

National Mental Health Services for Deaf Children in the UK: what have we learnt in the past decade

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Outlook

- Constanza 2006: 17 years
- Victoria 2011: 12 years

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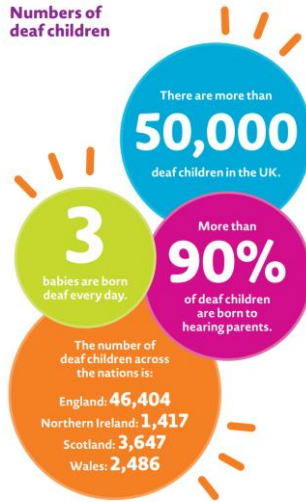
Setting the scene: information about Deaf children and young people in the UK (NDCS)

[crude-2022-england-report-final.pdf \(ndcs.org.uk\)](https://ndcs.org.uk/crude-2022-england-report-final.pdf)

Levels of deafness

- In the UK, half of deaf children are born deaf. The other half become deaf during childhood.
- Every deaf child is different and may have different levels of deafness:
 - unilateral (deafness in one ear): 22%
 - mild: 26%
 - moderate: 31%
 - severe: 9%
 - profound: 12%

Numbers of deaf children



Schools

- 78% of deaf children in the UK attend **mainstream schools** where they may be the only deaf child.
- 6% of deaf children attend **mainstream schools with resource provisions** – a resource provision provides specialist support to deaf children as part of a mainstream school.
- 3% attend **special schools for deaf children**.
- 12% attend **special schools not specifically for deaf children**.
- 1 in 5 deaf children have a special or additional need alongside their deafness.
- In **England**, only 1 in 5 deaf children have an **Education, Health and Care plan**.

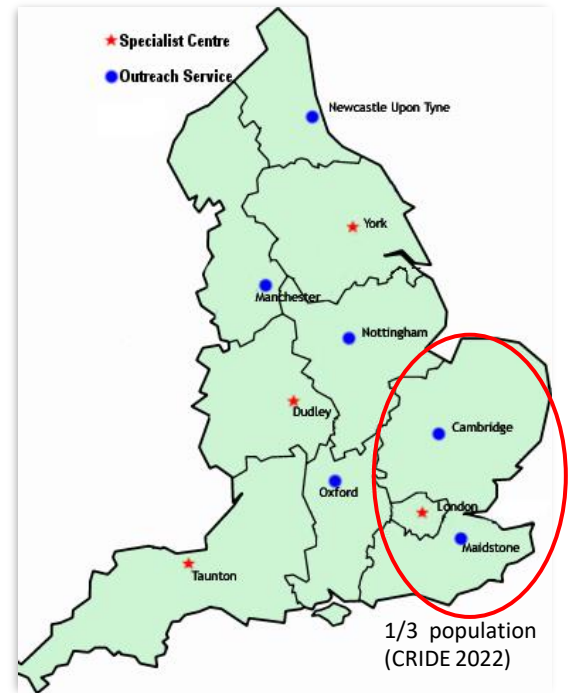
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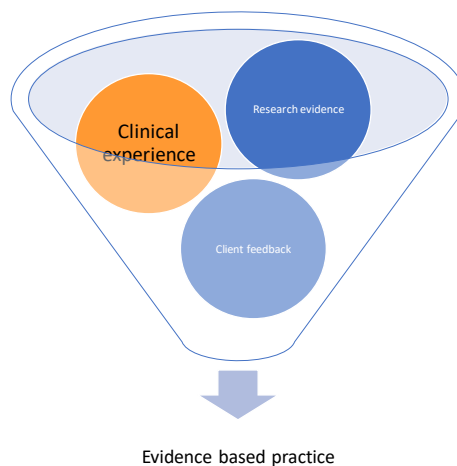
ND CAMHS: trip down memory lane

- 1991: Deaf Children and Family Service (outpatient). Springfield University Hospital, London
- 2000: Corner House, inpatient ward for deaf children
- 2005: pilot DCFS London, York and Dudley
evidence for inequality of access → bid
- 2010: National Deaf Child and Adolescent Mental Health Services (ND CAMHS)



