Dorset Children's Hearing Services Working Group (CHSWG)

Minutes from CHSWG Meeting on Tuesday 1st November 2022 (conducted via Microsoft Teams)

Present:

- Lisa Nind (Clinical Lead (Paediatric Audiology), East Dorset Audiology, Dorset Health Care (DHC)) • -LN
- Helen Williams (Audiology/ENT Service Manager, Specialist Services, DHC) HW
- Rachel Beeby (Clinical Scientist, West Dorset Audiology; Dorset County Hospital (DCH)) RB
- Simon Baird (Clinical Scientist, West Dorset Audiology, DCH) SBa
- Sarah Morris (Consultant Paediatrician, University Hospitals Dorset (UHD)) SM
- Sam Bealing (Teacher of the Deaf, Educational Audiologist, University of Southampton Auditory Implant Service (USAIS)) - SBe
- Ken Tucker (Educational Audiologist/Advisory Teacher, Dorset Hearing Support Service (HSS), • Dorset Council) - KT
- Ursula Murley (Acting Principal Advisory Teacher, Dorset Hearing Support Service (HSS), Dorset • Council) – UM
- Juliet Viney (Dorset Deaf Children's Society (DDCS) Trustee and parent representative) JV
- Steve Frampton (Consultant ENT Surgeon, UHD) SF
- Kate Lloyd-Hatchard (Operations Manager, Head & Neck Service, UHD) KL-H
- Charlotte Freeman-Lawrence (Deputy General Manager, Head & Neck Service, UHD) CF-L

	Topics	Actions
1	Introductions and apologies	
	LN introduced herself as chair of the meeting. RB (joint chair) and KT took minutes.	
	LN welcomed everyone	
	 Apologies received from: Kathryn Key (Senior Specialist Audiologist (Paediatrics), East Dorset Audiology, DHC) Elaine Okopski (Dorset Parent Carer Council) Karen Collins (School Nursing Clinical Lead – CYP Public Health Service, Bournemouth, Christchurch, and Poole, DHC) Gemma Hardman (Team Lead for Christchurch and Bournemouth East Paediatric Speech and Language Therapy (SALT) Service, DHC) Michail Chatzimichalis (Consultant ENT Surgeon, DCH) Jemma Buckler (Local Manager, Newborn Hearing Screening Programme (NHSP) Dorset, DHC) Dorothy Goodall (Teacher of the Deaf, USAIS) Hannah Brown (Local Engagement Officer, The National Deaf Children's Society (NDCS) Shirley Sorbie (DDCS Trustee and parent) 	

2	Matters arising	
	 Review of minutes from last meeting No amendments required 	
	 Review of Actions from last meeting RB sent out a glossary of acronyms/abbreviations with the minutes of the May 2022 meeting and also with the agenda for this meeting. SM will discuss the genetic panel and audit of babies referred from NHSP to her service for aetiological investigations later in the meeting as part of her service update. 	
	 Terms of Reference (ToR) RB volunteered to update the ToR based on the NDCS document on "What Works: Children's Hearing Services Working Groups". LN noted that the British Academy of Audiology (BAA) Paediatric Quality Standards should be added to the list of documents that underpin the CHSWG ToR. 	RB to update CHSWG ToR
	 Review of chairperson arrangements LN asked for volunteers to take over the role of chair as LN and RB have now been joint chairs for 3 years. LN outlined that it would also be useful for the new chair(s) to be able to attend the Children's Hearing Services Forum for the South West Peninsula on 24th Nov 2022. This meeting is being reorganised with a new format by Stuart Harris, Paediatric Audiologist from Plymouth Hospital NHS Foundation Trust. It is expected to be an annual meeting going forwards. UM and KT agreed to discuss with RB and LN whether they may be in a position to take over as joint CHSWG chairs outside the meeting. 	
3	Service Updates	
	Newborn Hearing Screening Programme (NHSP) – Jemma Buckler sent her apologies as she was unable to attend the meeting, but she forwarded a service update to be included in the minutes.	
	 NHSP Screening team staffing levels/issues: 1 vacancy; new screener awaiting start date. 	
	 Data/performance: Quarter 2; Currently meeting all 5 standards. Quarter 1; Standard 3 did not meet the acceptable level. Referrals into Audiology were too high. ≤1.6 acceptable level and Dorset had a referral rate of 1.9. Relates to approximately 1 baby a month. An audit shows it is the NICU referrals that are too high. Ongoing training is being provided by NHSP. 	
	 Gather survey completed. 183 responses since last meeting in May. 173 reported service to be 'very good', 10 reported the service to be 'good'. 	
	 Incidents: 1 NICU baby was screened by Southampton NICU, transferred to Poole Hospital, and rescreened by Poole NICU screener. Root Cause Analysis report completed, and actions completed. 6 babies were screened in a clinic with a machine which had given the incorrect QA check result. Screener noticed after clinic and all babies' families called and spoken to same day; all accepted a rescreen. Screening 	
	Incident Assessment Form completed.	2

