Multi-Sensory Impaired, Profound Learning Disabilities and Severe Brain Injury

Working with the most difficult client groups

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Helen Keller

• Helen Adams Keller was born a healthy child on June 27, 1880 in Tuscumbia, Alabama.

• At the age of 19 months, she was stricken with a severe illness which left her blind and deaf.

• At 6y she was taken by her parents to see Dr. Alexander Graham Bell and here met her teacher Anne Mansfield Sullivan.

• She learned the fingertip alphabet and in 6 months knew 625 words.

• By age 10, Helen had mastered Braille and could speak well enough to go to preparatory school.

• Helen lectured in more than 25 countries on the five major continents.
Helen Keller is NOT representative of the majority of congenital Deaf Blind ... 

- Often presenting with
  - No speech
  - No sign language
  - No finger spelling
  - Some may use a few “Objects of reference” linked to activities
Some Severe Challenging Behaviour

• Self-harming
  – Biting hands
  – Poking eyes
  – Banging heads off walls

• Few: Violent outburst to others

• Tactile Defensive
MSI Clients – how they presented

• Blind / Light perception only
• Deaf / unknown
• Moderate to Profound Learning Disability
• Other medical or complex needs
Acquired Brain Injury in UK

This includes all admissions for head injuries, strokes, brain tumours, meningitis, encephalitis, hydrocephalus, anoxia, CO poisoning, abscess and hyponatraemia.

- **1 million**
  Minimum estimate of people in the UK living with long-term effects of brain injury

- **558**
  UK residents per 100,000 sustaining a brain injury

- **Every 90 seconds**
  Someone is admitted to hospital in the UK with acquired brain injury

- **353,059**
  UK admissions to hospital with acquired brain injury in 2011-12

- **661**
  Northern Ireland residents per 100,000 sustaining an acquired brain injury in 2011-12, the highest rate in the UK
Head Injury

These indicate traumatic brain injury, ranging from minor brain injuries to severe injuries causing long-term disability.

- **213,752**
  Total UK admissions to hospital for head injury in 2011-12

- **169,673**
  UK admissions to hospital with a non-superficial head injury in 2011-12

- **33.5%**
  Increase in UK head injury admissions in the last decade

- **10,000 - 20,000**
  Number of severe traumatic brain injuries per year in the UK

- 2x
  More likely for men to sustain a traumatic brain injury than women

- **15-24 year old males and over 80 year olds**
  Groups most at risk of traumatic brain injuries
US figures

### Traumatic Brain Injuries (TBI)

**General:**
TBIs occur when the impact of a rapid acceleration, deceleration, or collision causes a brain injury. TBIs are classified as mild, moderate, or severe depending on the extent of damage to the victim's physical and cognitive abilities. TBIs can be especially dangerous if they disrupt blood flow to the brain or pressure in the skull.

**TBI Facts:**
According to the CDC, more than 1.7 million TBIs occur every year. Of these injuries:
- **52,000** result in death
- **275,000** cause hospitalization
- **1.4 million** require an emergency room visit
- TBIs cost **$76.5 billion** every year.
- **75%** of TBIs are concussions.

Children, teenagers, and the elderly are most likely to suffer a TBI. TBIs occur more commonly to males than females.

**Common causes:**
According to the CDC, the most common causes of TBIs are:
- Falls: 35%
- Car accidents: 17%
- Collisions: 17%
- Assaults: 10%

**Common symptoms of TBI:**
- Headache
- Dizziness
- Nausea
- Vomiting
- Lack of motor coordination
- Change in sleep patterns
- Emotional symptoms such as mood swings

**Serious symptoms of TBI:**
- Difficulty thinking or concentrating
- Severe headache or nausea
- Slurred speech
- Memory problems
- Unconsciousness
- Seizures

**TBI in sports:**
According to the CDC, more than 170,000 TBIs are suffered by children and teenagers during sports. The most common causes of these injuries were bicycling, football, playground activity, basketball, and soccer.

**Long-term side effects:**
TBI can have long-term side effects. Victims may suffer from physical and cognitive impairment for months or years following a TBI. A study published in the Journal of Clinical and Experimental Psychology found that 60% of TBI victims showed signs of emotional dysfunction. TBIs also increase the risk of epilepsy, Alzheimer's disease, and Parkinson's disease. Additionally, approximately 5.3 million Americans are living with a traumatic brain injury-related disability.