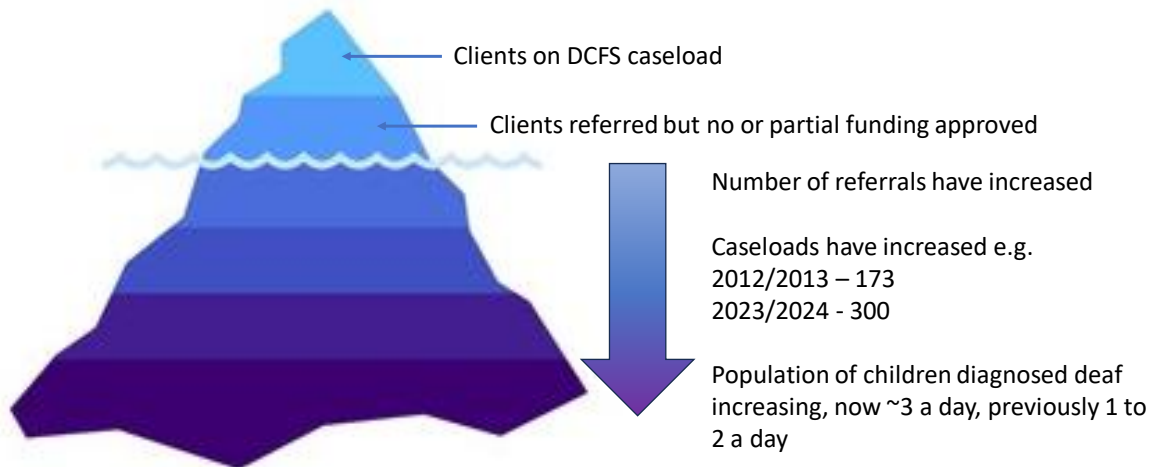
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What have we learned?



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The unmet need was greater than expected



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Multiagency work

- Increasing complexity of needs
- 1 in 5 deaf children have “special or additional need” (CRIDE report)
- Multi-agency work
 - Local authorities (e.g. SE region covers 54 local authorities)
 - Local teams e.g. CAMHS, audiology, social services
 - Schools (more mainstream)
- ND CAMHS includes...
 - Care coordination
 - Teaching and consultation about mental health in deaf children & YP
 - advocacy including deaf awareness



Time required is hugely variable so how to calculate per child?
Discussions about how to record this activity on client records

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- The challenge

- ND CAMHS teams cover a large geographical area, some areas with unreliable transport links
- Clients have additional burden of travel compared to hearing peers who can access geographically 'local' CAMHS services

- Research

- Retrospective study over 3½ years looked at impact of follow up appointment locations and engagement
- Providing follow-up appointments in community and school-based locations significantly increased attendance and reduced missed appointments

The learning – ND CAMHS need to go into schools and communities

Iqbal, Smith and Fernandez (2018)

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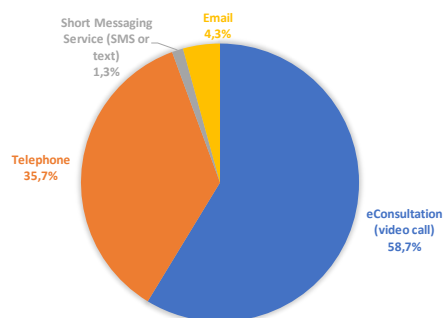
- The challenge

- What happens if ND CAMHS can't go to the community
- e.g. COVID pandemic



- Research

- 1659 appointments, 71.1% remote



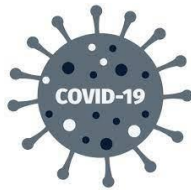
Dorette Ngemoh (2020/2021)

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- The challenge

- What happens if ND CAMHS can't go to the community
- e.g. COVID pandemic



- Research

- Not all clients engaged with remote appointments but video calls offers an alternative and reduces travel (e.g. to meetings)
- Further research could compare attendance rates of remote vs face to face

The learning – ND CAMHS need to be flexible

Dorette Ngemoh (2020/2021)

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Who are we seeing... amplification type

- UK '... estimated that 45% of children with severe or profound hearing loss have at least one cochlear implant.' (CRIDE)
- ND CAMHS
 - 34.6% clients have cochlear implant (Harem Azam, 2016)

