Deaf children with complex needs

Cyprus 2014
This talk

- Who are this group?
- Where are they?
- What needs?
- How can the needs be met?
- Multi-disciplinary
- Networking for families
Complexity?

- Physical
- Intellectual
- Social/emotional
- Sensory
- Medical
- Poverty
- Labels eg: “Mild”

- Evident at birth
- Evident at developmental stage
- Acquired

Is commonly associated with some conditions

All ages from pre-school to school leavers
Who

- Downs syndrome
- Learning disability
- Cerebral palsy
- Autism (Pervasive developmental disorder)
- CMV
- CHARGE syndrome
- Fragile X
- SLI
- Foetal Alcohol syndrome
- PMLD
- Multiplicity of syndromes-Cornelia de Lange; Dandy Walker, Hunter/Hurler; Othro; Goldenhaar........................
AND

- Children living in poverty
- Children living with abusive parents
- Children living with parents who have mental health problems
- Children who are the subject of sexual abuse
- Children with mild physical or intellectual disabilities
Profiling potential....

By understanding challenges

• Typical v atypical development
• Diversity of needs
• Limitations of standard assessments
• Defining meaningful outcomes
• Demands on staff time
Deaf children with complex needs

- May be in the school for the deaf
- Mainstream schools
- Other special schools
- At home
- Unidentified?
Baseline service entry....

Audiological assessment

• Based on standard protocols

• Ability to wait, recognise signal, demonstrate response in a structured and repeatable

OR may use objective tests as a baseline to work from..................but this can be misleading
Specific populations...

Objective audiological assessment may be compromised where longer latency responses are typical

- Children with Down’s syndrome
- Children with CHARGE syndrome
- Children with Fragile X syndrome
- Children with cerebral palsy**
Profiling potential

- Response to stimuli-general
- Ability to wait
- Response repertoire
- Latency of response
- Best time of day
- Specific phobias
- Evidence of response to sounds
- Drug regimes
- Ergonomics-sidelyer, wheelchair, headguard....
Essential that...

• Amplification if used is appropriately fitted, checked daily (stetoclip check) regularly put through a testbox

• Noise is controlled

• Input is meaningful

• Outcomes are identified, agreed and used
What might an outcome be?

- Reduced isolation and improved contact with environment
- To increase level of activity state of arousal in passive/apathetic children
- To calm and reassure restless/hyperactive children
- To allow experience and enjoyment of the sounds of music
• To prevent fright from sudden tactile encounters
• To develop alerting and warning function
• To support perception and recognition of objects and people in child’s environment
• To use non-verbal sounds as referential objects
• To stimulate functional use of voicing
• To reduce/extinguish annoying uncontrolled voicing
Profiling potential

- Communication skills
- Social skills
- Gross and fine motor
- Play
- Monitoring protocol
- Pragmatics protocol
- MacArthur CDI
- Pre-verbal communication schedule
What is in place?

- Objects of reference
- Pictures
- Symbols
- Sign – MAKATON, BSL, SSE
- Is it a shared code?
- Do families use the same code?
Does he/she have the opportunity to

• Express real choices?
• Accept and refuse objects and events?
• Comment on unexpected events?
• Problem solve?
• Participate in joint routines?
What is the message???
Choosing a communication system

- Must include family
- Look at motor control-oro-motor and extremity****
- User preferences
- Previous exposure

- CONSIDER a communication passport
- Practically useable
- Ergonomically acceptable
- Transportable
- Flexible
- Rate of use*
- Possibility of extending
- User community
- Socially acceptable
Specific populations

Pervasive developmental disorder/Autistic spectrum disorder:

• Little research data that provides clear guidance for teachers/parents
• Cochlear implants have been used with significant benefits reported (small numbers)
• Use of BSL and audition have been successful
• Applied behavioural analysis used to extinguish unwanted behaviours
Cytomegalovirus

- 50% of population have CMV
- In pregnancy infection linked to miscarriage, prematurity
- Leading non-hereditary congenital cause of h.loss
- 30-65% have sensori-neural hearing loss
- Symptomatic – early h.loss severe to profound
- **Asymptomatic-progressive**
- LD and CP commonly co-occur
CHARGE syndrome

- C-coloboma; H-heart defect, A-atresia chonae, R-retardation of growth, G-genital abnormalities, E-ear anomalies

- 50% have a severe/profound hearing loss
- Others frequently have major conductive loss and high freq h.loss
- Cupshaped pinna, middle and inner ear abnormalities, missing or abnormal auditory nerve missing or abnormal semicircular canals –balance problems
• Trad. amplification problematic – BAHAs and CI

• As with all children, an active listening programme needs to be implemented

• Early intervention that actively promotes and supports gross motor skills in linked to better outcomes
Recent research suggests 3 possible phenotypes

1) Regulatory disorder – difficult to regulate sleep/wake cycle, hunger/satiety cycle, to console themselves, manage emotions, plan activities

2) Executive function disorder

3) Post traumatic stress disorder resulting from pain, illness and multiple surgeries
Specific language impairment

• 6-10% of typically developing children
• Deafness is not protective against SLi
• Research suggests that deaf children with SLi will have equal difficulty with spoken or signed language
• Profoundly deaf children may have unrecognised SLi – only becoming apparent after CI when auditory access does not result in language growth
• Fragile X syndrome causes a wide range of disabilities mild to severe: cognitive, sensory and SLi

• Short attention span, hand flapping, and biting, poor eye contact, perseveration of speech, large prominent ears, tactile defensive and family history of LD
Behaviour

• There is always a trigger
• It maybe hard to identify-attention, confusion, pain, anger, wants or does not want something
• Is functional for the user
• Can easily be inadvertently reinforced
It may be....

