical Evidence Base

• 35+ years of personal adult experience living with DSL (Usher Syndrome III)
• 30+ years of professional experience working with wide range of “Deaf-Blind” (DB) adults
• Co-facilitated for 3 years Metamorphosis—a support group for DSL adults in Seattle
• Now VA researcher with funded 2 year Pilot Study: Self-Management Groups for Veterans with Dual Sensory Loss
What is deaf-blindness (DB) & dual sensory loss (DSL)?

- Least inclusive definition: “like Helen Keller” i.e. can neither hear nor see anything
- Most inclusive definition: A combination of hearing and vision loss that causes extreme difficulty: a) in attaining independence in daily living activities, b) achieving psychosocial adjustment, or c) accomplishing vocational or educational objectives (adapted from HKNC)
- Advantage of least inclusive definition: more services for those who really need them most
What is Dual Sensory Loss (DSL)?

- Both DB and DSL can describe same people. Some use DSI—for Impairment. Consumers generally reject the term “impairment”
- Earliest use I found: Gaylord-Ross (1995) on skills training for DD/DSI. DSL & DSI commonly used by 1999 and often since
- DSL/DSI preferred by non-DB specialists: audiologists, low vision workers, gerontologists etc. who see many hard of hearing & visually impaired, & few deaf or blind
DSL can be peripheral or central in origin and expression

1. Lew et al. (2009) described Veterans of Iraq & Afghanistan wars with central processing DSL due to blast induced traumatic brain injury
2. We’ve always known that some DB/DSL come from trauma and disease, may learn more by studying these Veterans
3. VA priorities: services and research about both TBI & age related DSL
What’s on your mind Juliet?

“What’s in a name? That which we call a rose by any other name would smell as sweet.”

Reasons for Names

• Helps people think and feel more clearly about themselves
• And talk to each other about shared issues
• Professionals can better think and talk about and to clients about barriers & solutions
• Rehabilitation agencies can develop and provide appropriate services
• Fiscal entities can make decisions and allocate funds
Diversity of populations

Various labels for the sub-groups of the population with hearing loss:

- Deaf or deaf
- Hard of hearing
- Late deafened or oral deaf
- Does the label deaf-blind (or minor variations) convey this varied population? Why use the most “severe” label for this group?
Miner (2008) DB Self-identity

- Qualitative interview study compared people in Denmark and NYC
- Found comprehensive services in Denmark, few services in NYC
- Danes mostly accepted DB label. Fit personal and community identity and services.
- NY’ers mostly rejected DB label. They seemed to FEAR the term!
Some History

• Wolf, Delk & Schein (1982) REDEX study (needs assessment funded by US Dept of Ed): 1st study to estimate a large number of “DB” (700,000) in US population; previous estimates around 16,000

• Karp & Santore (1983) showed that variability of HL in USH was often overlooked

• Variability in HL now recognized but not always well served in the full context of Vision & Hearing Loss
Comparisons & variations

**Visual language**
1. Tactile ASL for totally blind
2. ASL differences for residual vision: close, distant, tracking, tactile
3. Lighting & contrast variations
4. Varieties of sign language & culture
5. Training counselors, interpreters, LVTs etc.

**Hearing language**
1. Cochlear implants for total deafened: how to use
2. Different hearing aids, cochlear implants, ALDs, captions & speech reading
3. Different acoustical environments
4. Communication strategies & behaviors
5. Training counselors, audiologists, LVTs etc.
New Labels: DSL & VHL

• Some criticize label DB—too narrow & severe
• Some criticize label DSL—too general: We have 5 senses! DSL could mean – taste & smell impaired, after a bad meal
• My VA project uses both DSL (for professionals) & VHL—Vision & Hearing Loss (for Veterans)
• VHL is straightforward, informative and non-confrontational. May work best for VR clients!
• “Vision” comes 1st because much research shows VL greater impact on emotions than HL
So: When to use DSL (or VHL)

• DSL is preferred label for people who grew up in hearing & sighted world and still identify themselves that way.
• DSL services should target specifics of remaining hearing, vision, and identity
• DSL an umbrella term; can also cover all DB
• DB is much more powerful label when seeking funding. Some clients accept/are proud DB and seek out and join the “DB community.”
• Use what helps, where and when it helps!
Advantages of DSL & VHL labels

- Does not confront people with the frightening prospect of going totally DB
- Provides a less threatening label for professionals to talk to clients
- Allows for a better picture of diversity of the population
- May give some a name around which to accept or construct a positive new identity
VHL effects on life