East Dorset Paediatrics – Sarah Morris

Deafness gene panel testing

- Babies/children with bilateral moderate or worse sensorineural hearing loss (SNHL) used to be tested for Connexin 26/30 mutations, which are the commonest cause of autosomal recessive non-syndromic prelingual hearing loss. The expected number of babies/children with Connexin 26/30 mutations (20%) had been identified when SM last audited (which was some years ago – 2015/16).
- Referrers could ask for specific genes if that seemed relevant, but in babies without other physical features, it rarely was.
- In the last couple of years, a gene panel looking at a large number of possible gene abnormalities (100+) has been introduced. SM thinks that they still start with the Connexin mutation, and then look for others if that is negative. It takes much longer (over 12 months for the only positive one SM has had so far although the information says that it should take 4 months).
- Inherited or familial hearing loss can present in isolated (non-syndromic) form or as syndromic hearing loss, in combination with other specific phenotypic features. The genes included in the gene panel contribute to non-syndromic hearing loss as well as those associated with the following syndromic forms: Usher Syndrome, Waardenburg Syndrome, Pendred Syndrome, Perrault Syndrome, Chudley-McCullough Syndrome, Wolfram Syndrome and Branchio-oto-renal Syndrome.
- The presentation for patients with these conditions is variable, and in some cases, may appear to be isolated hearing loss. Prognosis is therefore also variable.
- Inheritance of familial hearing loss is gene-dependent and may show autosomal dominant (inherited or de novo), autosomal recessive or X-linked inheritance.
- The incidence of pre-lingual severe hearing loss at birth or during early childhood is approximately one per 1000 with a further one per 1000 children becoming deaf before adulthood.
- SM has not had any positive results in babies referred from NHSP yet but did have a 3-year-old boy identified with Pendred Syndrome.
- The gene panel looks for the following genes: ACTG1, ATP2B2, BDP1, CABP2, CCDC50, CD164, CDH23*, CEACAM16, CIB2*, CLDN14, CLIC5, CLPP, CLRN1*, COCH, COL11A2, COL4A6, CRYM, DFNA5, DFNB31*, DFNB59, DIABLO, DIAPH1, DIAPH3, EDN3, EDNRB, EPS8, ESPN, ESRRB, EYA1, EYA4, GATA3, GIPC3, GJB2, GJB3, GJB6, GPR98*, GPSM2, GRHL2, GRXCR1, HARS*, HARS2, HGF, HSD17B4, ILDR1, KARS, KCNE1, KCNJ10, KCNQ1, KCNQ4, KIT, LARS2, LHFPL5, LOXHD1, LRTOMT, MARVELD2, MIR96, MITF, MSRB3, MYH14, MYH9, MYO15A, MYO3A, MYO6, MYO7A*, NARS2, OSBPL2, OTOA, OTOF, OTOG, OTOGL, P2RX2, PAX3, PCDH15*, PDZD7*, PNPT1, POU3F4, POU4F3, PRPS1, PTPRQ, RDX, RPGR*, SERPINB6, SIX1, SIX5, SLC17A8, SLC26A4, SLC26A5, SLC4A11, SMPX, SNAI2, SOX10, STRC, SYNE4, S1PR2, TBC1D24, TECTA, TJP2, TMC1, TMIE, TMPRSS3, TNC, TPRN, TRIOBP, TSPEAR, USH1C*, USH1G*, USH2A*, WFS1
- Indications are Paediatricians can only ask for the 'monogenic hearing loss' panel (R67 in the directory). If there are other complicated features, geneticists or more specialist doctors can ask for more specific tests.
 Questions/comments:
 - SF highlighted the importance of pre- and post-test counselling to ensure parents understand the implications and possible complications of genetic testing.