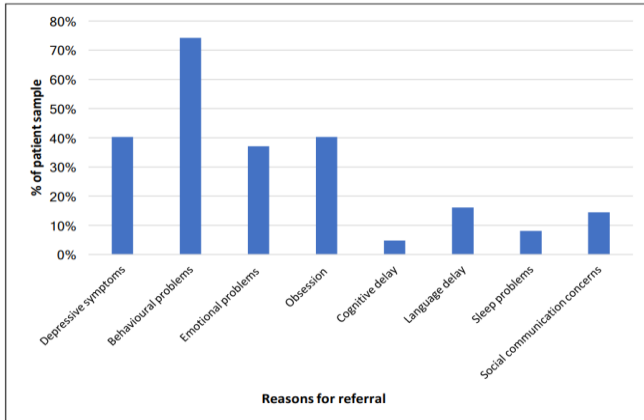
The learning:

- Research shows benefits to children receiving CI, especially at a younger age, improving speech and language abilities. But this does not automatically affirm the quality of social interactions
- Language and communication seem to be a mediating factor and if the CI has limited impact that development, child with CI will have similar mental health risks to those with no CI (see also Long, Umat & Din (2021); Michael, Attias & Raveh (2019); Huber et al. (2015))



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Who are we seeing... referral reasons



- ND CAMHS (2016)
 - Reasons for referral, 8 broad categories
 - almost 84% clients had more than one reasons for referral



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Who are we seeing... diagnoses

Primary ICD based diagnoses-initial	Frequency of diagnoses (%)
Depression and anxiety	16 (20.00)
Mixed emotions and conduct	15 (18.75)
ASD	10 (12.50)
Developmental disorders	8 (10.00)
ADHD	6 (7.50)
Other	7 (8.75)
Conduct disorder	3 (3.75)
No diagnostic	15 (18.75)

The learning

- reasons for referral tend to be multiple (complex needs)
- diagnoses indicate the mental health problems mostly being in the neurodevelopmental and mood and anxiety categories



ND CAMHS (2016)

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Who are we seeing... diagnoses (cont)

The learning

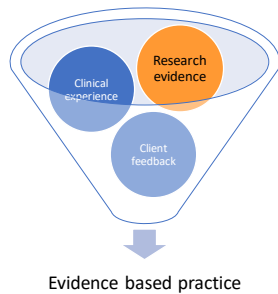
- Small sample sizes but there are indications of associations between type of school attended and behavioural difficulties
- Those deaf children with more complex needs, behavioural and emotional problems ending up attending schools with access to more support (i.e. unit of deaf residential)



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Evidence – based practice

• The challenge



- the research evidence is very limited
- carrying out research while carrying out a clinical caseload is challenging

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South West London and St George's **NHS**
Mental Health NHS Trust

Evaluation of the clinical utility of QB Test for assessing attention deficit hyperactivity disorder (ADHD) in deaf children and adolescents – Protocol

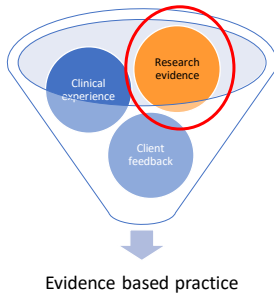


Deaf Child, Young Person & Family Services (National Deaf Child & Adolescent Mental Health Service, NDCAMHS) – South eastern branch



Evidence – based practice

• The learning



- more successful research outcomes
if in collaboration with universities

Journal of Autism and Developmental Disorders (2022) 52:553–568
<https://doi.org/10.1007/s10803-021-04931-y>

ORIGINAL PAPER



Adapting and validating the Autism Diagnostic Observation Schedule Version 2 for use with deaf children and young people

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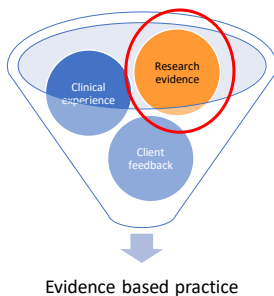
Abstract

We report a Delphi Consensus modification and first validation study of the Autism Diagnostic Observation Schedule – 2 with deaf children and young people (ADOS-2 Deaf adaptation). Validation included 122 deaf participants (aged 2–18 years), 63 with an Autism Spectrum Disorder (ASD). This was compared to a National Institute for Health and Clinical Excellence (NICE) guideline standard clinical assessment by blinded independent specialist clinicians. Results showed overall sensitivity 73% (95%CI 60%, 83%); specificity 71% (95%CI 58%, 82%), and for the more common modules 1–3 (combined as in previous studies) sensitivity 79% (95% CI 65–89%); specificity 79% (95% CI 66–89%) suggesting this instrument will be a helpful addition for use with deaf children and young people.

