

Children's Hearing Services Working Group

8th May 2012 10:00 to 12:15

Minutes

Present

Sarah Morris (Chair) – Consultant Community Paediatrician Poole Hospital
Peter Copestake (Secretary) – Parent Representative
Andrea Arnott – Audiologist/Dorset Local Manager NHSP
Beverley Bell – Principal Advisory Teacher, Hearing Support Services
Geraldine Hanney – School Nursing Bournemouth & Poole
Jeremy Tweed – Head of West Dorset Audiology Services
Lesley Copestake – Parent Representative
Lisa Nind – Paediatric Audiologist, East Dorset
Debbie Ravensdale – NDCS Regional Family Officer
Rachel Lachlan – Staff Grade Paediatrician, East Dorset
Sam Bealing – Educational Audiologist, Hearing Support Services
Shirley Sorbie – Parent and Dorset Deaf Children's Society Representative
Tony Corcoran – Clinical Lead of East Dorset Audiology Services
Nikki Wells – Health Visitors Bournemouth and Poole
Jules Benton – LDD Coordinator Connexions
Jo Ridout - Parent Representative
Rachel Beeby – West Dorset Audiology Service
Rollo Clifford – Consultant Paediatrician Dorchester Hospital
Emily Youngerman – Public Health Registrar, NHS Dorset

Apologies

Eunice Gibson – Speech and Language Therapist
Gareth John – ENT Consultant Poole Hospital
Tina Collinson – Public Health Clinical Service Manager (DHUFT)
Glen Ford – ENT Consultant Dorchester Hospital
Karen Wheat – Community Service Manager
Sophia Callaghan – Public Health Consultant B&P PCT Commissioning
Kelly Sherman – Parent Representative
Rebecca Ward – NHS Dorset Public Health
Sarah Collinson – NDCS Regional Director South West
Carolyn Bowyer – Community Services Manager, DHUFT

CC

Martin Smith – Head of Hearing and Vision Support Services

1. Introduction and apologies

Sarah welcomed everyone to the meeting and confirmed the apologies that were given including those of Carolyn Bowyer and Gareth John.

Sarah recognised all the good work that Tony had contributed to the service and that this was the last meeting he would attend as he will be retiring in the summer. In recognition, Andrea had brought muffins for everyone to go with the tea and coffee.

2. Minutes of the last meeting

Sarah asked for any comments on the minutes of the meeting of the 22nd November 2011. None were made and the minutes as distributed were accepted.

3. Matters arising

No items were raised as matters arising.

4. Speech and Language Therapy (SALT) questionnaire

Shirley provided an update on progress that had been made from actions on behalf of DDCS.

Paul Sly has changed roles and been replaced by Suzanne Rastrick. There was a parents meeting in October and the improvements seen to date were commented on. The extra time of now 3 days a week instead of the previous 1 were making a difference. The concern was would this carry forward past the end of March? The follow up review confirmed that although Erica's time would be decreased to 15 hours (2 days), 2 other people will be trained (one in East and one in West Dorset), each delivering one day a week so this would be a net gain of another day's coverage. This rebalance had been achieved without extra funding; however, there was still a bid for extra funding on the table.

Beverley provided an update on the HVSS questionnaire which now includes SALT, and the new pathways for referrals which are easier to follow.

Sarah said Shirley deserved the praise of the group for her perseverance in getting the SALT provision to this point through her hard work and effort.

Shirley said as great as the current situation is, there will still be a need to ensure a focus is maintained.

5. Newborn Health Screening Plan (NHSP)

Andrea provided an update on the QA visit in July 2011; the action plan from the visit is actively being worked on and the National team were happy with the status. The next QA visit is due in October 2012 and will be a remote event. Emails will be sent to request contacts and they will choose the cases they want reports on, via ESP number to Andrea. This is expected to be completed in March 2013 and will be reported on in the May 2013 CHSWG meeting. A discussion took place on the need for parental consent for the requests. Tony confirmed that parents do sign up for approval of the use of data for service improvements, however, it was agreed that information governance be contacted before the releasing of data.

Tony confirmed that the actions from the previous action plan were all 'green'.

- The introduction of VRA testing to community audiology clinics in East Dorset is under review by Emily and the PCT, with review by Poole Hospital of all aspects of Community Paediatrics including audiology also underway.
- There was a discussion on Infant distraction tests in the community. East and West Dorset have different approaches with the West having more use of VRA currently.
- The use of Guthrie cards for CMV testing if required is in place.
- Care pathways extended to include medical referral.

Tony distributed the document detailing the new Guidance for screening providers and the new flow documentation for this process. This included change to targeted follow up on babies who pass the initial tests but require follow up due to risk factors.