- General impacts across published studies:
  1. Increased depressive symptoms—VL primarily
  2. Poorer general health
  3. Decreased participation in social activities: visiting friends, phone calls, movies, church etc
  4. Harder time shopping, preparing meals, managing money, doing housework
Psychosocial Issues

- Grief
- Loss of actual independence
- Loss of sense of personal control, self-efficacy, self-concept
- Stress
- Distrust & anger
- Depression

- Adapt/accept/resign?
- Encourage use of pre-morbid coping skills
- Build interdependence with allies
- Skills training
- Assistive technology
- Spiritual resources
Interactive Effects of DB/VHL

Greater than VL or HL alone, or sum of impacts of VL & HL:

Each sense a resource for adaptations to impairment in the complementary sense; these resources are compromised by the co-occurrence of HL & VL:

\[ HL + VL = HL \times VL \]
Examples of Interactive Effects of DSL

- **HL - V**: speechreading difficult or impossible, hearing aid controls, captioning, visual signaling devices
- **VL – H**: localization cues for mobility, voice inflections for meaning, audible signaling devices, speech output devices
- **DB/DSL**: use vibration and touch
- Interactive effects: huge even with partial hearing & vision losses!
How Many DB & DSL People are there in US?

• We don’t know. All we can do is estimate.
• The Helen Keller National Center provided these numbers:
  – 50,000 Americans with Usher Syndrome (all types)
  – 80,000 DB Americans total from all childhood causes (include USH)
  – Up to 1.2 million total, all ages and causes
Usher Syndrome: most common genetic cause of DB & DSL

- Usher 1 (USH1) — born profoundly deaf, progressive vision loss due to RP, balance loss
- Usher 2 (USH2) — born moderate hard of hearing, RP may show later, balance normal
- Usher 3 (USH3) — born normal to mild HL, RP later, balance loss
Usher Syndrome

• National Institutes of Health: http://www.nidcd.nih.gov/health/hearing/usher.htm

• 4 babies out of 100,000 have Usher Syndrome (all types—I, II, and III)

• 90-95% USH1 & USH2; 5-10% USH3

• 3-6% of babies born deaf have USH1

• 3-6% of babies born hard of hearing have USH2 & 3

• USH1 more easily accept DB label

• USH2 & USH3 may or not accept DB label, most prefer DSL or VHL
Demographics of DSL

- Sansing (2006) found estimates ranged from 1.4 – 1.9 million Americans, all ages
- Brennan & Bally (2007) estimated new cases of DSL @400,000 annually; 3.5 – 14 million Americans could have DSL by 2030
- Desai et al. (2001) estimated 7 – 21% of those over 70 experience DSL
How Many DSL/DB of working age?

Best Life Span Estimates I found, from UK:

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NOTE: USA has five times the population of UK

http://www.sense.org.uk/about_us/five_year_strategy/deafblind_population
More Prevalence Numbers—VL

- NIH National Eye Institute estimates 1 million legally blind in US
- Total estimate of VI: 3.5 to 14 million, most age related (AMD & diabetes)
- 20 states refuse driver’s license if 20/40 or less
- VA low vision services: VL ≥ 20/70; other services require legal blindness
- VL ≥ 20/80 impedes speech reading
- Causes: macular degeneration, diabetes, glaucoma, cataracts, trauma, RP etc.
More Prevalence Numbers—HL

- Hearing loss estimates: 31.5 to over 40 million
- 65+ year olds: 3rd most common health problem 1/3 have HL, 1/2 of 75+ yr. olds
- 18 – 44 year olds: 6.7% have HL
- 45 – 64 year olds: 17.5% have HL
- Men – 19.1%, Women – 11.1%
- 800,00 – 1.2 million – severe to profound HL includes D/deaf people
- Causes: noise, age, genetics, trauma, illness, ototoxic drugs etc.
Key Topics for People with DSL

1. Identity
2. Adjustment
3. Language
4. Community integration
5. Technology

1. DSL or DB or VHL or?
2. Fear and acceptance
3. Spoken and/or manual English? ASL? Braille or?
4. Community of origin? DB community? None?
5. Cochlear implants ALD Hearing aids CCTV iPad Text-to-speech Phones/TTY/ VP/TRS and MUCH more
Suggestions: Amplification

