

## **Haringey and Enfield CHSWG**

### **Minutes of the CHSWG Meeting Held Via Zoom On Tuesday 28<sup>th</sup> February 2023 at 9.30am**

#### **ATTENDEES**

Chloe Khan (CK) – Chair (QTOD)  
 Ruth Fitzell (RF) - Parent Representative, Enfield  
 Hannah Brown (HB) - Local Engagement Officer, NDCS  
 Alison Miles (AM) – Parent and Vice Chair Governors BN School, Blanche Nevile School  
 Kathryn McCarthy (KMc) - Deputy Head BN Primary  
 Kinjal Mehta (KM) - Paediatric Audiologist, St Ann's  
 Emily Brooks (EB) - QTOD, CI at RENT UCLH  
 Jaana Jutila (JJ) – Teacher of the Deaf – Highlands  
 Joseph Schneck (JS) – Audiologist, GOSH  
 Wendy Martin (WM) - Clinical Coordinator, Speech and Language Therapy Service for Children who are Deaf (Camden, Islington, Haringey)  
 Martine Monksfield (MM) – President of BATOD

#### **APOLOGIES**

Dr Radha Narayan (RN) - Consultant AVM Whittington  
 Abi Oakham (AO) - Haringey Deaf Specialist Speech and Language Therapist  
 Meera Sebastianpillai (MS) - Paediatric Lead Audiology, Whittington Health  
 Bharti Solanki (BS) – Sensory Support Team Manager  
 Caroline Fanning (CF) - Service Development Manager – Enfield SEND  
 Zibby Loakthar (ZL) – Parent, Haringey  
 Jeanette Martin (JM) - Lead TOD with CI Team at GOSH  
 Cherry Bloss (CB) – Specialist Speech and Language Therapist - Deafness

#### **INTRODUCTION**

CK – All members introduced themselves.

#### **REVIEW ACTIONS FROM PREVIOUS MEETING**

- **Action MS - Section on new paediatric website on CHSWG and parent forum. Draft to be shared with members / parents.**
  - KM fed back that the website has not been updated yet as the format does not currently support the required information i.e., images.
- **Action - audiology clinics – CHSWG posters to be displayed in waiting areas. QR code to be displayed. New families informed. RF to generate QR code.**
  - Parent update – cards with QR codes to sign up to parent group given at last NLDCS catch-up in December. A5 size QR code pamphlet to be designed to be shared by professionals/put up on noticeboards.
- **Action – all members – Volunteers needed for establishing a focus group looking at extra-curricular activities. Please contact chair.**
  - Ongoing.

- **Action – implant centres – Information shared with parents about how to access emergency support from those knowledgeable about CI. Explore possibility of CI passport. Implant centres to feed back at next meeting.**
  - Advice is to see the local A and E service.
  - RNENT has a Clinical Nurse Specialist. EB will speak to service managers about developing a summary for parents detailing procedures to follow in the event of an illness or emergency.
  - HB – ENT do not regularly attend other CHSWGs but would be an important source of advice in this case.
  - JS – Mr Nash is most likely to provide a response to this enquiry. BAHA users can attend a walk-in service at GOSH where ENT is called straight away. This is all included in handouts given to families. JS is unsure what information is given to families of children with CI.
- **Action – all members – Families to be made aware of NDCS courses. [Learn British Sign Language Online | National Deaf Children's Society \(ndcs.org.uk\)](https://www.ndcs.org.uk)**
  - Shared by all.
- **Action – members from UCLH and GOSH – Identify and contact relevant professionals from ENT to invite to CHSWG meetings.**
- **Action - Clinics to advise chair re who to contact for NHS representation at CHSWG I would be grateful for some contact details for this.**
  - HB – attends another CHSWG that reached out to a health commissioner and received a response recently querying why attendance would be beneficial.
  - HB to share contact details for the CHSWG.
  - HB suggested that an alternative approach might be to ask for feedback on specific issues/them to review minutes
  - WM – commissioners chaired Camden and Islington CHSWG a while ago. This has a big impact due to capacity for discussing budget. It is possible that commissioners might engage more with the NCL CHSWG.
- **Action- CK Amend and circulate plan. Chair and members to follow up agreed actions. I am missing one group's feedback (I have from Abi's and Kinjal's groups). I will circulate the plan asap for review.**
  - Circulated. No feedback received for making amendments.
- **Action – volunteer needed – Develop a list of reputable online resources for learning BSL that can be shared with families. DEI and schools to review before use. Please could a member or members volunteer to coordinate this.**
  - CK in process of consulting with others before sharing with group for their input.
- **Action CK – Collate and share contact details for all CHSWG members.**
  - Achieved.
- **Action – Reinstate focus group looking at support for families post-identification of deafness. I will email previous members but please let me know if you would want to be involved.**
  - Limited capacity so this has been carried over. Please contact chair if you would like to participate. RF offered and KM already involved previously.

#### **Action – RF –**

**A5 size QR code pamphlet to be designed to be shared by professionals/put up on noticeboards.**

**Action – all members –**

**Volunteers needed for establishing a focus group looking at extra-curricular activities.**

**Action – HB**

**Share CHSWG contact details for advice on inclusion of health commissioners.**

**SERVICES UPDATES**

- No questions, comments, or actions.

