The HANDLE ®Institute

CASE STUDY Bilateral Hearing Loss Defined as Due to Bone Damage and/or Nerve Damage Proved Reversible

Presented by Marlene Suliteanu, OTR/L and Certified HANDLE® practitioner

These case studies, each submitted by a Certified HANDLE® Practitioner, demonstrate outcomes achieved through implementation of an individualized HANDLE program. The acronym stands for the Holistic Approach to NeuroDevelopment and Learning Efficiency. The HANDLE paradigm for understanding behaviors and their root causes is thoroughly explained in *The Fabric of Autism: Weaving the Threads into a Cogent Theory*, by Judith Bluestone, the creator of HANDLE and the founder of The HANDLE Institute. For intimate insights into client and family experiences of HANDLE, see *The Churkendoose Anthology*, with commentary by Judith Bluestone.

For each of the clients in these Case Studies, the practitioner began with a comprehensive assessment, the findings of which led to a Neurodevelopmental Profile, which in turn formed the basis for a program of activities complex in their neuroscientific premises and very simple to implement. Thereafter the client's program was modified about monthly in accord with changes achieved in the interim. Each client participates in twelve to fifteen activities regularly; the practitioner, in writing up the case study, names those activities in brief without the full details and explicit information each client-family receives in why and how to implement the program. Go to **www.handle.org** for more information.

Introduction

This case study represents one unusual and dramatic experience of the effects of a HANDLE program. The parents of a young teenager struggling academically and socially brought her to my therapy practice for an assessment in hopes that schoolwork and social skills would improve. She presented with long-term deafness in her right ear attributed to bone damage, and a recently identified loss of hearing in her left ear described as due to nerve damage. Her hearing losses in no way constituted something they or we thought to change in any way. Yet to everyone's astonishment, in addition to significant gains in tactile sensibility, cognitive function, emotional responsiveness and communication skills, over the six months of her program she also regained her hearing!

Clinical History at Intake

Client (referred to as "P") is 15-year-old female.

Nutritional Status

Client is poor eater, underweight.

Birth History:

Premature, born at 28 weeks; in NICU 5 days, needed oxygen first day, tube fed for few hours, then bottle-fed using breast milk. P struggled with sucking.

[Note: learned subsequent to the initial assessment that during pregnancy, having been diagnosed as anemic, mother was put on a regimen of iron at a supportive-dose level.]

Health History

At age 4, client had open heart surgery for a "hole in her heart" that was sutured. She developed a heart disease called Long QT Syndrome; doctors said it was incurable. She was put on meds and 6 months later the hole was gone, to the surprise of the doctors. Recent cardiogram showed no problem. At age 7, diagnosed as being deaf in her right ear due to bone damage; began wearing a hearing aid at that time. Note: diagnosis made by an MD based on assessment with a "machine" in the office. At age 11, diagnosed with partial hearing loss in her left ear due to nerve damage.

Developmental History

Fussy eater until about 3 years old; trouble chewing ever since about 6 months old (teeth emerged); at 5 years old was allergic to milk; milestones as follows:

- Sucking – 5 days old
- Rolling over (not sure age) but considered delayed
- Sitting up/pulling self up – 6 months
- Crawling – 7 months
- Walking – 15 months
- Talking – 2 years
- Self-toileting – 2 years
- Dressing self – 4 years
- Feeding self – 2 years
- Going up/down stairs (not sure age) but considered delayed
- Drawing or writing – 7 years
- Deciding handedness (not sure age) but considered delayed
- Participation in rhythm activities (not sure age) but considered delayed

Academic or Vocational History

IEP in 1st grade identified P as having "developmental delay" and being a "slow learner," warranting special ed day class and speech therapy. Continued this up to 6th grade. Since then P has been home-schooled; mother considers her as "improved" since that change.

Participation in HANDLE Program

Referral Concerns

P's parents learned of GET ABLE and HANDLE through a friend whose son had "been transformed" by his participation in the program. The friend told client's mother that HANDLE would probably "help" P similarly. Despite financial and geographic hardship, they decided to commit to the full 6-month program. They expressed their concerns as follows:

1. In answer to this question: What are the concerns or goals that bring you to GET ABLE? mother said, "My goals for my daughter are to live with peace and be confident to express herself to communicate more. To not feel stressed or so uncomfortable all the time; not to feel so confused all the time.