As detailed in section 2 of the recommendations of change to current practice in the document Tony distributed, new practice will mean targeted follow up of babies that have clear response onscreen with the following risk factors will cease:

- Family history of hearing loss
- IPPV > 5 days/ECMO
- Neuro-degenerative or neuro-developmental disorder (unless known to have associated hearing loss, e.g. Downs Syndrome)
- Jaundice at or above exchange transfusion level.
- (Note that targeted follow up for babies whose only risk factor is a stay of > 48 hrs in NICU has never been recommended)

Newborn Health Screening Plan (NHSP) continued

The meeting discussed the document and the impact of changes.

- There was discussion on the impact of DNA's. Nikki explained the 'cold call' process. Health visitors do make chase ups beyond 3 months. One of the key concerns discussed was transfers from abroad and Niki did express concern that the transfers from abroad are not recorded in the database so a miss was likely. Failsafe with child health to link to transfers abroad.
- For progressive deafness the school entry screening was still in place.
- Tony confirmed that parental concern was still a key trigger for follow up investigation.
- New children to the area would get a health visitor 'transfer in' visit.
- The Dorset community based program has a good structure in place to follow-up children who miss the screen.
- In 2011 7,777 screens were performed and on average Dorset has between 7,500 to 8,000 births a year.
- 1 in 10 when found to be profoundly deaf passed distraction tests – the IDT is not a good screen.
- Sarah confirmed the recommendation was to follow the advice from the NHSP and change to the recommended approach.
- This approach should free up time.
- Tony to revamp the flow documentation following the discussions at the meeting and feedback from Rollo and others.
- Shirley was concerned about the 'one child' who would be missed with the new approach.
- Rollo explained how in certain cases some of the screening may do more harm than good.
- Nikki explained how the checks at 2 years of age (where there are 3 follow ups for children who fail to attend) would highlight language difficulty and other indicators for further investigation.
- Rollo highlighted the concern that vulnerable families may be missed but discussions concluded that this would be tracked and managed through the routes that saw such families supported.
- Rachel L asked should distraction tests still be done and the meeting discussed this.
- The effect of the changes would be measured in 2015 and there may be change again. It will take until 2015 for the measurements of the data to present the required results to allow measurement.
- Geraldine will take the new guidelines to the next Health Visitors meeting.
- Jules confirmed there are now SENCO's in nurseries at the Children Centre's and they also flag up issues for families. There is also SALT in each Childrens Centre which can provide referrals.
- Niki and Geraldine confirmed that Training is given to pre-school providers.

It was confirmed at the meeting that the new approach was to be adopted.

Andrea confirmed that there are now 11 link health visitors: 3 in Bournemouth, 3 in Poole and 5 to cover the rest of Dorset. However, 2 do not yet have brain stem screening equipment. The overall position is looking better and all have been to an OSCI day with 19 gone through training in last 9 months.

Andrea now has a new administration assistant who has been in place for the last 3 months.

6. 2nd Tier clinics (East Dorset)

There is an internal review by Hannah Elton ongoing and Emily is carrying out a PCT review on audiology. Rachel L confirmed that the 8 month distraction tests undertaken are small in number. They are probably not sustainable for the future. Rachel also confirmed that referrals for two year olds can go to 2nd tier Audiology. There was a discussion on where VRA should be placed and Sarah confirmed if it was seen as a gold standard to be deployed into the community it would be too expensive to deliver so may best be placed in 3rd tier Audiology.

Children seen at the 2nd Tier in East Dorset:

	2009 – 10	2010 – 11	2011 – 12
Pre school	722	772	857 (more new tests than follow up)
School age	1067	1177	1104 (more follow up than new tests)

The referral process was discussed and Nikki raised the question of finances – are community paediatricians cheaper or more expensive than audiologists? Commissioners need to look at the ongoing reviews and assess the way forward.

GP's can take the route to refer directly to ENT consultants – normally with a presumption the child may have glue ear.

Rollo explained the issues that GP's have linking to ENT/Health Visitors/Community Paediatricians and Audiology on email communications and how the various systems in use do not link well together currently to make this an easy process. The meeting discussed the gaps in the process and Rollo confirmed that a more holistic review of the process from Health Visitors to ENT consultants was required.

Emily explained how out of the NHSP QA visit the review of the Community paediatricians and the facilities was requested. The review has just started with data collection and investigation into pathways and financing. Sarah confirmed it was good that the review was underway.

7. Hearing and Vision Support Services (HVSS)

Following updates from Erica Davies, the questionnaires that go out to parents now cover Hearing Services/Audiology/SALT.

Sam confirmed that there is still discussion about Auditory Processing Disorder (APD), as this remains an area that arises fairly regularly. There is a need for education on responses on how to reply to it being raised. Local diagnosis may still require a private referral to Southampton costing over £600 per assessment and often the assessments are not conclusive. It is often found that the diagnosis is found to be from an 'internet diagnoses'. Sarah raised that often the root cause may be other issues. However, as this continues to be prevalent question then it will continue to a focus on how best to respond and manage the requests for investigation.

