

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; Odho; 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

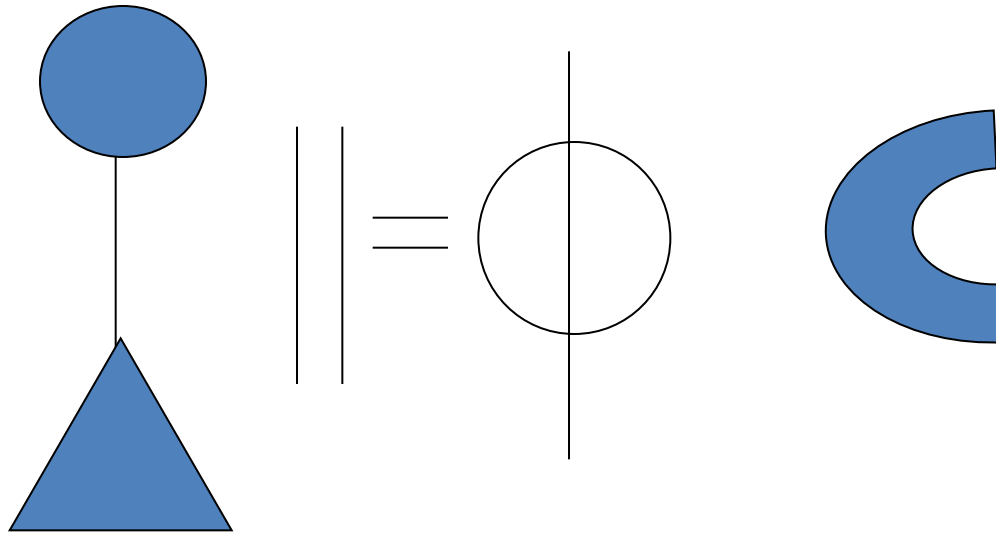
What is in place?

- 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-oromotor 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

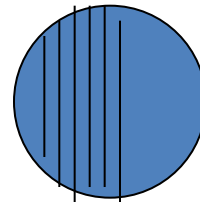
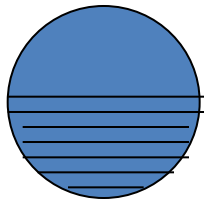
Communication

- 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. hemianopia 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§ionId=5> (CMV)
- www.chargesyndrome.org
- <http://www.frda.org.education/whatis.shtml>

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
- Communication passports
www.callcentrescotland.org.uk
- Communication aids project
www.becta.org.uk/cap
- For a great magazine focussing on sensory impairment and PMLD