Keywords Deaf · Autism Spectrum Disorder · Assessment · Delphi consensus · Child · Diagnosis · Sign language · Autism diagnostic observation schedule

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Evidence – based practice



Theory practice links

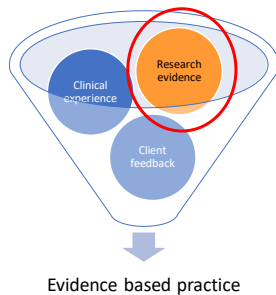
- For clinical work now
- For planning future of services

Current

- ND CAMHS audit days
- QI work streams

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Evidence – based practice

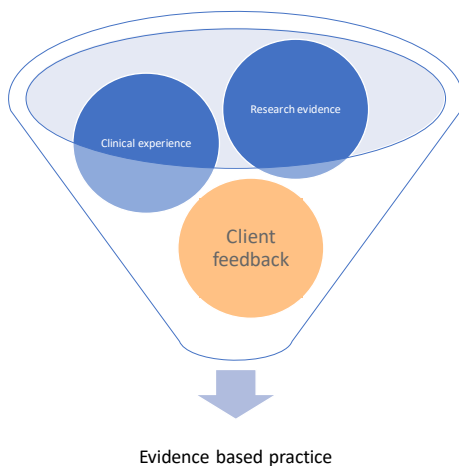


Future

- Establish more (international) professional links ... importance of congresses like this one
 - To implement for clinical work now
 - For planning future of services
- Dissemination network across the relevant services (e.g. Paediatrics, Audiology, Education)
 - Small initiatives: coffee mornings for parents/carers of newly diagnosed children
- Shared multiagency approaches and views, regionally and nationally
 - Lack of appropriate access to language not considered neglectful from a social care or educational perspective

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What have we learned?

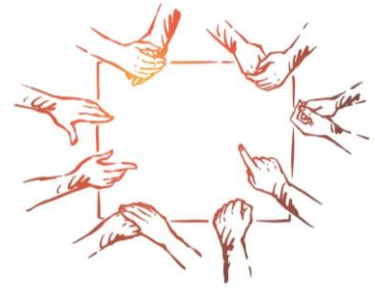


Themes of client feedback

- Consistently positive feedback re family support workers, some YP meeting a deaf adult for the 1st time
- Value our knowledge and understanding about deaf development e.g. ASD presentation attributed solely to being deaf
- Feel validated

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Staff feedback - challenges



Deaf

- Personal relationship more likely in deaf staff as small community
- Staff development opportunities more limited

Hearing

- Learning BSL
- Learning deaf culture
- Feeling de-skilled when first start

Variation in team make up of deaf / hearing staff has an impact on shaping service and delivery

Learning – ongoing research and projects (more info in Lenka Novakova's presentation)

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Work ourselves out of a job ... Role of prevention

- Address language deprivation
 - Informed choice and support re communication modality → accessible communication at home
 - Schooling to meet the communication and learning needs
 - BSL bill, BSL GCSE for all children
- Address deaf identity
 - Families introduced to richness and variety of deaf culture
 - Deaf peers and role models
- Support in the networks
 - Teachers with relevant skills and understanding
 - Specialist Social Care services for deaf children (Sensory Teams)
 - Tier 2 (school-based) services for deaf children



Deaf Trauma - Deaf Mental Health

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References

- [Huber et al. \(2015\) Mental health problems in adolescents with cochlear implants: peer problems persist after controlling for additional handicaps - PMC \(nih.gov\)](#)
- [Iqbal, Smith & Fernandez \(2018\) The impact of mental health services at outreach clinics and nonclinic sites on the attendance of Deaf children and young people and families- SORA \(sgul.ac.uk\)](#)
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- [The READY Study | For young people - The READY Study - The University of Manchester](#)
- Millennium cohort study [The association between childhood hearing loss and self-reported peer victimisation, depressive symptoms, and self-harm: longitudinal analyses of a prospective, nationally representative cohort study - PMC \(nih.gov\)](#)