2. In answer to this question on the Intake Questionnaire about specific social or recreational concerns, mother wrote: "P is overwhelmed, stressed, confused sometimes when dealing with relationships. But very sweet and wanting friendships. Her communication with others is a problem. She struggles." Additionally she offered, "P is … very hard on herself. Most of the time seems like she's trapped inside herself. I love her very much and want her to be able to live freely in expression. She has a lot to offer."

3. When asked at the assessment, what would you wish were going easier for you, P answered: to learn things faster. Her parents answered: not hurt herself, she picks at her fingers*; less social confusion; more sure of herself alone (parents not around). *We subsequently learned that P actually uses implements to hurt herself, not just picking.

Initial Assessment

The initial assessment, March 11, 2008, in the GET ABLE office, was led by an intern who herself happens to be deaf in both ears, wearing hearing aids. This coincidence enhanced the interaction between the intern and the client specific to their uniquely shared experience of the world and added much to P's sense of safety during the assessment.

Please see the attached supplement that details the findings of P's assessment and their relevance in a functional context, a narrative explanation of the Neurodevelopmental Profile.

Initial Program

Crazy Straw with eyes closed; 14 oz. water distributed over the day to enhance visual system.

Wall Paper (with small size paper) to enhance visual system and air production.

Face Tapping with cotton balls for sensory integration.

Skull tapping for interhemispheric integration.

Joint Tapping (Independent corner push-offs for upper body) for proprioception.

Suspended ball:rolling pin for visual system and interhemispheric integration.

Buzz Snap with hands and feet for improved tactility, muscle tone, proprioception and energy.

Sunrise Sunset on bare skin, not on shirt sleeve for interhemispheric integration, tactility, rhythm.

Ball Pass Crawl while seated for interhemispheric integration especially language processing.

Ear Muffs and Side-to-Side Tip while seated against wall for vestibular and visual systems.

Ball Back Roll (Rainbow version) for vestibular and visual systems.

Quarter Turn Roll (assisted as needed) for vestibular system.

Peacemaker Massage (roll ball clockwise) for tactility, muscle tone, and proprioception.

Two-Finger Spinal Massage (back and thumb independent) for autonomic nervous system (calming).

Follow-Up

Reinforcement/Fine-Tuning Visit: 3-22-08

Family report: Wriggling less while sleeping. Fell asleep right away one time. Less finger picking. Away at camp for a weekend; didn't do vestibular activities.

Clinician's observations: Suspended Ball (rolling pin) fully integrated. Vestibular activities not performed slowly enough.

Program changes: DC Suspended Ball. Replace Wall Paper with Blow Soccer. Replace ¼ Turn Roll with Spinal Twist. New: Jiggle Bridge/Sternum/Navel; Kneading.

Reassessment & Program Review #1 of 6: 4-18-08

Family report: P said, "I can feel things."and "I jumped on the bed, which I never do."

Mom: P. doing really well with division (math); still wants to erase whole question if needing a correction. Hasn't been hurting herself; no finger picking. No longer needs cotton balls for Face Tapping; it feels good.

Clinician's observations: P able to put finger straight to middle of mouth with eyes closed. Ball Pass Crawl: P tried standing and moving, cognitive lead rather than body leading.

Program changes: New activity challenges with Swivel Chair Directionality for spatial orientation; Weighted Cuffs (1-2 lbs.) on left wrist and ankle for up to 10 minutes, at rest to "wake up" right hemisphere.

Change Blow Soccer: use cotton ball

Change Ball Pass Crawl: standing and walking

Other recommendations: Emphasis on trusting body as sensory input becomes reliable.

Reassessment & Program Review #2 of 6; 5-16-08

Family report: P not initiating her program; family moved temporarily and didn't bring all supplies.

No objects used to hurt herself. Tactile sensation better—she complains of pain. Hurting her lip; still can't feel tooth brushing, spits out toothpaste in order to feel the brush.

P gained a little weight.

P accepted as client by Crippled Children's Services which will pay for hearing aids. Currently having problem with wax build-up.

Writing content is better. P: "That, I'm proud of!"

Re activity program: first time P used the weights she felt fatigued (said "never before" experienced that). Crazy Straw and Weights "help a lot" especially with remembering steps in math problems. Added conversation to Sunrise Sunset. Wants very hard pressure of the ball in Peacemaker Massage (so much that Dad was worried he's hurting her).

Clinician's observations: Blowing (air available) with cotton ball is too easy; able to play "soccer" across the table and control for "croquet" game. Functional effect: speech is audible! [Demonstrated Tok Bak for self-recognition of vocal volume].

