Brighton and Hove Children’s Hearing Services Working Group (CHSWG)



  

**Minutes of meeting held on 14/06/2018**

**Present**-Rob Low (audiology); Alison Davis; Anna Jenkins (parent reps); Jacob Oaks (NDCS); Janine Blundell (Paediatrics); Ange Ward (community audiology); Caroline Palmer (SNT); Sul Regan (SNT); Anne hindle (Bevendean HSF); Polly Strauss (NHSP); 2 BSL Interpreters.

**Apologies**- Pro Das (ENT); Katy Liriano (SALT), Helen Murtagh (Healthy Child Team); Maria Kyriacou;

**Agenda**-

* Apologies
* Matters arising from previous meeting
* Service updates
* Feedback from parent reps
* Care pathway and mapping
* Data protection
* CMV
* AOB

**Matters arising**

* Need to update invite list
* Did Kathy Felton from CCG receive invite? – we need a link to this group to enable / influence change.
* Invitation to Pro Das sent but no reply. We would like to encourage ENT attendance – discussed offering a topic to go on agenda and allow 30mins? New ENT Mood Bhutta – created Sussex hearing lab to look at research topics related to ENT/audiology in this area – would be a good person to invite to next meeting.
* Emma Daniel – local councillor – invite for a particular meeting?
* Local NDCS invite?

**Service Updates**:-

**Sul Regan and Caroline Palmer: Sensory Needs Team**

Staff changes: 2 staff leaving. Recruited an experience TOD and ED Audiology to start in September.

Sul gave training to Health Visitors – we discussed the role and availability of HVs. NHSP stopped being done by HVs and changed to maternity care, meaning there is less contact with HVs. HV role has changed – used to be health promotion but now is focused on safe guarding so number of visits given has reduced.

Sul is meeting with the team leads for East and West Sussex to encourage more joined up working. The three teams recently had a joint training day for all staff provided by AV.

Caroline Palmer FSW has moved our Time Out sessions to Saturdays to enable more families to attend. In addition the Deaf Youth club is proving to be popular and providing an outlet for teenagers.

Talking hands café offers lots of activities. Through the WhatsApp group, Caroline enables families to stay connected and promote activities.

Funding has been raised for two theatre trips, including going backstage for a workshop.

**Rob Low- Audiology**

This is a difficult time in terms of staffing: 2 maternity leaves to cover – no response to adverts for cover for laura (from end of August) so the department may need to be reworked.

Good news on relocation: the business case is currently being reviewed to prepare a final version. The trust has now allocated half a million for the move to the top floor of the children’s hospital. Rob gave some detail on the provision there. ENT will be across the corridor.

The lack of communication with ENT and difficulty accessing information was discussed, and parent reps asked if they could be involved to support. A proposal was sent to Mood Bhutta, including an arrangement where audiology would follow up after grommet surgery if the move takes place – this would help ENT reduce patient time. Rob wants to extend this so that all hearing referrals come through audiology first. Parent reps commented that this would be much more efficient.

18 week initiative: 2 audiologists, plus 2 ENT consultants to clear the waiting list – 30 children seen per day at weekends.

**Jacob Oaks- NDCS**

NDCS have launched a campaign as £4 million being cut to services – NDCS will be approaching government on that issue.

Youth Advisory Board about to launch their campaign.

The government are allowing the idea of BSL on the national curriculum to be followed up.

**Parent Representives**

Website: hopefully will be up soon. The Whatsapp group created by Caroline Palmer is very successful and this can be used to promote the website once up and running. There was a discussion re data protection issues.

Ali has been in contact with her local MP re the relocation of audiology.

PACC – asked to write a provision statement about this from the parents’ point of view. Conclusion of report will be useful to send to MPs.

Anna – meeting with AMAZE re improving access for Deaf CYP to access leisure activities in Brighton and Hove. HLS students don’t feel that they can access leisure in the city such as gyms and the swimming pools. There was a discussion about how access to such areas could be scaffolded.

**Ange Ward- community**

Vanessa head of service returned to work from maternity – FTE over 3 days. The Crawley admin person has resigned and recruitment under way.

**Janine Blundell – specialist paediatrician**

The deafness panel is taking a year to give results – Janine is going to meet a geneticist in London to discuss the time it takes. More investigations are showing more causes of deafness – used to be 95, now 108 plus. Janine is not going to offer the whole genome to the parents as much of it can’t be interpreted yet. Janine wants to use the deafness panel but has to be honest with parents that it may find alterations that can’t be interpreted.

CMV: Janine wrote to Katie Fiddler (infection control). Bloods need to be closely monitored. Problem in the group of children being tested: if the cause of deafness is CMV and the child is under 4 then they can be put on medication or not - if it is going to slow down progression parents want it. Janine gave the example that with a bay, early development would modify neural development and so medication would be considered – hopefully a research study being done will show evidence of success. There was a discussion about when to medicate – Janine refers to Katie Fiddler. Anna asked at what age medication stops – Janine: hearing loss plateaus at about 7 years.

Janine also talked about the fact that the neonatal blood spot used to be kept for 10 years but now only until 4 years of age. A child could be CMV positive but there may be another cause of the HI, and Janine wouldn’t want to miss the other cause.

**Polly Strauss NHSP**

No changes to service apart from a couple of staff changes. Looking at possible new community clinic location due to parking issues. Still screening 90% of children – meeting targets. 2017: picked up 8 babies with confirmed HI, including a number of premature babies. Maternity service group: 20% of all screens may need repeats, but this is below the national average. 2 screeners are going through the diploma route.

**CMV – whole group discussion**

Polly: More babies’ CMV urine samples are being requested. Babies with low weight, small head (inter uterine growth restriction) – katie fiddler is in the loop so there is early treatment. National protocol is only a 10 month follow up. Janine: this should be a bespoke service.

Jake – there is a survey out by CMV action and the NDCS to gather evidence if parents are concerned about the bloods being destroyed at 5 years.

Janine – talked about education and prevention: talks to midwives and HVs.

Sul – talked about nursery nurse exposure – gave a recent talk to HV’s and included CMV awareness. Sul gives out CMV action document to nurseries to be circulated among staff.

Rob: why aren’t we doing screens for CMV salive – in London, audiologists take a saliva screen. CMV can be confirmed from saliva or urine. Need confirmation of SNHI.

Janine: need the saliva as early as possible. CMV could have come from the breast milk and not be the cause of the HI. Need saliva within 3 -4 weeks from birth. Discussing with Katie fiddler about how this could happen in Brighton.

Janie: audiology could request blood spots – costs about £36 to get blood spot done.

**Care pathway and mapping** please can completed pathways be sent to Sul so that these can be added to our CHSWG web page on the council website.

**AOB**- none

**Next meeting scheduled for Thursday 18th October 2018 at Hove Town Hall**