- SF questioned whether there should be guidance documents in place if more clinicians can request these tests, but SM was satisfied that Paediatricians should be able to have these conversations with parents as they are used to doing it in other areas, such as for children with neurodevelopmental conditions. The Genetics Team are also coming to speak to the Community Paediatricians next month about counselling.
- SM commented that gene panels are not as complex in terms of counselling as whole genome requests.
- SM said that ENT could refer to Paediatricians to request genetic testing.
- SM's experience is that parents are generally pleased to discover the cause of their child's hearing loss even if this does not change the management.

Audit of findings from aetiological investigations for children diagnosed with permanent childhood hearing loss (PCHI) following referral from NHSP:

• Please see Appendix 1. SM asked people to contact her if they have any questions about this or need further clarification/ explanation.

Questions/comments:

- SM discussed that for children investigated prior to the new gene panel testing where no cause was identified for their hearing loss, there is the possibility of offering this now if they are re-referred. However, SM does not have sufficient capacity to go back through all of these children. LN suggested that it is something that could be considered at Audiology review appointments, e.g., if parents have ongoing concerns about the cause of their child's hearing loss.
- SF commented that he was mindful of the children where identification of a genetic cause could have implications for the family or affect management, e.g., children with a mitochondrial DNA mutation that put them at increased risk of aminoglycoside ototoxicity.
- SM highlighted that these mutations are not part of the gene panel and would have to be requested separately (R65 in the directory).
- SM emphasised that history-taking and examination of the child are always the most important parts of the aetiological investigation and guide which tests need to be requested.
- SF and SM had a brief discussion about the challenges brought about by a wide group of paediatricians seeing children for investigation in terms of expertise. SM addresses this by seeing babies referred from NHSP herself, but no one clinician has the capacity to see all of the school-age children. Hence outcomes are much more difficult to capture and audit for this group.

Aetiological investigation course – Attended by SM on 10th/11th October 2022

- Locally, we are still following the most recent guidelines from the British Association of Audiovestibular Physicians (BAAP), which are from 2015.
- There are also guidelines for investigating permanent conductive hearing loss and progressive SNHL from 2018 which SM hadn't seen before. SM will read and implement these.
- The discussion about diagnosing (and perhaps then treating) congenital Cytomegalovirus (cCMV) infection is one that needs to be had locally. Otherwise, SM does think there is anything we need to change based on the course.
- Most professionals would wait until a child can lie still in a scanner before arranging this unless there are other indications for a scan.
- Interesting talks on vestibular function and on Auditory Neuropathy Spectrum Disorder (ANSD) which SM needs to disseminate to the paediatricians seeing the older children.

Questions/comments:

- In terms of aetiological investigations, RB asked about children with significantly asymmetric hearing thresholds that don't reach aetiological investigation criteria and whether they should have an MRI scan to check for acoustic neuroma (AN).
- SF said he would be pleased to see children for which this was concern. AN is uncommon in children but not unheard of and is usually bilateral. He would consider Neurofibromatosis type 2 (NF2) diagnosis in these cases and look for other indicators such as lens abnormalities, cutaneous changes, family history etc.
- SF would also consider other causes including enlarged vestibular aqueduct (EVA) where there is a more open communication channel for fluid between the inner ear and the brain. In these cases, a moderate head injury can cause sudden stepwise deterioration in hearing. Therefore, imaging which detects this can be helpful as it may modify parental behaviour in terms of the activities the child is permitted to engage in (e.g., contact sports etc.).
- SF acknowledges that awake MRI in younger children can be challenging due to artefacts, but he is concerned about the risks of delaying until the child is old enough able to lie still in the scanner. SF has seen a good regional presentation on getting children through MRIs at an earlier age including the use of play therapists. Feed and wrap is also an option in young babies.
- SM agreed that feed and wrap in young babies is good but by the time SM sees children, they are often too old for this. There is apparently no consensus among professionals over putting children under general anaesthetic for scans because of the inherent risk. SM's opinion is that this should be discussed with parents and joint decisions made on a case-bycase basis.