**STRATEGIC CHSWG**

- Set up to cover services across North/Central London.
- Had first meeting recently chaired by Steph Halder at RNENT. Looking at common areas of focus that can be addressed at a more strategic level.
- There is a lack of understanding about ICS (Integrated Care Systems) Partnership and where deafness features, if at all. How can we bring deafness to the attention of those who make decisions? How can we feed into the ICS in our area?
- Strategic CHSWGs are very early in development. There is only one other in West Yorkshire.
- CK and WM to update group following the next NCL meeting.

**BSL WORKING GROUP**

- Curating list of what's available.
- KMc raised issue around shortage of trained BSL tutors, which is likely to get worse with the introduction of BSL GCSE. BN being contacted by other provisions to request support.
- NDCS – one-to-one NDCS lessons. Have until 5<sup>th</sup> March to sign up. For kids aged 0-7.
- BSL tutor group (ABSLTA – Association of BSL Teachers and Assessors) chaired by Emma Illiffe has reported on the decreasing number of qualified tutors. Some assessments were previously English heavy which created a barrier to native BSL users becoming tutors.
- We could invite a BSL tutor, perhaps Emma Illiffe, to the next meeting.
- Contact Signature for update/feedback on the situation.
- Agreed that the Haringey and Enfield Sensory Support Team has good support for BSL with full time DEI.
- AM – information needs to filter out from the deaf community about other places to access support for BSL e.g. St. John's. Access to BSL is broader than access to language. It involves the broader culture around BSL.
- EB – access for young people post-16 is not good. What is available for the older age group?
- JJ – Highlands is trying to recruit a BSL tutor currently, through liaison with Remark. This proved too costly so MM has been supporting the school with finding someone privately. They currently have a BSL club on offer but this is informal use of signing and not led by a qualified tutor.
- HB – there is valid concern about the lack of tutors available to teach the potential GCSE. A survey is out at the moment to get an idea of interest for the subject. This will help to plan for the number of tutors needed.
- HB – 1:1 signing classes did very well recently. There are also family classes with the potential for up to 6 members joining. The NDCS has an eligibility framework for accessing these.
- See website for group online classes.

**Action – BSL group –**

- Seek feedback from Emma Illiffe and Signature.
- Explore access post-16.
- Explore options for inviting Emma or another tutor to the next CHSWG.

**Action – HB –**

- Send link for NDCS BSL classes and for NDCS survey.

**Action – CK –**

**Finalise and send out BSL resource list.**

**TERMINOLOGY AND LANGUAGE USE**

- Martine Monksfield (MM) joined to discuss document 'Moving towards using positive language around Deafness' written by the Deaf Teachers of the Deaf group.
- The document proposes that 'impairment' is no longer used.
- The use of HI (Hearing Impairment) is usually due to lack of exposure to other terminology.
- The use of VI (Visual Impairment) can be confusing as this does not have the same meaning as impairment does for the deaf community. There is a strong difference in culture and language within the deaf community.
- WM fed back that Camden and Islington CHSWG has accepted changes and have written terminology into their ToR. Their action plan aims to look at a position statement that can be shared with partners.
- MM has spoken with the DfE and most are in agreement with the changes. The GCSE curriculum will hopefully be in place for September 2025 and all content uses 'deafness' not 'hearing impairment'.
- JS – query whether there is published data about which terminology parents prefer to use. MM – the information is based on discussions with deaf people (all levels of deafness).
- MM – children with mild-moderate deafness have limited access to the deaf community. This means services are gatekeeping based on self-selected criteria.
- Research focuses on SEMH for students not accessing specialist services.
- JS is a hearing aid wearer and uses 'hearing impairment' and 'hearing loss'. What about the adult cohort?
- MM – BATOD is keen to lead with positive terminology from the beginning, while acknowledging and respecting that some people do not identify with 'deaf.'
- AM – it is important to acknowledge parent views.
- EB – SEMH is a big issue for deaf children and young people. Need to be mindful of the impact of negative terminology.
- RF – gave example of new friend with unilaterally deaf child who is not comfortable with using 'deaf'.
- MM – medical professionals offer only a deficit model of deafness. Use of positive terms would be beneficial for SEMH.
- KM – some parents disengage. From a clinician's perspective, some might stop attending appointments. It is important to get the formula right for parents. KM will take back to the audiology team at St Ann's.
- WM – suggested use of alternative terminology e.g. 'hearing status' at the start of the journey to overcome some of the issues raised.
- MM – acknowledged that some families / cultures find 'deaf' very difficult given their knowledge about deafness. The biggest impact on this is access to deaf professionals for supporting understanding. This is a very sensitive area and BATOD wants to work on the document to make sure it is sensitive and relevant.

- WM – professionals from GOSH and RNENT have already agreed to positive terminology within the Camden and Islington CHSWG.
- Broadly people are in favour of moving forwards with this, and recognition of the importance of positive language from the outset BUT need to address concerns raised about how this would be received during the early diagnosis stage and how it would be received by children/adults with mild or moderate hearing loss.

**Action – all members –**

**Look at terminology at next CHSWG to build into action plan and ToR.**

**AOB**

- HB is leaving as the NDCS is reshuffling officers allocated to the 130 CHSWGs. Only 7 local engagement officers. Joanna will be joining at Haringey and Enfield.

**Next Meeting**

**Tuesday 6<sup>th</sup> June 2023 - 9.30 - 11.30am**