Ball Pass Crawl: P able to keep pattern with walking. Sunrise Sunset and Swivel Chair Directionality also integrated. (Note re Directionality: no misses with 1½ to 1¾ revolutions each time).

Kneading feet: asked P to attend/notice if can begin to be able to spread her toes (never could do that).

Program changes: Blow Soccer with a bead, as a game (needs "opponent") and move toward Blow Croquet.

Kneading: add hands independently.

Options for Side-to-Side Tip: edge of bed or in chair instead of against the wall.

New activities: Hug 'n Tug. Had good immediate coordination to perform. Bounce Bounce Scoop is challenging.

Other recommendations: Cod liver oil (not synthetic). Seek consultation for toxic load assessment especially regarding heavy metals (low-level iron residual from fetal ingestion? Possible contributor to malnutrition?).

Reassessment & Program Review #3 of 6: 6-13-08

Family report: Ear infection (outer ear) for a couple of days; scratched a lot.

Graduated! Starts high school in the fall.

P battling sicknesses; mom had flu too. Multiple MD appts.

Seems to have "gone back" even to talking less, tired more, eyeballs rolled up.

Fingers better. No objects used. No sores.

Emotional descriptions now especially re pain of losses.

Re activity program: Lost ball for Bounce Bounce Scoop; didn't make a Blow Croquet setup yet. Favorite is Buzz Snap. Kneading activity "hurts" — never used to feel even a stone on foot; relate Kneading to (1) scratching ear (sensitivity) and (2) maybe drained wax? Jiggle Bridge helps with breathing.

Clinician's observations: Discussed correlation between sensory experience and emotional experience: "feeling" is the same word.

Side-to-Side Tip: good pacing, good timing of hand to "help" regain upright

Program changes: Modified Bounce Bounce Scoop with focus on 2 bounces; size of ball should be about size of your hand.

Modified Hug 'n Tug with elbows propped on tabletop, alternate "pull" not continuous pull.

Kneading of feet by mom; hands independently.

Reassessment & Program Review #4 of 6: 7-18-08

Family report: Remembering things better. "Haven't been hurting myself; still biting my lip some." Feels tooth brushing more; mint toothpaste bothers (tingly).

Biting nails: it hurts to bite or tear them too short

Getting accustomed to sand and water (beach)

Re activity program: Mom said hair brushing was better when doing Skull Tapping every day, but they haven't done Skull Tapping for 2 weeks so hair brushing is worse. Bounce Bounce Scoop has become "easy."

Clinician's observations: Bounce Bounce Scoop: counting a bit, hesitated a bit when attempted conversation.

Checkerboard activity introduced: so challenging she immediately became totally fatigued. Defer.

Program changes: Modified Bounce Bounce Scoop by add conversation. Remember to ask mom for Skull Tapping and Joint Tapping.

New: Blow Pipe (replaces Blow Soccer/Croquet). Lummi Sticks. Object Memory Game.

Reassessment & Program Review #5 of 6: 9-6-08

Family report: MD say ears draining normally! (never before). P can feel/hear it happen sometimes.

Image in front of her eyes that was "lines" now takes shapes; when she closes left eye it/they go away. Dad: maybe due to "exhausted brain." P doesn't sleep well, often doesn't eat well — malnutrition?

More sensitive to smells, notices more. Mother says P is looking more relaxed lately. Brushing and washing her hair! No dandruff. No more self-injuring; only picks at some cuticles. Gets very frustrated with errors in math homework

Re activity program: Never began Lummi Sticks (no dowels yet) or Object Memory Game. Tapping activities relax her. Kneading: wants harder pressure. Peacemaker Massage now almost to tailbone: she's happy about it. Blow Pipe: well done especially due to full breath. Buzz Snap makes her "hyper" now. Jiggle Bridge helps focus and memory-tracking.

Clinician's observations: Detox advice: discussion re indicators vs. risks.

Weighted Cuffs on hold: she's too emotional? and not achieving cognitive processing sought, namely getting to the gist of a subject instead of so much detail.

Buzz Snap on hold: too much "electric" energy release?

Introduced Rhinoceros: good initial attempt with 3 rings; unable to "find" rings on tabletop without looking. Reinforced need to do the Object Memory Game.

Other recommendations: Use tactile support for handwriting such as finger painting, sand, now that tactility is less an issue.

Reassessment & Program Review #6 6 10-11-08

Note: precisely 7 months since began]

Family report: Audiologram yesterday: essentially normal left ear ("nerve damage") and right ear ("bone damage from birth").* No need for hearing aides!* P heard practitioner's voice (about 25' distance) "better than with my hearing aids."