New local meeting

A paediatrician working in the South West has arranged a meeting of doctors working with children with hearing loss – the first meeting was in September 2022 and SM couldn't attend but the next one is in the diary for 7th December 2022. There are new guidelines from British Academy of Audiology (BAA), which we can discuss locally. Again, SM does not think we do badly re: aetiological investigations but we do not meet the expected timelines.

CMV testing (and possible treatment)

- Only about 1 in 20 babies picked up via the NHSP have 'asymptomatic' cCMV; it causes more deafness than this but is often progressive and if the diagnosis is made after 28 days, then it is too late to treat.
- Previously, treatment with intravenous drugs was the only option but oral treatment is available now, which can halt progression of the hearing loss or even reverse it. However, these drugs still have significant side effects (e.g., bone marrow suppression). Therefore, they may not be the right option for every baby.
- There is no national guidance or pathway yet, but pilots are taking place across England and Wales where a salivary sample is taken at the point of referral from NHSP. This needs to be done before 4 weeks and if the baby is subsequently diagnosed with a SNHL and is CMV positive, treatment can be offered.
- It can be the audiologist or the screener that takes the sample.
- One of the issues locally is that we test urine for CMV (rather than saliva), which is trickier to collect from babies, and we don't usually know about the babies until they are several weeks old, so it is too late to arrange to see

them and organise tests in time to think about treatment.

- SM said that she will get together with Dr Deepa Shenoy, Consultant Paediatrician from DCH to move forward with this. They will need to discuss options with the virologists from the Infectious Diseases Team in Southampton and then think about who would take the sample.
- On the plus side, numbers will be small (Only 1 in 20 babies picked up with a permanent hearing loss from NHSP have cCMV now).

West Dorset Paediatrics - No representative present and no update received

Dorset Hearing Support Service (HSS) – Ursula Murley

Data re: current caseload - Nov 2022

- 58 'A' category children have weekly or fortnightly visits to provide support with hearing aids, radio aids and accessing the curriculum.
- 257 'B' category children have monthly, half-termly or termly visits
- 58 'C' category children have termly, twice a year or annual visits
- 4 students are attending a specialist residential school for the deaf due to complex communication needs (all post-16, sign language users)
- Active cases currently on the Dorset HSS caseload is 477
- 172 children who are diagnosed with unilateral (one-sided) hearing loss or mild hearing loss and are not aided, for these children an annual information report is sent to school and follow-up provided by request.
- 308 children who are 'clinic review', these children have been referred by Audiology but are not currently aided; these children are covered by the graduated approach (which is needs-led).
- Total number of children currently on the HSS database is 957
 - o 506 Dorset
 - o 433 Bournemouth, Christchurch & Poole
 - o 18 Neighbouring Local Authorities
- 164 main case children have an Education, Health and Care Plan (EHCP).
- 67 main case children attend a local special school (these children will have another leaning need in addition to their hearing loss).
- A massive housekeeping project is currently underway to tidy up the database.

Staffing update:

- UM appointment to Principal Advisory Teacher confirmed August 2022.
- Two long-standing teachers (50 years' service for Dorset between them) retired at the end of the summer term they both worked part-time, and their hours have been covered.
- HSS current staffing levels
 - Acting Principal Advisory Teacher (1.0 FTE)
 - Eight qualified teachers of the deaf (7.7 FTE)
 - One Educational Audiologist (0.9 FTE)
 - One Sign Language Support Worker/deaf role model (0.5 FTE)
 - One Technician/Specialist Teaching Assistant (1.0 FTE)
 - One Trainee Teacher of the Deaf, commencing January 2023 (1.0 FTE)

Training for schools and settings:

- Continual programme of bespoke and small group training in schools for individual pupils.
- Webinar programme to be developed and return to face-to-face conferencestyle training event (previously put on hold due to Covid).

HSS activities for children:

- Pre-school group Poole Group, monthly meetings
- NDCS Technology Bus June visits were cancelled, so will be rescheduled, possibly February 2023.
- Summer Activity Day 29th June 2023 with the Vision Support Service focus on Music and Craft

HSS updates and projects:

Strategic priorities identified and working groups established across Hearing and Vision Support Service (HVSS) team:

- 1. Principals of co-production supporting families and settings:
 - a. Surveys
 - b. Case studies
- 2. Digital First model of service delivery:
 - a. Local Offer
 - b. Resources and Inventory
- Provide advice and support re: Accessibility and Reasonable Adjustments:
 a. Update all leaflets
- 4. Social, Emotional and Mental Health support (based on feedback from children, young people, and parents post-Covid):
 - a. Information on Local Offer
 - b. Social stories resources to support self-esteem.
 - c. UM has written a piece on deafness and mental health for Shirley Sorbie to put in the DDCS newsletter.
- 5. Preparation for Adulthood (again based on feedback from students and parents):
 - a. Future pathways tracked and reported
 - b. Local Offer information
 - c. Workshop for students on applying for Disabled Student Allowance, knowing what support they are entitled to etc.

