

# Communication, Cognition and Congenital Deafblindness – An International Perspective

Jonathan Reid

Sensory Coordinator – The Health and Social Care Alliance Scotland

National Coordinator – See Hear Strategy

Coordinator – Nordic Cognition Network in relation  
to Congenital Deafblindness



# What is Deafblindness?

- No clinical definition within Scotland, or indeed across many EU countries.
- Two main fields to consider: Congenital and Acquired
- Acquired Deafblindness can arise through Usher Syndrome i.e. to be born with profound deafness, and to lose sight in middle age
- Deafblind Scotland estimate between 20,000 and 31,000 people in Scotland with Deafblindness
- Low reliability within data for congenital deafblindness confounded by co-morbidities and mis-diagnoses

# Clinical vs Functional Assessment within the congenital field

- Both are of equal importance, however, like ASD the assessment process is based on functional assessment
- There are very few standardized functional tests which do not rely on vision and hearing to pass
- ASD and Congenital Deafblindness can present in similar behaviors
- Age of onset and language acquisition is key
- Comparison between Norway and Scotland

# The Nordic Definition...(adopted by WHO)

- Deafblindness is a combined vision and hearing impairment of such severity that it is hard for the impaired senses to compensate for each other. Thus, deafblind-ness is a distinct disability.
- To varying degrees, deafblindness limits activities and restricts full participation in society. It affects social life, communication, access to information, orientation and the ability to move around freely and safely.
- To help compensate for the combined vision and hearing impairment, especially, the tactile sense becomes important.

# Critically...

- Deafblindness is a third, unique, condition – not just the summation of sight and hearing loss
- Deafblindness will impact three main areas of Communication, Information and Mobility (orientation)
- The distinction between Congenital and Acquired Deafblindness is based on language acquisition within the human infant
- However! – Language and Communication are two distinct concepts

# The Nordic Cognition Network in relation to Congenital Deafblindness

- Set up through the Nordic Welfare Centre, a member of the Nordic Council
- Norway, Sweden, Finland, Denmark, The Netherlands and Scotland
- Mixture of practitioners, theorists, teachers, neuroscientists and psychologists
- Recent publications include “Revealing Hidden Potentials – Assessing Cognition in Individuals with Congenital Deafblindness”, and a series of webinars focused on each chapter of the book. (Link in further information).

# The Tactile Working Memory Scale

- Peer reviewed and published through NVC
- An assessment tool which considers the Bodily-Tactile Modality to measure cognitive potentials and strategies within the individual
- Aims to develop distinction in terms of determining Congenital Deafblindness from ASD, Learning Disability etc.
- Currently two professionals in Scotland being trained to 'roll out' this work in 2022 via the Scottish Sensory Hub at the ALLIANCE
- Similar 'roll out' across many EU countries and accompanying work towards a 'pan-European definition of deafblindness'

# Communication IS Connection

- - I can only realise my potential, through others....
- Martin Buber – 'I and Thou' (1923)

# Communication IS Connection

- “Human beings, themselves, cannot *mean* anything... Their actions are nonsensical until coordinated with the actions of others... If I extend my hand and smile... the gesture hovers at the edge of absurdity until reciprocated by another...”
- Thomas Gergen, (1991).

# In conclusion...

- Greater awareness, pathways and support are required within the deafblind field, and particularly within congenital and elderly populations
- The communication partner's competencies are critical in terms of 'scaffolding' towards language, tactile communication and co-constructed meaning
- The incidence of deafblindness is too small to be reliant on local or national provision alone. International cooperation and collaboration is key to developing research and practice, such as the TWMS, and Scotland is well placed, via the ALLIANCE to drive forward influence on the international stage

# Thank you!!

- ...and questions...
- Jonathan Reid
- [Jonathan.reid@alliance-Scotland.org.uk](mailto:Jonathan.reid@alliance-Scotland.org.uk)