

Haringey and Enfield CHSWG

Minutes of the CHSWG Meeting Held Via Zoom On Tuesday 7th November 2023 at 9.30am

ATTENDEES

Chloe Khan (CK) – Chair (QTOD Sensory Support Team Haringey and Enfield)
 Kathryn McCarthy (KMc) - Deputy Head Blanche Nevile Primary
 Kinjal Mehta (KM) - Paediatric Audiologist, St Ann's
 Lisa York (LY) - Local Managing Barnet/Enfield/Haringey, NHSP
 Wendy Martin (WM) - Clinical Coordinator, Speech and Language Therapy Service for Children who are Deaf (Camden, Islington, Haringey)
 Joanna Wanmer (JW) - Local Engagement Officer NDCS
 Bharti Solanki (BS) – Sensory Support Team Manager, Haringey and Enfield
 Caroline Fanning (CF) - Service Development Manager – Enfield SEND
 Zibiah Loakthar (ZL) - Secretary of NLDCS, Parent Representative Haringey
 Helen Taylor (HT) - Headteacher Blanche Nevile School
 Jaana Jutila (JJ) - TOD Highlands PDS, Enfield
 Smeeta Modaia (SM) – SEN Advisor, Enfield
 Lorraine Everett (LE) - Consultant in Audiovestibular Medicine, St Ann's

APOLOGIES

Ruth Fitzell (RF) - Parent Representative, Enfield
 Alison Miles (AM) – Parent and Vice Chair Governors BN School, Blanche Nevile School
 Abi Oakham (AO) - Haringey Deaf Specialist Speech and Language Therapist
 Dr Radha Narayan (RN) - Consultant AVM Whittington
 Emily Brooks (EB) - QTOD, CI at RENT UCLH
 Jeanette Martin (JM) - Lead TOD with CI Team at GOSH

INTRODUCTION

CK – All members introduced themselves.
 WM – Volunteered to take minutes.

REVIEW ACTIONS FROM PREVIOUS MEETING

- **BS** - Sensory support team to highlight NDCS offer at regular opportunities beyond initial visit.
 - raised at staff meeting – highlighted on initial visit and then highlight benefits at different ages/stages along with local NLDCS.
- **Clinics** - Display QR poster in public areas.
 - achieved in waiting areas.
- **CK** - Coordinate sharing of information amongst members for support groups/clubs/activities. started but not shared with all.
 - Discussed possibility of a shared document for all to access with the aim of developing a central point of reference so it is easier for parents to find information. Could use the local offer? Need to promote this for parents/ families to access. Discussed local offers

often using professional language, which can be hard to access. The standard of local offers varies immensely across the country.

- NLDCS can advertise to members – send to ZL.
- Local offer websites include lots of links to relevant information.
- BS - PUD (Personal Understanding of Deafness) also has links to relevant sites.
- Information sharing can be limited within certain services. We could use One Drive or Google Docs but some services may be blocked.
- **CK** - Share minutes/information with health commissioners.
 - Contact details to be obtained via relevant members.
- **CK** - Invite representative from ABSLTA – Association of British Sign Language Teachers and Assessors.
 - Invitation to attend a future meeting to be sent where relevant.
- **JW** - Update on NDCS offer to be shared.
 - The NDCS is setting up more BSL classes for families. Email the service team if families want to attend, not JW directly.
- **All members** - All services to push engagement with parent group.
- **CK** - Ideas to be pulled together for a draft document about terminology, which can be reviewed by members at the next meeting.
 - Main agenda item - discussed below.

Action – CK to contact managers regarding the local offer and see how this could be updated.

Action – CK to share minutes more widely i.e. with Health Commissioners.

Action – CK to explore the possibility of a shared drive.

Action – All services to readvertise parent group information to encourage engagement.

SERVICES UPDATES – Comments and Questions

- KM – Baby and Toddler Group is starting up again at Blanche Nevile every Wednesday afternoon. This is open to families across all boroughs.
- JW - Clarification about the referral pathway to advice and guidance officers at NDCS. Referrals are made via the helpline. Parents contact the helpline and the team then provide information (phone/text/BSL). If they are not able to fully support, they will then refer to AGO.
- KM – An information booklet is being developed for families; detailing information related to a new diagnosis. The aim is to provide all information in one place. KM would like feedback and would be keen to work with other members to develop a joint resource.
- **NCL CHSWG**
 - CK was tasked with gathering responses to the questions:
 - **What's working well for you and your family / child?**
 - **If something could be different, what would you suggest?**
- We need to find two parents to trial the two questions to be used as a small sample. This can then be shared more widely to the parent community at a later date.

Action – BS, KMc, and JJ to gather responses to the questions from two parents/carers.