Patricia Kricos (2007) Hearing Assistive Technology Considerations for Older Adults with Dual Sensory Loss. *Trends in Amplification*, 11, 4, 273-279, December (one of a few articles on the subject)

- Hearing aids should be provided even for mild or moderate hearing loss to compensate for loss of visual information
- Fitting both ears critical for better understanding and localization
Amplification continued

• Binaural fit reduces stress and listening effort, increases overall relaxation
• Slower listening algorithms may improve comprehension, especially where there is cognitive involvement or stress
• Advantages to automation: directionality, volume and fit to environmental acoustics
• Turbin: Manual control also has advantages, human mind is slower but smarter
Amplification continued

- Critical to match the hearing aids. Matching electroacoustic and microphone characteristics aid localization and comprehension.
- Individuals vary in choice of controls. Some find ITEs easiest to manipulate, then BTE, others find the reverse true.
- Use CCTV and large print to teach hearing aid controls & education about features/limits.
Amplification continued

• Know an audiologist with CCTV? Give her one?
• Ease in using HA controls and changing HA batteries: selection & training
• ALDs, both FM and Bluetooth, help compensate lack of vision & optimize residual hearing. Requires extensive patient education.
• Post-fitting support necessary. We will discuss our VA support group project.
Orientation & Mobility Training

• Very little published about O&M for VHL; nearly all writing and professional education about total DB
• But O&M instructors have many DSL questions
• Using FM on street helps communication but reduces environmental awareness
• Localization: delicate cognitive process involving microseconds and dB fractions in differences between ears
O&M continued

• Modern hearing aids, some using Bluetooth, can be programmed to work together. But how much real localization is possible?
• Compression circuits increase soft sounds and decrease loud ones, the opposite of what you need for localization!
• Directional microphones increase audibility on busy streets—but in which direction?
Other Communication issues

- Sign language: ASL or PSE or ESL or none?
- New Captel phones: selectable fonts & colors
- Can VHL person use Voice Over features on iPhone or iPad? Read screen icons, outside?
- Touch: the hands as “back channel” for voice inflection, facial expression, body language
- Seeing captions on TV and CART: Zoom!
Purposes of VA Pilot Study

- NOT make recommendations to providers in Audiology or Blind/Low Vision Services
- Value added group services for Veterans; all have had services in VA clinics
- Provide psycho-educational info & training
- Promote Collaborative Self-Management
- Provide opportunities for Peer Support
What is Patient Centered Care?

- NOT “Counselor centered”—patients and counselors are both experts who collaborate
- NOT “Disease centered”—emphasis on illness experience, the personal context of the biological condition
- IS Biopsychosocial
- IS about counselor – patient communication
- IS driven by patient choice
Carl Rogers
“On Personal Power”

“It is not that this approach gives power to the person; it never takes it away.”
Existing Support Groups for Individuals with DSL:

Helen Keller National Center
Confident Living Program (CLP)

HKNC Senior Services Coordinator, Paige Berry on our team
CLP is residential, 2 - 7 days
Purposes of the CLP

• Quality information about vision and hearing losses
• Enhance coping skills
• Exposure to new devices
• Positive experiences to build confidence, self-worth & success
• Offer choices for making own decisions
WELLNESS & POSITIVE PSYCHOLOGY


HEALTHY LIFESTYLE WHEEL
(Oregon Office on Disability & Health)
Introductions

• Introduction of group members to each other is crucial for harnessing the power of peer support
• Give each group member time to tell their own story: how DSL has and is affecting them
• Group Facilitator provides both general and specific information and manages the interactions and time
Managing Yourself

• Healthy life style: food, exercise, positive thoughts & feelings (CBT), being active
• *Seated* stretching exercises―National Center for Physical Activity and Disability (NCPAD) www.ncpad.org/videos
• Conscious breathing, relaxation and affirmation
• Stretch, breathing begin all sessions, homework for session 1
Breathe  Relax  Affirm

For Providers & Patients

In  Out
Deep  Slow
Calm  Ease
Smile  Release

Present Moment  Peaceful Moment
Problem solving: Managing VHL

1. Manage body, heart and mind
2. Use lifelong skills
3. Use VA resources
4. Step by step: break the problem down. Take your time.
5. Be flexible
6. New perspectives: old ways, new ways?
7. Hardware: low tech & high tech
8. Collaborate with partners
The TRIOS

