

Minutes of Pan Berks CHSWG 19th March 2019

Attended: Louise Dix (SLT, CHSWG West Chair), Lisa Bull (Ed Aud, CHSWG East Chair), Kate Smith (Parent Rep/Berkshire Deaf Children's Society), Helen Farthing (Family Support Worker/Play Therapist Deaf CAMHS), Alex (interpreter), Liz Parker (University of Southampton Auditory Implant Service), Jane Peters (Head of Berkshire Sensory Consortium Service), Paula Luckett (School Nursing team), Laura Hancock and Val Holdich (Newborn Hearing Screening Programme), Helen Begbie (SLT), Ani Sahakian, Katie Ireland, Constantina Georga (Clinical Scientists- Audiology, Royal Berkshire Hospital), Isabel Lugar (Clinical Scientist-Audiology, King Edward VII, Windsor), Hazel Needham, Community Paediatrician, RBH

Apologies:

Olivia Whiteside (ENT), Helen Kirkham West Berkshire, Jenny Chopra (Paediatrics, East Berkshire), Sam Barnard (Parent/BDCS), NDCS Rep (Eva Jolly has left), Lisa Buxton (Health Visitor), Sarada Murthy (Paediatrics, East Berkshire, Retiring)

The Journey of a Hearing Impaired Child in Berkshire

The theme of this meeting was to explore this journey through services, giving each contributor a chance to **highlight** anything in particular that the wider team and Berkshire families can help each team with in terms of reminders, information, prompts, follow up, feedback etc. Kate Smith our parent representative kindly offered comments and feedback throughout the journey, with her comments grouped in one place for the purpose of the minutes.

Newborn hearing screen

- RBH- within 2 days of birth in the ward- two screens, dedicated screeners
- Wexham- midwifery screeners
 - HV are in 3 diff organisations
 - Achieving for Children
 - Berks healthcare

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- Solutions for health
- Screeners- Wexham no access to Rio.....RBH- access to Rio
- Finding the children is a concern... mainly the babies that move into the area- sometimes difficult to locate
- Data MUST go onto Smart4Hearing/ESP to keep a track of the babies
- Must be registered by the GP to get an NHS number. Cannot screen until they have an NHS number

RBH Audiology

- After screen- come to Audiology-
- Constantina (NHSP / Audiology link) Team lead for electrophysiology service
- Home/hospital appts depending on family needs
- Liaise with families, arrange appts, make sure that families are not lost in the system
- Filling in database. Challenge- no admin support- clinicians doing the admin for this
- Different families- some very on board, some are very reluctant to engage
- Communication between services and families is absolute key to effective Service
- Katie Paed Rehab Lead
- Dealing with diagnosis- emotions of family
- Little bit of a grey area to begin with- difficult to get a full picture of the hearing loss
- Would like to increase joint visits in the home with Education Service (SCS ToDs)
- Ani Paed Assess Lead
- Progressive losses, glue ear.....becoming a significant chunk of caseload- fewer families going down the grommets route. RBH are proactive at managing conductive losses
- Monthly MDT meetings

KEVII Audiology

- ABR usually completed in the Audiology Dept, occasionally at the home
- Refer to ENT, SCS, SALT, Paed at point of diagnosis
- Termly MDT meetings to discuss caseloads

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- Currently fitting Phonak Sky Q and Sky V hearing aids to the paediatric population

Parent perspective- Kate

- Lots of info given to parents at the point of diagnosis... it's a lot to take on board and to process, please revisit early suggestions/signposting
- ToD now trying to enskill the CT- parents found this difficult to begin with
- Feedback from BDCS parents is very positive
- BDCS are trying to encourage other families to join
- BDCS membership is mainly the younger age group- looking at ways to engage the older age group

Paediatrician- Dr Needham (RBH)

- Come from screen, school screen, otherwise known to Medical services <5years
- Assess for underlying medical conditions
- Find out cause ?? Family audiograms, bloods, scans
- Reports are copied to SCS
- EPR is challenging!
- Dingley moving – which has caused some challenges
- Please help support attendance for 'Family Audiograms' post diagnosis

SCS- Jane Peters (Head of Service)

- Work across Berkshire- 6 LAs
- Ed Aud attends Paed rehab clinics in East and West
- Diagnosis- Ed Aud does a home visit to take the child onto the caseload
- NATSip matrix – guide for level of support a child/family will need
- Teaching/Advisory programme of support
- ToD will then be allocated and will then work with the family and then nursery, school- all the way to 18/25 if EHCP
- Work closely with SALT

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- Joint working with HV is challenging and we want to look at this as something to improve, there have been some really useful joint appointments eg at 2 year Health Review
- Statutory school age- referral must come from the school
- Independent schools- SCS does not have a duty to support these children. Service must be bought in
- Capacity building within the schools
- Preschool- working closely with Audiology and CI centres
- Working closely with BDCS
- Additional needs- we may be the only Service working with this family
- Same service in each local authority
- However, each LA has different agendas re their Sensory support provision- always a challenge for SCS

DeafCAMHS (Helen Farthing)

- Referrals to DeafCAMHS appears to be on the increase (nationally?)
- DeafCAMHS would really like to increase the links and work more closely with Services in Berks

SALT (Louise Dix)

- Used to be separate Services- now across Berks
- SALT is referred to at the same time as SCS
- SALT write to family to say that they are aware of the child
- Advise families to work closely with ToD/Paed/Aud- establish hearing aid wear
- Refer back to SALT when it is appropriate- be guided by parents and professionals and development of child's SaL
- Then work closely with SCS and HV
- *Sometimes our next involvement with a family or child is at request of the family or teacher of the deaf, not a routine contact- please remind families they are welcome to contact by email/phone/text.*
- Conductive losses- Specialist SALT for HI does not see these temporary losses

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- Joint working is really important, MDT meetings are invaluable
- ToDs are very skilled at knowing when to call back into SALT
- RBH commission
- KEVII- GP commission

School Nursing- Paula

- Take over from HV team
- Offer hearing test to ALL children
- If the child does not pass they will be tested again 6 weeks later. If they do not pass the second one, school nurse will call parents and refer to Audiology
- Parents can self refer and GP can refer
- 10% of children will be referred to Audiology
- Can signpost to lots of different services
- East- only seen if there is a specific request
- Children screened at school in Wokingham, West Berks, Bracknell, Slough, Reading
- Be aware RBWM do not have universal school age hearing screening

USAIS (Liz Parker)

- Referrals come from Audiology
- Usually from screening, but sometimes from a progressive loss
- Referral acknowledged within 5 working days
- Aim is to make contact with the family within 6 weeks of referral
- ABR traces are acceptable as a referral
- *Key message: Refer asap*
- Assessment process is information gathering- to be able to give parents an informed choice- children are not necessarily referred 'for an implant' but for assessment
- Parents can withdraw at any point during the process

Liz continued with a presentation to the pan Berkshire CHSWG on the updated NICE Guidelines and University of Southampton Auditory Implant Centre assessment procedures.

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Close of meeting

Thank you for all your extremely valuable contributions to this meeting. We look forward to the next annual Pan-Berks CHSWG in 2020. If you have any particular ideas for a theme for the meeting please do let Louise or Lisa know

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Next East CHSWG and West CHSG will be advertised by separate email