Call d'Oliveira & Associates at 1-800-992-6878 for a free consultation.
Effects

- **Behaviour and personality**
  Anxiety, depression, loss of motivation, difficulty controlling anger, and impulsivity

- **Cognitive**
  Problems with memory, attention and concentration, low tolerance of noisy or stressful environments, loss of insight and initiative

- **Physical**
  Loss of co-ordination, muscle rigidity, paralysis, epilepsy, difficulty in speaking, loss of sight, smell or taste, fatigue, and sexual problems

Initial diagnosis of severity of injury is not a reliable indicator of long-term problems
Relationships with family and friends can be placed under immense strain
Relatives report that the ten most difficult problems are personality changes, slowness, poor memory, irritability, bad temper, tiredness, depression, tension and anxiety, rapid mood changes, and threats of violence
The number of people with learning disabilities in England

- Public Health England estimate that in England in 2012 **1.14 million people had learning disabilities.**
- This included:
  - **236,000 children** (identified at School Action Plus or above in DfE statistics as having either a primary or secondary SEN associated with learning disabilities)
  - **908,000 adults aged 18+,**
    - of whom 199,000 (22%) are known to GPs as people with learning disabilities
    - and 404,000 (44%) were receiving Disability Living Allowance
A Personel account

- Four years experience of working with
  - Deaf / Blind
  - Profound Learning Disabilities
  - Acquired Brain Injury
Service Considerations

“Thank you for calling Customer Service. If you’re calm and rational, press 1. If you’re a whiner, press 2. If you’re a hot head, press 3....”
Aim of intervention

- Normally we aim to utilise residual hearing for optimal speech intelligibility. As speech communication will not be achieved with these client groups the objectives are:
  - Confirm a healthy ear*
  - Awareness of environment / people
  - Enjoyment of sound / music
  - Stimulate to reduce challenging behaviour
Service requirements

• Dedicated Audiologist(s) – to gain as much exposure & experience as possible

• Intensive intervention: Regular weekly Clinic session for client until monitoring stage (ie Assessment / Fitting / Follow up)
  – Same day
  – Same time
  – Same room

• Object identifier for room (eg Plastic Ear on Door) & Audiologist (eg unusual watch or bracelet)

• First appointment allow time for client to explore room / people – they need to feel safe (perhaps no examination or assessment on the first visit)
Same carer!

- The same carer **must** be encouraged to attend each appointment
  - They can help identify true responses & changes in behaviour
  - They can provide useful real life anecdotal information

- They must be engaged in the process
  - To understand the importance of intervention
  - To instigate consistent Hearing Instrument use

- *(2 year Birmingham study of LD revealed high level of medically related issues)*
  - Sometimes quick turnover of staff
  - Hearing may have a low priority compared to other needs
Baseline: It is important to observe MSI client in natural surroundings

- Information is needed specifying:
  - Motor ability
  - Vision
  - Re-inforcers
  - Attention span
  - Method of communication

- **Functional level of hearing ?:**
  - Observation should involve sounds which form part of their everyday lives and routines and the same sounds under different acoustic conditions
Levels of Functioning

1. **Awareness / Reflective**: Unintentional e.g. Blink

2. **Attention / Alerting**: intentional – frown, stilling

3. **Localisation**: Locating source

4. **Discrimination**: Responds differently to different sounds e.g. noise

5. **Recognition**: Relates sound with meaning e.g. name

6. **Comprehension**: Linguistic association, transferring learned patterns to new situations
Communication mode

- Own gestures
- Signs – BSL, SSE, Makaton
- Coactive /adapted sign
- Objects of reference
- Symbols including tactile
- Line drawings
- Deafblind manual alphabet
- Block alphabet
Approaches

• Those with no useful residual vision may need you to touch them & them to touch you

• Tactile personal symbols are useful to give them reassurance about who you are. Introduce yourself in the same way each time.

• Adopt a “total communication” approach – speech / sign / gesture

• Proceed at their pace considering possible anxieties about being in a “strange situation”, they may need time to adjust
Assessment
The assessment challenge

• The management of Multiple Handicapped Hearing impaired (MHHI) is difficult due to
  – **Idiosyncratic behaviour**, learning styles and highly individual nature of responses
  – **Unusual life experiences**; prolonged hospitalisation, multiple surgeries or recurrent medical conditions may influence co-operation for yet another “procedure” to be carried out.
  – **Significant others** may have little concern for hearing, when they need to focus on other needs
  – When multiple handicaps exist, their effect may have more impact than simply summing the problem areas
  – **Many audiologists** – process driven - see only a small number of MHHI clients making it difficult to acquire expertise & think outside the box
Interactive sequence
(McInnes & Teffery 1986)

1. Actively resists
2. Passively resists
3. Tolerates
4. Co-operates passively
5. Enjoys
6. Responds co-operatively
7. Leads
8. Imitates
9. Initiates
Internal factors which may influence their use of hearing

- Hearing loss
- Ear infections
- Wax
- Tinnitus
- Epilepsy
- General health
- Medication
- Pain
- discomfort

- Fatigue
- Motivation level
- Emotional state
- Hunger / thirst
- Physical position
- Demands on other disabilities
- Developmental level
- Relationship with sound source
External factors which may influence their use of hearing

- HA worn & working
- Level of background noise
- Relevance of sound
- Distractions
- Acoustic quality of environment
- Attitude of carers
- Intensity & frequency of sounds
- Sensory overload
Sensory “overload”

- Sensory “overload” can be observed, (causes problem with testing) as the visual distractions are used to maintain attention.

- This visual input may utilise all their concentration and therefore distract them completely from the auditory stimulus – brief sessions required for limited attention.

- Neurologically impaired clients may require more time to respond. Some may respond better with a touch cue to ear
Visual impairment

- **Visual field** - Does the person see the object being used, or is it placed in the wrong position? too far away or too near?

