TEACHERS NOTES

Topic content

A. About deafblindness

UK statistics relating to the incidence of deafblindness

- 356,000 people have combined sight and hearing impairments*
- 40 deafblind people per 100,000 of the population
- 447 congenital rubella births 1971-1980 (before introduction of vaccination of schoolgirls in 1970 and MMR vaccination of all children in second year of life in 1988)
- 38 congenital rubella births reported 1991-2000.

**Statistics are estimates and taken from Action on Hearing Loss Facts and Figures July 2011 and Sense.*

Types of deafblindness (the categories below are generally used in relation to whether a person becomes deaf or blind first, and how long they had a single sensory loss before they became deafblind)

- Acquired deafblindness – gradual or sudden loss of hearing and vision, often but not necessarily in old age (includes partially-sighted deafened, partially-sighted hard of hearing, and people who have Type 3 Ushers*)
- Deaf visually impaired – people who were born deaf, or who became deaf in early childhood, experiencing gradual loss of vision, often but not necessarily in old age (includes BSL users, and covers Type 1 and 2 Ushers*, deafblind BSL users, etc)
- Blind hearing impaired – people who were born blind, or who became blind in early childhood, experiencing gradual loss of hearing, often but not necessarily in old age (includes blind partially deaf, blind deafened, blind hard of hearing)
- Congenital deafblindness – people born without hearing and vision.

** see **http://tinyurl.com/3nwnygr** for information on Usher Syndrome and also on next page.*

Causes of deafness

- Heredity
- Viral causes (e.g. meningitis)
- Ménières disease
- Age related (Presbyacusis)
- Industrial and noise-induced.

Causes of blindness

- Cataracts
- Diabetic retinopathy
- Glaucoma
- Macular degeneration
- Retinitis pigmentosa (RP)
- Viral causes (e.g. Meningitis).

Causes of deafblindness

- Premature birth
- During pregnancy (e.g. Rubella)
- CHARGE
- Genetic (Usher syndrome):
  - Type 1 Usher – born profoundly deaf, become blind through Retinitis Pigmentosa (RP), usually starting around 8-12 years old. Have balance problems in childhood
  - Type 2 Usher – born partially hearing (moderate to severe), become blind through RP in late teens/early adulthood. No balance problems in childhood
  - Type 3 Usher (rare – usually found in Finland). Have gradual hearing and sight loss in adulthood. May have balance problems later
- Other syndromes
- Illness, e.g. Meningitis
- Ageing.

B. The impact of deafblindness

The effect of deafblindness on the individual's:

- Identity and sense of belonging (including the difference between deafblind and Deaf visually impaired people, in terms of their language and cultural affiliation):
  - Congenital deafblindness – total life experiences revolves around deafblindness
  - Acquired deafblindness – identity, etc influenced by previous experience of being sighted hearing people
  - Blind hearing impaired – identity, etc influenced by previous experience as a blind person
  - Deaf visually impaired – identity, etc influenced by Deaf cultural background.

- Opportunities to socialise – the importance of shared experiences, and shared communication methods:
  - Communication between deafblind people:
    - through tactile contact
    - through technology, email and the internet.
  - Communication between Deaf visually impaired people:
    - sharing a language (BSL)
    - hands-on signing.

- Well-being:
  - Blindness affects:
    - ability to read written material
    - mobility and orientation
    - access to objects.
  - Deafness affects:
    - audible communication with others
    - acquisition of language.
  - Deafblindness affects all of the above and can also affect:
    - relationships with others
    - access to information
    - confidence
    - personal independence
    - personal choice
    - mental health issues.

  This can result in lack of fulfilment, isolation and social exclusion.

Factors influencing the above

- Age of onset:
  - Birth
  - Childhood
  - Adolescence
  - Adulthood
  - Family background.
- Support given at onset:
  - Communication adaptations
  - Financial support
  - Counselling
  - Mobility and orientation
  - Availability of support workers, e.g. Communicator-Guides.
- How dual sensory loss occurred:
  - Sudden
  - Gradual
  - Through old age
  - Accident
  - Illness.
- Attitudes of others:
  - Ignorance
  - Stereotyping
  - Supportive.
- Attitudes of the deafblind person – coming to terms with deafblindness:
  - Shock, fear
  - Anger, frustration
  - Denial
  - Depression, isolation
  - Bereavement
  - Acceptance (not always achieved).

- The educational experiences – depending on the age of onset:
  - Acquisition of language
  - Acquisition of culture
  - Mainstream or special schools.