More visual distortions: lines and shapes. Only occurs when she faces a flat surface, not if people are in front. Very frustrating.

Motor skills: more focused, better coordinated.

Clinician's observations: Spinning in chair, comfortably.

Reassessed: 1) Ear/nose task continues challenging. 2) Intake Questionnaire, multiple input (not just mom) on the form. 3) Visual functions: a) tracking: needed to stop after 2nd arc for each "target" b) Brock String:

*A copy of the audiometric testing with comparison with P's original testing was provided by family, and resides in client's GET ABLE file.

1 bead, each focus. c) 3-D glasses: no "white" anywhere but dot did not move. [Note: when she "sees" lines and shapes, it goes away when she closes left eye.]

Program changes: Hula Hands, assisted, especially for rhythm/synchronicity.

Other recommendations: Share this story! [Family agrees]. Hiatus until about January '09.

Outcomes

Summary

This young woman came to GET ABLE for a HANDLE program to address social and academic challenges related to sensory-motor issues that compounded her deafness as limitations on her ability to succeed in her life; neither she nor her parents (nor this therapist) sought or anticipated the direct and dramatic impact the program had on her hearing. They are all elated; I am astounded. I theorize that regularly implementing the HANDLE vestibular activities and doing the Kneading activity on hands as well as feet steadily began to cause fluid to loosen or otherwise enable the stapes, malleus and incus bones to transmit sound waves to the cochlea of her right ear. Primarily Face Tapping but also Crazy Straw and her blowing activities apparently facilitated function in whichever auditory nerves had deteriorated enough to have caused the deafness in her right ear.

More "usual" – and had they been the only changes they would have been impressive on their own — were dramatic gains in her tactility system. Previously unable to feel pain at all – she reported not knowing she had incurred an injury until she saw herself bleeding — P. was self-injuring in attempts to arouse some sensation. She had sacrificed personal hygiene and appearance (despite puberty as a predictably opposite motivator) because things like face washing and hair care were intolerable. Now not only does she not need to hurt herself, cares for her appearance with pride, and describes sensory input consistently, but she has added an emotional corollary: she acknowledges feelings. The absence of that had caused her mother much anxiety and distress in years past.

Her parents' and P.'s stated hopes for the outcome of the HANDLE program (see Referral Concerns on page 2) were achieved — and, obviously, surpassed!

Future Plans

1. The family has not yet obtained authorization for toxic-load assessments. I have written a letter in support of doing so, with explanations for my recommendations.

2. Client and parents want to continue with a HANDLE program in 2009. I have urged deferring until at least January so that P can begin to feel comfortable with her significantly altered ability to respond to life's challenges. Continuing concerns relate to (1) cognitive processing for academic tasks as well as other learning, (2) language usage, including handwriting &/or typing, topic/content and organizing her thoughts, and (3) social interaction skills for age-appropriate relationships.

3. At this time home schooling will continue into high school. I know of no plans for identifying a public school willing and able to meet P.'s needs, but that is not out of the question once the family establishes more permanent residency. (They are living with P's grandparents.)

What Makes This Case Unique

(or why have I written it up in such detail, to share)

Besides the wonderfully supportive and engaged family, who all (including both siblings) never missed an appointment despite having to drive almost 3 hours each way between their home and my office, and minimizing P's consistent motivation, what's clearly most "unique" about this case is the unexpected and truly startling outcome of a reversal of deafness. Gains in other sensory-motor systems occur almost routinely with clients who participate in this kind of HANDLE program; not recovery of hearing, the loss of which, and the confirmation of recovery, were identified by audiometric exam entirely unrelated to HANDLE or to me.

The client, Priscilla Gonzales, requested that her real name be used. This reflects her pride and ownership of her recovery.

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Case Study Supplement: Narrative Report of Assessment of P

[NOTE: wherever a number appears in the "Data" column, it refers to the family's assessment on the Intake Questionnaire, on a scale of 1 to 10, of the frequency/severity of the statement as applied to the —client: 1 is low, 10 is high.]

Olfaction: sense of smell

- Bothered by strong smells: 10
- Has a stuffed nose

Those two seemingly unrelated examples of P's hypersensitivity to smell actually demonstrate the same thing: her "stuffed nose" protects her from the potentially constant irritant of smells in the environment, and also (compounding deafness) causes nasal-sounding speech. Note: as other sensory systems will serve her more reliably, P won't need to rely on olfaction.