HSS staff training:

- Sam Bealing and Dorothy Goodall are visiting the HSS to give an update on new cochlear implants.
- Also, Ilse Friedrich from Oticon is delivering some training on the Opn Play hearing aids and EduMic.

Questions/comments:

- A discussion took place about battery safety in schools as it is not uncommon for HSS advisory teachers to visit in school and find loose batteries in trays/bags etc.
- The HSS are looking at copying the battery safety warnings from the NHS Audiology reports to put on the bottom of their reports too.
- Also linking in with waste disposal team. There is a Dorset Council policy for disposal of batteries (but there is not one for Bournemouth, Christchurch & Poole (BCP) Council).

- UM will reach out to other Local Authorities to see what they do.
- HSS will make schools aware of battery safety.
- There is often a complacency and lack of knowledge around battery safety.
- LN Audiology can raise battery safety at review appointments to increase awareness.
- KT highlighted that hearing aids with tamperproof battery drawers are only tamperproof when worn/switched on (as battery drawer needs to be opened to turn the aid off), which is an issue.
- Consensus was that we all want to do everything we can to prevent any incidents involving batteries.
- LN raised the issue of social media influences on children and young people (e.g., Tik Tok). UM noted that the NDCS is a good resource for positive role models.

East Dorset Audiology - Lisa Nind

- The British Academy of Audiology (BAA) has recently published Quality Standards in Paediatric Audiology, which also has an audit tool attached. This covers a wide area including access, communication, assessment, aetiology, management plans, skills, and collaborative working. LN and Katie Key (Senior Paediatric Audiologist) have completed the audit tool and are working through the standards. This will be an on-going project. A BAA senior colleague recently remarked that if any service thought they were meeting all standards they should look again.
- The service is continuing to fit the new family of Oticon hearing aids with significant success so far. These are being supplied to children with a newly diagnosed hearing loss, and audiologists are changing other children over to the Opn Plays on reviews. The service has also been very helpfully supported by KT (HSS) who has advised on certain cases where it would be helpful to try the new aids at an earlier date. The feedback from children/families so far has been incredibly positive.
- There is still a proposal for East and West Audiology Services in Dorset to merge and as part of this, services continue to work towards a single pan-Dorset IT system.
- Recruitment into Audiology continues to be difficult, and the service has been looking at new ways to deal with this. A new adult rehab clinical lead is starting next week.
- Paediatric waiting lists remain high. Katie Key and LN are continually reviewing these to ensure urgent patients are seen on time, or patients are brought forward where there is a significant concern.
- This year the service has seen an increased number of children where clinicians have not been able to test them in clinic a sedated hearing assessment is required (12 patients this year so far compared to 5 last year in total). This assessment takes out a clinician for a whole morning and is therefore very costly for the service.

Questions/Comments:

- LN and SF discussed the pathway/process for wax removal in children and young people with hearing aids in East Dorset where the wax is preventing impression taking for earmoulds.
- SF said that he will try to accommodate these children, but ENT has long waits for aural care following Covid. Urgent patients are currently waiting 6 weeks.
- Neither GPs nor ENT are currently funded for wax removal.

- ENT receive referrals for children from primary care for de-waxing who haven't come through Audiology.
- If they have been seen by Audiology, ENT can prioritise those with associated hearing loss, but SF admits that this is potentially a waste of Audiology time/resources.
- LN and SF agreed a pathway for urgent cases (via secretaries for consultant attention), but referrals via other routes will have to wait longer.
- LN asked SF whether there are any contraindications to using olive oil drops for a prolonged period for wax softening. SF was not aware of any (other than the usual contraindication for wax softening drops of eardrum perforation), but some say distilled water is just as effective. In contrast, sodium bicarbonate can cause irritation of the skin in the ear canal if used for a prolonged period. SF felt that all children should swim to help with wax!