• We sought to find strategies to enhance learning through simplicity and repetition
• Conceptually derived from the Aggressive-Passive-Assertiveness trio frequently used in clinical and educational practice and validated in social skills training research
Change

Learn to change the things you can change,
Learn to accept what you can’t change,
Cultivate the wisdom to know the difference
TRIO: 3 Ways We Deal with Aging

1. I can do everything, just like I used to! (denial and anger)
2. I can’t do anything now (helplessness, passivity)
3. I can do, but **differently**. Sometimes myself, and sometimes with your support (collaborative self-management)
TRIO: Living Productively with VHL

1. Independence: I can still do it just as always
2. Dependence: I can’t do anything, do it for me
3. Interdependence: I can do most things, sometimes in a new way, and seek assistance when appropriate
Living with vision loss in VHL

• Key issues: self concept, depression, change in role
• Compare to normative aging issues
• Giving up driving
• Issues around medical care: getting to doctor, reading prescription labels etc.
• In class exercises to practice problem solving; follow up homework
Dealing with Hearing Loss in VHL

• Aggressive/Passive/Assertive Communication Relationships Trio
• Communication strategies, with some alteration since CANNOT depend much on visual cues
• Practice with vignettes and personal issues
• Assistive Listening System throughout the entire course
Multiple microphones with FM
ASSISTIVE TECHNOLOGY

- Providers from VA Audiology & Low Vision Clinics will show several devices and take Q & A
- Veterans themselves bring “favorite” AT for show & Tell
- Discussion on “internal barriers” to AT use: fear, embarrassment, dexterity etc.
- Underutilization of AT a major issue!
Technology: DAISY MP3 PLAYERS
Text to Speech

SELECTABLE VOICE, PITCH, SPEED

Can Read Along With Magnified Text

OUTPUT JACK FOR HEADPHONES OR NECK LOOPS

www.thelowvisionstore.net $1495.00
11 The EasyRead Edition is optimized for reading enjoyment for readers with normal vision. The text is set in comfortable 11 point type.

13 The EasyRead Comfort Edition is optimized for readers who find that reading small print requires effort and causes eye strain but they do not need large type. The text is set in 13 point type.

16 The EasyRead Large Edition is optimized for readers who need a standard 16 point type.

16 The EasyRead Large Bold Edition is optimized for readers with reduced vision who need bold 16 point type.

18 The EasyRead Super Large 18 Edition is optimized for readers with significantly reduced vision who need bold 18 point type.

20 The EasyRead Super Large 20 Edition is optimized for readers with significantly reduced vision who need bold 20 point type.

24 The EasyRead Super Large 24 Edition is optimized for readers with severely reduced vision who need bold 24 point type.
Not Sherlock Holmes’ Magnifier

⇒ MANO Portable CCTV ($595.00)
⇒ 4.9 ounces, 3.5” x 2.9” x .9”
⇒ 3.5” TFT screen, 2X - 8X continuous zoom magnification
⇒ hold up to 6” away or place directly on reading material
⇒ viewing modes: full color, white on black, 4 other combinations
⇒ freeze frame mode allows storage of 3 snapshots for later viewing

thelowvisionstore.net
Managing Emotions

Mind – Heart – Act Trio

1. I can choose helpful thoughts
2. Which makes it possible to choose healthy feelings
3. Which enables me to choose productive behaviors
STRESS IS PHYSICAL & MENTAL

Do you have a favorite way to relieve stress?

• Strenuous Physical Activity
• Breathing Exercises
• Relaxation Training
• Affirmations
• Meditation
RELATIONSHIPS: Family, friends, caregivers, others

INTERDEPENDENCE TRIO

1. He doesn’t need any help
2. He’s helpless. I’ll take care of everything
3. Let’s negotiate. We can both do our part. We take care of each other

I’ll walk a bit in his shoes, see what DSL is like
Simulations for Significant Other

Purposes: not just the sensory experience, but the kick in the gut emotional experience

• Gently guide SO, drag SO—how do those feel?
• Leave SO at bathroom door—make sure you wash your hands, use & throw away towel!
• Guide to hall, let SO find Fire door, door to outside, first step up & first step down
• TV with sound low, listen from 2, 5, & 10 feet
• SO wears ear plugs, whisper to from 2, 5, & 10 feet away
Bringing it all together in the final session

- Re-integration into the community
- Local recreation resources
- Aging issues and resources
- Plans for the future—what you learned, what you will use in your life
- Graduation!
THANK YOU

Questions?
Comments?

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