TERMINOLOGY AND LANGUAGE USE

- CK created a draft document following MM's presentation and the subsequent discussion. All information included in the document came from the last meeting.
- The aim of this piece of work is to encourage consistency in language use across all professional groups who are working with deaf children and their families.
- The document focuses on the use of positive language / terms that the deaf community are comfortable with and will be positive for deaf children, young people, and their families.
- Discussion re different terms i.e. if family don't want to use the term 'deaf'.
- Terminology is important but also want to engage parents - feel need to be cautious with parents and then using terminology led by parents not professionals. Sensitive and personal topic. How does it work if a family prefers the term hearing-impaired? E.g. adults who have lost / losing their hearing / children with mild levels. These group may prefer different terminology. However, there is also currently a significant group of deaf people who would prefer not to have 'hearing impaired' used when dealing with the clinics.
- The term 'hard of hearing' is comfortable for the deaf community and could be used by some families. Simple explanation from professionals about language i.e. "We use the term deaf but you can use the language you feel most comfortable with".
- It is important that families have exposure to and awareness of the deaf community from as early as possible. This comes from information shared by all professionals.
- Can have the discussion about the spectrum of deafness – can choose to be part of deaf community or whatever terminology works. Professionals to allow access and empower families – should not be the gatekeepers of this information.
- NDCS uses 'deaf' for all levels and keen to empower families to widen access and raise awareness. The mainstream media is promoting a positive image of deafness - the focus is now to raise awareness.
- Terminology is an important discussion but often the issue is around acceptance.
- Language use can have negative connotations and support a deficit model of deafness.
- All professionals need to think about how we use language and if it is negative. The aim is to use positive language consistently to encourage a positive model of deafness from the start.
- We can add footnotes / information to explain thinking in the document.

Action – language use document to be shared with all members.

ACTION PLAN

Representation

- Still an issue of representation from social care across both LAs.
- Deaf CAMHS – it is difficult to get regular attendance due to capacity. Is there a possibility of an update once each year, including issues, challenges, how CHSWG can engage and support them.
- JW – will pursue this and CK keen for annual/bi-annual update. Can't maintain as so many across London.
- Representative from specialist provision - Highlands + Blanche Nevile. Smeeta to follow up with Brimsdown to request representation.

Statutory i.e. EHCP update

- SM - the SEN update from BT includes:
 - Enfield now has an annual review tracker and is working to update this. Currently achieving over 70%. New system will support with keeping on track
 - Plans will be reviewed/ at least at the end of each key stage and between if big changes
- BS – lots of work being done around this in Haringey – banding, funding and annual review process. Tracking of AR processes a high priority. All SENCOs having training re annual review process.
- Advice - more regular updates of plans.

Voice of parents and young people

- Currently – regular parent reps at CHSWG but parent forum does not have many subscribers.
- Need to establish a forum for young people – need to think about how this can work by Summer 2024. JW – engagement with young people is likely to be a focus across all CHSWGs. The benefits under NCL CHSWG are that overlaps can be identified and groups can work together.
- Is there a local LA participation and engagement officer / local engagement officer – remit to engage in community re involvement with youth work (may even have a budget).
- Views can be gathered via forums/clubs.

Action Plan can be sent out over email to read through again.

Action CF - ask disability team for a representative from social care.

Action BS - find out who the local engagement officer is and if they have a budget

Action - Parent engagement sub-group to meet.

Action – Establish youth participation sub-group

PARENT BOOKLET

- Tess Torjussen joined the meeting to share her information booklet. She is the parent of a deaf child in an area outside of London.
- Tess created an information booklet for parents at the point of identification. Reason for writing - lots of new parents went home without any information and therefore needed to do lots of research themselves.
- Irrespective of language used, it is important to know that there is a community out there and that sign language is a positive thing.
- Wanted to create a document to support parents and a positive introduction to the deaf community/sign language etc.
- Wanted to promote deaf children as children using happy, positive pictures.
- Tess has created a template without local information so other areas can add own information.
- Liaison with different services i.e. linked in with head of Audiology and spoke to TOD / sensory. Checked with the deaf community re language so that it works for everyone.
- Now shared at point of identification. The CI centre is interested but may look at new one for families going through CI process.
- Tess happy for information / template to be used with other local information and other professional information.
- BS - There may be the way that TODs are introduced at the beginning re 'support' rather than focus on 'teacher' and education so people know what they are being referred to.

- Tess spoke of the initial wait 48 hours before TOD is contacted – long and lonely time.

Action – KM to join group for developing Haringey and Enfield booklet. Members who are interested to contact CK.

Action – CK to follow up - Tess to contact other families and get agreement/consent to share their stories.

AOB

None.

Next Meeting

27th February 2024

11th June 2024

End.