- The result of epilepsy
- PMT
- Psychotic or psychiatric illness
- Endorphin release from self injurious behaviour
- A learnt response that can be unlearnt

- BEWARE of fuzzy statements.....
Multiple Agencies

- Have different working paradigms
- Different vocabulary
- Need to actively work together !!!!

- Parents find other parents the best source of support
Getting parents together

• Practical workshops
• Ideas to use at home
• Meeting the needs of siblings
• Practical break for parents from 24/7 care
What does ToD bring?

Specialist knowledge, understanding and skills:

- Room acoustics
- Communication – pre-verbal and early stages
- Language spoken and/or BSL

An appreciation of the affect of deafness on learning and access to the curriculum
Options...

- Monitor
- Advise and monitor
  - Assess situation, advise and monitor
  - Assess child needs and advise
  - Assess child needs, learning environment, school communication policy and advise
  - Assess holistically, advise on teaching communication approach and tactics, use of IT, music etc-consultancy
- All above and active involvement with child or whole class group
Identification: what next.....

- **Begin planning cycle**
- **Cascade**: perceptual affects of deafness, potential impact on learning
- **Audit**: learning environment
- **Assess**: individual child
- **Child specific research**: identify potential contra-indications, trigger points, areas needing further exploration
As for any deaf child........

- Audit visual and auditory environment
- Ensure daily psycho-acoustic checks
- Ensure fortnightly electro-acoustic checks
- Check if more than one programme is activated on aids
- Advocate for obtain and set up FM amplification
- On going-build up audiological profile**
- Is the child wearing and using h. aids?
Communication

- With family
- With school
- With other professionals
- Set appropriate targets that will support development
Programme needs....

- Structure-giving predictability
- Horizontal- with interleaved progression possibilities
- Agreed success criteria?
- Feedback: how long before you change tack?
- To include home within plan
Communication

- Having something to communicate
- Having a method of communicating
- Recognising someone will value a contribution
- Recognising a turn
- Having an interested partner who shares your means of communication
Communication

- What is in place?
- Magic ball or more formal?
- Has there been progress?

- Usual areas: contingency, attunement, synchrony, joint attention, CDS, turn taking, any use of sound, gesture......
Basics....

• Can you get eye contact – does the child employ gaze following behaviour?
• Do you know child’s visual status
e.g. heminopxia may just be noted as “visual difficulty”
Challenges faced by children

• Reduced capacity to interact with and explore the environment
• A reduced capacity to play and interact with others through movement and vocalisations
• A reduced capacity to express emotions, needs and thoughts
• Little experience of initiating communication, dependence on adults, lack of experience of being a conversational partner, only being asked yes/no questions
Curricular Access

Intrinsic limits

• Cognitive limits
• Physical ability
• Sensory status
• Social skills
• Emotional awareness

Extrinsic limits: US and the “system”

• Expectations
• Experience
• Level of support
• Understanding of individual needs
• Opportunities
• Interest of others
• Societal/service limitations
First things first....

- An understanding of the child at home & school
- Ed Psychologist assessment - eg Snijders-Oomen Non-verbal intelligence test
- Real life experience + previous learning as a baseline
- Chunked information and tasks

Clear start and finish with limited options
Access

- Objects of reference vision? motor control, cognitive link
  - Photos: digital camera child’s choices/taken by child
  - Pictures: vision, relevance
  - Symbols: user community
  - Gesture/sign system: user community, motor control
  - Sign language: 98.9% location, 92.8% handshape, 99.1% motion
- Spoken language
- Use of computer programmes: Apps
Great resources

- www.cafamily.org.uk
- www.down-syndrome.org/information/education/curriculum/?page=3
  Practical ideas on differentiating the curriculum for children with DS
- http://www.nhsdirect.nhs.uk/articles/article.aspx?articleId=660&sectionId=5 (CMV)
- www.chargesyndrome.org
  Resource on Friedrich’s ataxia
- www.fragilex.org.uk
  Fragile X syndrome information
- www.nas.org.uk will try to help with queries on autism
• ACE centre  
  [www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)

• Communication passports  
  [www.callcentrescotland.org.uk](http://www.callcentrescotland.org.uk)

• Communication aids project  
  [www.becta.org.uk/cap](http://www.becta.org.uk/cap)

• For a great magazine focussing on sensory impairment and PMLD