- The deafblind person in society:
  - The rights deafblind people have as a consequence of their unique dual disability
  - Relevant legislation affecting deafblind people especially child and adult protection
  - Relevant legislation that upholds the human and civil rights of deafblind people.

C. The importance of the environment

The importance of environmental factors in ensuring optimum conditions for communication with a deafblind person

- Getting the deafblind person to where they need to be in order to communicate (see also D)
- Setting up the physical environment
- Accommodating the communication needs and preferences of the deafblind person
- How the environment and other factors affect communication:
  - Distance – proximity for good communication versus invasion of personal space
  - Lighting
  - Backgrounds – visual and auditory:
    - visual distractions
    - vibrational distractions
  - Acoustics
  - Personal attire
  - Importance of touch
  - Importance of smell, a) as an aid to personal identification and b) in personal hygiene
  - Use of senses to alert to changes in environment: sound, remaining sight, wind (e.g. opening doors), vibrations, smell and touch.

- The importance of informing the deafblind person about what is happening in the environment:
  - Confidence building
  - Trust.

- Hearing dogs and Dual dogs – the role they play in alerting to environmental changes.

D. The importance of the environment

Principles of communication with people with a dual sensory loss

- Principles of communication with people who have a hearing loss and a sight loss (identifying and meeting the person's communication needs)
  - Make yourself known, approach from the front, s/he may see you or sense you, e.g. draught from body movement, etc
  - Touch lightly on arm or shoulder and allow him/her to finish what s/he is doing
  - Say who you are when addressing the person, including what you are there for
  - If you have a unisex name, (e.g. Chris), say if you are a man or woman
  - Use short sentences
  - Position yourself appropriately
  - Establish physical contact
  - Explain things that are happening in the environment
  - Inform the deafblind person if someone has moved
  - Share communication preferences with those who need to know
  - Announce when you are leaving
- Importance of confidence, trust and respect for successful communication with a deafblind person:
  - Finding out and respecting the deafblind person's preferred method of communication
  - Alertness to the importance of touch, smell, sound or vibrations, remaining sight, wind (e.g. opening doors)
  - Confidence in establishing proximity and touch (if appropriate) in communicating with a deafblind person, despite this being potentially counter-cultural
  - Gaining the deafblind person's confidence and trust that the communication will be effective.

Communication methods and devices used by the four groups of deafblind people

- Methods and devices that make use of residual sight and hearing
- Tactile methods:
  - The functions of the Deafblind Manual Alphabet
  - The functions of the Block alphabet
  - BSL and other adapted sign (e.g. Sign Supported English, Signed English, Makaton, Paget Gorman) used Hands-On

  - Using objects
  - Using symbols (including Bliss and Rebus symbols)
  - Using tactile written forms (Moon and Braille).

- Advantages and disadvantages of these for deafblind people:
  - Lipreading – pace, rhythm, re-phrasing, eye contact, contextual clues, facial expression, gesture, body language, suitable distance, suitable lighting, quiet environment (with reference to visual distractions/background noise)
  - Body language, facial expression and mime
  - Low vision aids (magnifiers, etc)
  - Hearing aids and cochlear implants
  - Induction loop systems
  - BSL and other adapted sign (e.g. Sign Supported English, Signed English, Makaton, Paget Gorman) used in a visual frame
  - Manual alphabet (fingerspelling)
  - Notewriting and large print
  - Pictures
  - Cued Speech.

- How and why they are used by different groups of deafblind people:

  Acquired deafblindness:

  - Focus on both residual hearing and sight:
    - Speech, lipreading
    - Notewriting and large print
    - Pictures
    - Body language, facial expression, natural gesture and mime.
  - Devices:
    - Hearing aids/cochlear implants
    - Induction loop systems
    - Low vision aids.
  - Tactile methods
    - Deafblind Manual and Block alphabets
    - Moon and Braille.

Deaf visually impaired:

- Focus on residual sight:
  - Lipreading
  - Notewriting and large print
  - Body language, facial expression, natural gesture and mime
  - BSL Visual Frame
  - Manual alphabet (fingerspelling).
- Devices:
  - Low vision aids
  - Pictures.
- Tactile methods:
  - BSL Hands-On signing.
- Other signing (manual) systems:
  - Sign Supported English/Signed English
  - Paget Gorman
  - Makaton.
- Other text-based tactile systems:
  - Deafblind Manual Alphabet
  - Moon and Braille.

Blind hearing impaired:

- focus on residual hearing:
  - Speech.
- Devices:
  - Hearing aids/cochlear implants
  - Induction loop systems.
- Other text-based tactile systems:
  - Deafblind Manual Alphabet
  - Moon and Braille.