8. Paediatric care pathways and diagnosis

Sarah covered CMV testing and explained the process used across Dorset, Bournemouth and Poole. The NDCS 'Understanding your child's hearing loss' booklet is used across the region, and has meant Rollo's own document is no longer required. Sarah stated that the NDCS has a whole range of very good booklets that provide advice and guidance.

Sarah introduced Rollo's new guidelines for investigating and management of sensorineural hearing loss in children that were circulated at the meeting.

- Rollo went through the document covering areas such as Jervell Lange-Neilsen syndrome, a rare condition that can be detected via an ECG but specialist reviews of the ECG are required.
- The use of MRI's and Rollo said a regional review of the results here would be a good idea.
- Progressive hearing loss is quite common in occurrence and there needs to be a mechanism in place to ensure review of late diagnoses is made. Rollo confirmed a specialist approach is required here; investigation can be complex and expensive here with the use of MRI's etc.
- **Action: Sarah to review with Lisa and Rollo and work out what is best to do here.**
- **Action: Rollo to send Sarah the detailed numbers to communicate to the group.**
- The overall approach in East Dorset is the same as Rollo described.
- **Action: Tony to send details to Rollo on the East Dorset approach and Tony will also look to see if it can be added to the Website.**
- Sarah discussed Guthrie cards, CMV and signed consent from the parents to allow for investigations. When a genetic test, or other test, was positive how far should investigations go to? Guidance is to continue to explore all possibilities but in particular with CMV this may be very time consuming, and may not change management.

9. SNHL diagnosis 2011, East and West Dorset

Sarah discussed the details from East Dorset that were distributed to the group. One of the key areas highlighted was that the feedback loop to Community Paediatricians needs to be tightened up.

For West Dorset, Jeremy and Rachel B discussed the 5 cases in 6 months from October 2011 to April 2012. Andrea was asked if additional data could be provided so further analysis can be undertaken.

There were instances where cases had not had referrals back but had later been found with hearing difficulties. More analysis and reviews on the root cause of the miss is required.

CMV infection is associated with a high risk of progressive hearing loss. Sarah explained that this diagnosis can be difficult to make; if a child presents later (after 1 year) with a progressive loss, tests looking for an in-utero infection can be very hard to interpret.

Children known to have a congenital CMV infection should have regular monitoring of their hearing, probably up to 10 years or so of age. Jeremy could not recall having seen a CMV referral.

Sarah confirmed that mothers are not screened for CMV and Rollo said that most babies who have had an infection are ok and do not have CMV-associated hearing loss.

Action: It was agreed that at the Meeting next May all the data for 2012 (East and West) should be presented to the group for review so the data tied into the same timeline as a comparison.

10. 2011 Annual Report

The annual report was discussed and Sarah confirmed that two supportive responses were received, from Jean O'Callaghan (Chief Executive at Dorset County Hospital) and Kim Drake, (Service Director at Children's Social Care in Bournemouth).

Sarah reminded the group that we have an action to review the groups Terms of Reference and requested that the secretary forward a copy to the group with the minutes and request feedback. One key area that requires consideration is the term of office for the chair and secretary; should there be a rotation as previously suggested?

The review of the Terms of reference to be on the Agenda for the November meeting that may be extended to 2 hours 30 minutes to allow this review to take place.

11. AOB

Sarah provided an update on how Dorset was performing against national standards for grommet insertion and time to completion of NHSP screen; overall Dorset was on track. (Information from the NHS Atlas of Variation in Healthcare for Children and Young People). Andrea confirmed the measure of 95% screened on time was closely met.

Jules Benton updated the group that due to organisation changes she no longer represents Connexions. In Bournemouth, schools are the representatives for Connexions from September 2012, a Bournemouth Local Authority decision. Parents will need to ask for support after school for college and university. HVSS can support without a statement post school.

Jules Benton also updated the group on the changes to the rules on school leaving age. The current Year 10's will need to stay in learning to 17. The year 9's will need to stay in learning until 18. There was a discussion on the possible impact and Jules said it was key that the parents chase any required support.

Andrea circulated to the group an article from the Sunday Times about cochlear implants and one family's experiences.

Date of the next meetings:

- Tuesday 20th November 2012, 10:00 to 12:30, Seminar Room 3, Postgraduate Centre Poole Hospital
- Tuesday 8th May 2013 Dorchester, Location TBC -Time: 10:00am to 12:00 Noon
- Tuesday 19th November 2013, 10:00 to 12 noon, Room TBC, Postgraduate Centre Poole Hospital