West Dorset Audiology – Rachel Beeby

- Work towards the proposed merger with East Dorset Audiology is ongoing. Still waiting to hear when TUPE of staff to Dorset HealthCare will take place. In terms of the pan-Dorset IT project, the team are currently configuring and testing Auditbase.
- All babies referred from the Newborn Hearing Screening Programme for immediate assessment are being offered an appointment within 4 weeks, often much less.
- There have been some challenges at times meeting the 6-week diagnostic target for pre-school and school-age paediatric assessments and seeing unaided review patients on time. However, pre-school and school-age aided reviews are being seen on time.
- Staffing for paediatrics is currently okay.
- So far this year, the service has had 3 new diagnoses from NHSP plus one baby with unilateral microtia/atresia where screening was contraindicated. We have also had 4 new diagnoses in older children.
- The service is starting to look at the new British Academy of Audiology Paediatric Quality Standards and will work on this jointly with East Dorset Audiology.

Questions/comments:

 HW briefly discussed that the pan-Dorset Audiology merger has been delayed due to technical issues with the information technology (IT) system, but that once this is in place, it will have benefits to ENT in terms to being able to access audiometry results and patient notes.

University of Southampton Auditory Implant Service - Sam Bealing

COVID 19:

- Routine reviews and outreach now ongoing and are getting back on schedule. HSS can alert USAIS if they feel that anyone needs to be seen urgently.
- Waiting lists for scans now reduced so the service is getting back to pre-Covid schedules for assessment.

Other News:

Training courses:

- Providing training/update to the Dorset HSS soon.
- 'Cochlear Implants the Basics' now resumed in person at Southampton. This will be slightly earlier in the year now – moved from October to September.

 Troubleshooting workshop – being organised for end March / beginning of April 2023 Radio aid/remote microphone system training and workshop to be run every 2 years – due 2024 	
 Staffing changes: A new Clinical Psychologist has joined the service, working mainly with adults to free up Dr Louise Lee to work with children and young people (CYP) to deal with issues such as deaf identity/ self-esteem etc. The service has a new Clinic Support Manager – Cath Grimer. There are also a few changes within the admin and customer service teams where recruitment is in progress 	
 Recent company developments: Cochlear are launching a new processor (N8). USAIS will update services once we have further details, and it has been trialled with adults, but it uses the same receiver as the previous model. Update on the new Advanced Bionics processor (Marvel), which has an integrated receiver for radio aids: Started roll out to children who are overdue/due for their upgrades. The service is continuing to liaise with the Dorset Hearing Support Service to ensure that the new radio aid configuration is available to prevent CYP being without a radio aid and will be monitoring how the CYP are finding the new setup closely. BAHA 6 is being rolled out 	
 Questions/comments: SF suggested that scans could be done locally (in East Dorset) if it helps. SBe clarified that USAIS are not offering the Advanced Bionics cochlear implant to new patients because of recent internal device issues. Instead, they are being cautious until they are certain the issues have been resolved and are only offering Med-El and Cochlear at the moment. 	
East Dorset ENT – Steve Frampton	
 There are known ENT waiting list issues. About 1051 paediatric patients are currently waiting and 7000 adult and paediatric patients combined despite insourcing and extra clinics. This is due to an uptick in GP referrals since the pandemic. Glue ear pathway – not all patients are being triaged correctly/consistently by ENT to distinguish those who have already undergone 3 months of watchful waiting/tried autoinflation (who should be triaged as urgent) versus 	

- those that haven't.
 Often paediatric patients are referred directly to ENT rather than to Audiology first for hearing-related issues.
- SF questioned whether it would be better for all for initial referrals where hearing loss is the sole issue (i.e., no pain/recurrent ear infections etc.) to be directed to Audiology. Then if they meet the NICE criteria and are referred back by Audiology to ENT, SF would press upon colleagues that they should be triaged as urgent for consideration of grommets/surgical intervention. LN commented that she thought this was already the procedure. SF said that some still coming through directly from primary care, but he would try to prioritise those from Audiology.
- A discussion took place about the reduction in Audiology clinics running alongside ENT clinics following the pandemic. As a consequence, there are some children who have been discharged from Audiology on the basis that they were expected to have a repeat audiogram alongside their ENT