Congenital deafblind – individual communication needs:

- Focus on residual hearing and sight:
  - Speech
  - Lipreading
  - Body language, natural gesture and mime
  - Notewriting and large print

  - Pictures (Makaton pictures)
  - Symbols (blissymbols, rebus symbols)
  - BSL Visual Frame.
- Devices:
  - Low vision aids
  - Hearing aids/cochlear implants
  - Induction loop systems.
- Tactile methods:
  - BSL Hands-On signing.
- Other signing (manual) systems:
  - Sign Supported English/Signed English
  - Paget Gorman
  - Makaton
  - Cued speech.
- Other text-based tactile systems:
  - Deafblind Manual Alphabet
  - Moon and Braille.

E. Mobility

How deafblindness impacts on the mobility, movement and orientation of the individual and how this in turn impacts on communication

- Barriers to mobility:
  - Lack of vision
  - Balance
  - Orientation
  - Colour contrast
  - Light
  - Unfamiliar territory
  - Lack of accessible information
  - Confidence.

- Access to mobility:
  - Canes
  - Guide/dual assistance dogs
  - Familiar territory

  - Accessible information
  - GPS technology
  - People, e.g. communicator guides
  - Mobility training and route planning.

- Importance of communicating information about location and movement:
  - Gives deafblind person confidence
  - Preferred guiding methods of deafblind person
  - Preferred pace and speed of movement
  - Orientation – the need to communicate where objects, things and people are in relation to the deafblind person.

Tactics for alerting a deafblind person to danger, and for supporting them in their move to a safe place

- Importance of planning for emergencies:
  - What you would do if there was an alarm or alert
  - What responsibility you will take for assisting in an emergency
  - Who else is available to be called on in an emergency.

- Principles of safe guiding:
  - Your pace needs to match that of the person you are guiding
  - Allow them to hold your arm/shoulder securely before you start walking
  - Give adequate room round obstacles
  - Watch out for hazards at head height, especially if the person you are guiding is taller than you
  - Watch out for bollards and other obstructions in the walkway
  - Explain loud noises or movements of other people that may alarm
  - Explain changes in ground surface, for example if you are walking from a carpet to a hard surface, or if surface underfoot is or is about to become particularly uneven
  - Give adequate warning of a change in level, and explain the nature of the change (e.g. one step up/down)
  - Keep your guiding arm still and relaxed
  - Many deafblind people have additional mobility needs not linked to their deafblindness, e.g. older people who will require more physical support when being guided, those who rely on walking aids, wheelchair users, those with balance problems, those with cane or guide/dual assistance dog.

F. Language and communication services

Communication professionals

- Deafblind Manual Interpreters:
  - Describe which particular group(s) of deafblind people they work with, the services they provide; the length/type of training needed.
- BSL/English Interpreters (Visual Frame – Hands On):
  - Describe which particular group(s) of deafblind people they work with, the services they provide; the length/type of training needed.
- Lipspeakers:
  - Describe which particular group(s) of deafblind people they work with, the services they provide; the length/type of training needed.
- Notetakers (Electronic and Manual):
  - Describe which particular group(s) of deafblind people they work with, the services they provide; the length/type of training needed.
- Speech to Text Reporters:
  - Describe which particular group(s) of deafblind people they work with, the services they provide; the length/type of training needed.
- Cued Speech Transliterator:
  - Describe which particular group(s) of deafblind people they work with, the services they provide; the length/type of training needed.

Providers of other communication-related services

- Communicator-Guide:
  - Describe which particular group(s) of deafblind people they work with, the services they provide; the length/type of training needed.
- Versabraille providers (Electronic Notetaker linked to Braille output reader):
  - Describe which particular group(s) of deafblind people they work with, the services they provide; the length/type of training needed.
- Communication Support Workers:
  - Describe which particular group(s) of deafblind people they work with, the services they provide; the length/type of training needed.
- Specialist teachers for multi sensory impaired/deafblind children:
  - Describe which particular group(s) of deafblind people they work with, the services they provide; the length/type of training needed.

- Teaching support staff:
  - Describe which particular group(s) of deafblind people they work with, the services they provide; the length/type of training needed.
- Social workers:
  - Describe which particular group(s) of deafblind people they work with, the services they provide; the length/type of training needed.

Other technologies and services

- Technology to assist hearing:
  - Computers and the web including accessibility functions.
  - Radio aids, hearing aids and cochlear implants.

- Technology to assist vision:
  - Computers and the web including accessibility functions.
  - Braille outputs (versabraille, Braille printers).
  - Low vision aids (CCTV, scanners and magnifiers).