- **Glare** from lighting or table tops – those with cataracts and other visual impairments may have problems in these conditions.

- **Contrast** plain clothes that provide a contrast with hands if you sign and materials should be black on yellow for pictures & symbols.

- For people with MSI, Difficulty integrating information from senses - messages received are distorted & incomplete so learning difficulties and developmental delay is inevitable, even if the person is not intellectually impaired.

- They may have far more potential than is apparent.

- Reinforcer – Air puff / Bright torch
Contributing issues

- They may experience feelings of total isolation and may retreat into their own world as the only way of feeling safe, with a greater risk of developing self-injurious or challenging behaviour.

- Reduces potential for interaction
  - Impact on relationships
  - Language development
  - Problems with touch-accepting & touching others

- Reduces potential for understanding
  - Memory difficulties
  - Problems understanding and generalising between objects & situations
“Invasive” procedures

• Otoscopy / OAE’s / Impressions
• Many MSI are Tactile defensive – you may have to work towards procedure:
  – Aromatherapy massage
  – Hands
  – Face
  – Neck
  – Ears
• Possibly move towards cotton wool in ears for 2 mins / day
ERA

- Tactile defensive – rip of electrodes
- Body movement ++, chewing, grinding teeth
- Mild sedation – not enough
- High sedation / anaesthetic may not be an option with other medical complications.
Considerations

• VRA (with bright probe lights) - require individuals to have
  – Head control in a supported sitting position
  – Self regulated looking ability
  – Cognitive attainment of object permanence
  – Anticipation of re-appearance of objects
  – Awareness

• Many MHHI clients have abnormal muscle tone, having either hyper or hypotonia; which challenges them obtaining & maintaining an ideal posture & movement.
Stimulus must have meaning!
Pure tones & NB noise are meaningless.

- Voice of carer
- Telephone ring
- Cup & spoon
- Biscuit / crisp packet
- Doorbell
- Vacuum cleaner
- Boiling kettle
- Toilet flushing
- Hairdryer
- Clock tick
- Car engine
- Police siren
- Washing machine
- Microwave beep
- Pouring water
- Favourite object?
- LING Sounds

Consider making recordings – then present Free Field with SLM
Responses

• The greatest difficulty is establishing the certainty of an observed response.

• As well as a limited capability of voluntary movement, extraneous behaviours make interpretation difficult i.e.
  – Tremors
  – Seizures
  – Myoclonic jerks
  – Self-stimulating behaviour
  – Stilling
Reliability among observers

0 = No Response
1 = Low Response (brief /difficult to determine)
2 = Medium Response (obvious but little interest)
3 = High Response (occupied by stimulus)

Each observer scores separately
Agreements /disagree + agree x 100
85% plus reliability should be aimed for
Video Recording of responses

• Increase or stilling of movement of any part of body

• They will need *time* to receive, perceive, interpret and respond to requests or stimulus

• Repeat several times and wait for response

• You may only see it first time if the stimulus does not hold enough interest for the person
Using individualized behaviour..

- Self-stimulation can interfere with responses. However it can be utilised e.g. Rocking –
  - By beating a drum rhythmically in time to the rocking and then introduce a double beat
- Any change or hesitation?
Aurithmics

• Client lies or sits on a resonance board or mattress and is exposed simultaneously to sound, vibration & light.
• Any consistent responses are encouraged; maybe tap of a foot, hand controlled on/off
• Visual stimulation is gradually withdrawn
• Vibro-tactlie stimulus withdrawn
• Intensity & type of sounds varied
SALSA: Short arousal to light sleep audiometry

• Case study: JL – good vision, SLD, uncoordinated movements, no evidence of hearing, Petit Mal epilepsy.

• Responses difficult to observe – occasionally appeared to still to sounds, but had “absences” throughout the day.

• One appt- very tired: He demonstrated an obvious response to even quiet sounds – arousing from even his semi sleep state towards location of sound

• Procedure was adopted early morning / late evenings
Hearing Instrument Fitting
Fittings

- May again require a program to introduce to physical feel of HI – massage ears / cotton wool for few minutes each day
- Introduce slowly in controlled acoustic environments, including gentle music
- Watchful for over-aiding or recruitment
- Observe responses / changes in behaviour

- Make sure Key carer is fully informed & instructed,
  - keep a diary
Case Study: SW

- Reasonable vision, mild learning disability
- Capable of PTA – but responded at MCL not threshold
- Careful introduction & fitting of instrument
- HA’s bitten in half over & over again
- Visit to home – open plan, screaming residents, television full on, kitchen attached to lounge with radio for staff, kettle boiling etc.
- Instigated quiet area, HA’s worn only in controlled environment with one to one conversation / music
- HA’s worn without destruction
Intervention works! Case Study: JH

- HL considered to be significant – unknown levels
- Vision suddenly deteriorated
- Challenging behaviour considerably worse
  - banging head off wall – caused internal bleeding – became wheelchair bound
  - Violent towards staff
- Responded to loud music right ear.
  - Cotton wool on 1 tape
  - Velcro on another - started to make choices
  - Challenging behaviour improved to a point staff could work with her
Thank you