Tactility: sense of touch

- Self-injures; picks at fingers
- Needs to see injury to realize she has hurt herself
- Uncomfortable in water: 9
- Complains about face washing, hair brushing: 10

Because this sense is so basic and, actually, essential, P tries to give herself enough tactile input to feel something. Since she feels no pain, she keeps trying. What she doesn't realize is that she is so extremely hypersensitive to tactile input that her brain protects her by blocking pain. As for the hygiene activities, our face and scalp/hair are among the body's most sensitive areas; although washing them may not seem too vigorous, it is to anyone as hypersensitive as P apparently is. As her tactility system normalizes she will not need self-injury and she can attend to her hair care more.

Vestibular system: supports all motor function

- Balance problems: 10
- Dislikes roller coaster rides
- Plosive sounds intercepted her accurately hearing spoken nonsense syllables
- Difficulty writing with eyes closed; does not have first name retained in motor memory

Fast or abrupt movement shuts down the vestibular system. The main organs of the system lie in the inner ear, between the passage through which sound waves enter and the organ of hearing (the cochlea), with the result that plosive sounds like "k" and "p" block the waves' access to whatever hearing P can use. Regularly using the HANDLE vestibular activities will begin to diminish the impact of plosive sounds, among other benefits.

Kinesthesia & kinesthetic memory: sense of movement, retention of motor patterns

- Difficulty writing with eyes closed; does not have first name retained in motor memory

P may have difficulty learning tasks that involve a motor pattern, like dance steps. Speech is among the most complex kinesthetic tasks; with hearing loss that impedes the prerequisite input to copy, her pronunciation may lack precision. Her goal of improving her handwriting will need gains in kinesthetic memory.

Muscle tone: the resting state of all muscles; the readiness of all muscles to respond to task challenges

- Lots of propping (supporting her posture)
- Taps fingers hard on the table

- Presses hard writing with pencil (3-point prehension)
- Difficulty sustaining eye contact

The first challenge to which our muscles must respond is gravity; propping is how P needs to support upright posture, due to low tone. It also impairs the ability to modulate or control the degree of force used in any task; tapping too hard may exemplify that. Probably gains in muscle tone will positively affect her handwriting. The tiny muscles of the eyes apparently can't hold the position of forward or focal vision enough to keep looking at you. Low tone fatigues P quickly. As her tone stabilizes, her eye contact can improve, including its duration (sustaining it) without fatigue.

Proprioception or proprioceptive awareness: sense of position in space, sense of relativity among body parts and whole body in surroundings; extended to include social boundaries; prerequisite for prepositional (language)concepts, math concepts*

[Proprioceptors (the organs of this sense) are located at all joints.]

- Difficulty with fingertip task copying demonstrated thumb-to-fingertips activity)
- Difficulty getting to sleep
- Dislikes using a trampoline when others share it
- Seeks deep touch and snuggling up to others: 10

* Note: P is doing grade 3 math

Among the ramifications, an important one for P relates to how proprioceptive deficits impair her sense of social boundaries. She may be "in your face" or unclear about what's appropriate. Similarly but in an opposite way, being crowded by other bodies confounds P's ability to define her safe space. Coupled with kinesthetic memory concerns (above), inaccurate proprioceptive information limits her learning demonstrated motor skills (if she can't "find" the needed body part). The brain's survival function depends on not-conscious use of sensory input, so inaccurate proprioceptive information feels very unsafe when she's asleep; anticipating that would make sleep something to avoid. Among the ways proprioceptors are stimulated, one comes from hugs and snuggles: tight pressure at joints. Another self-awareness sense dependent on proprioception: feeling "in" one's body. P doesn't, yet.

Audition: sense of hearing; processing sound

- Hearing loss in both ears, identified as due to bone damage in the right since birth and nerve damage in the left more recently; hearing aid in the right.

Affects all social and academic interaction, importantly including her self image

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Oral-motor functions: specific use of mouth and related structures

[influenced by muscle tone (above) as well as anatomy]

- Narrow palate
- Vocal volume very low
- Dislikes chewy foods

Probably as muscle tone improves, so will P's ability to produce enough air to support more volubility, which in turn may boost her confidence for social interaction (which was one of the goals named by her parents).

The HANDLE Institute presents these case studies to demonstrate the successes of the HANDLE approach and pique the interest of researchers and funders in engaging in clinical studies to further examine the efficacy of these interventions. For more information about The HANDLE Institute, go to **www.handle.org.**

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