	appointment, which then hasn't happened. SF therefore asked if East Dorset Audiology could continue to monitor these children rather than discharging them. Otherwise, their audiogram may be out of date by the time they see ENT, which can lead to further delays in treatment.	
	 HW provided feedback that work she was involved in with NHS Dorset looking at ENT waiting times and efficiencies etc. has unfortunately been paused as they are now focussing on other areas (e.g., patients waiting more than 104 weeks. 	
	• There are staffing challenges in East Dorset Audiology, but HW advised that a new adult Audiology lead is starting next week, and the plan is that there will be 3 new audiologists available to support ENT in the New year. Need to look again at how best to support ENT.	
	 SF asked if there is a regional microtia and atresia service/muti-disciplinary team (MDT). SM and LN both confirmed that they have no knowledge of this locally. SF wondered if this is something we need to consider as a group. SM was supportive of this idea. 	
	 JV enquired about psychology services for parents and children as there is nothing currently in place in Dorset through the NHS or HSS. JV found this input very helpful when her family were going through the cochlear implant assessment process with her daughter. This she felt that it would be valuable for the families. 	
	 SF asked about balance assessment and rehabilitation in children, which seems to be a gap in the services offered locally. At present children need to be referred to Portsmouth for this, which may involve another long wait. SF asked if there was a local resource to help these children, even if they couldn't deliver a full diagnostic/therapeutic service) or whether this is something we might hope for in the future. SM highlighted that following clinical examination, balance assessment is only needed for a minority of children with hearing loss, but that it is appropriate for some children and there is no provision for this locally. Vestibular rehabilitation is currently delivered by the physiotherapy service in adults. However, SM did not think that local paediatric physios would feel they had the expertise to see these patients. SF wondered if there was a local resource that could be used or instigated locally. HW agreed to ask their adult balance clinical lead, Karen Dewhurst, to raise this at the vestibular network group she attends for Dorset alongside physios and see what options there might be. HW will also make some enquiries. 	HW to make enquiries about local resources for balance
	 It was acknowledged that there is no funding for paediatric balance assessment and rehabilitation but that numbers are small. SBe will also ask at USAIS about this. 	rehabilitation in children
	West Dorset ENT – No representative present and no update received	
	School Nursing – Apologies received from Karen Collins; no update available	
	Paediatric Speech and Language Therapy (SALT) – Gemma Hardman was unable to attend the meeting as she is currently on maternity leave However, Erica Davies, Clinical Manager for Children and Young People's Speech and Language Therapy sent the message below to the group:	
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	Gemma Hardman, Hearing Impairment Lead in our service has just had this article published, as she is currently on maternity leave, she has asked if I would share it with you all.	
	Open access to the article is available at <u>https://authors.elsevier.com/sd/article/S0021-9924(22)00093-4</u>	
	Please do share with any colleagues who may be interested.	
	Children's Social Care – No representative present and no update received	
	Dorset Deaf Children's Society – Shirley Sorbie was was unable to attend the meeting at short notice as she was unwell and sent her apologies	
	National Deaf Children's Society – Hannah Brown was unable to attend the meeting due to short notice calendar changes and sent her apologies	
	NHS Clinical Commissioning Group – No representative present and no update received	
4	 Any other business JV introduced herself as the parent representative. She is now also a DDCS trustee. JV asked everyone to please share anything that would benefit children and parents in Dorset. JV mentioned recent and upcoming events held by the DDCS including their Harry Potter trip and the Christmas party. The DDCS are also trying to link parents together via their Facebook page. JV asked how the HSS disseminate information to parents about events, which UM explained is via the termly newsletter, occasional mail shots and also via visit report forms. The next HSS newsletter is due before Christmas. JV asked if everyone aware of the Cochlear Implanted Children's Support Group (CICS) <u>https://www.cicsgroup.org.uk/</u> SBe reported that CICS is promoted with new families, but perhaps it should be promoted/revisited to remind families later down the line. UM will include it in the next newsletter. UM highlighted that local parents want to see local children who have does well and achieved their ambitions. Hence the aid is to put more social stories in the HSS newsletter from children and young people of all ages. Date for next meeting discussed and agreed. 	

Date for next meeting: Wed 10th May 2023, 10am-12pm, Microsoft Teams