

APD TESTING AND WHAT YOU NEED TO KNOW - MAY 2018

APD is a medical condition not a learning difficulty, although it can cause learning difficulties in some people. Therefore, only an appropriate medical specialist, (only a consultant in audiology or audio-vestibular medicine, in fact), is qualified to diagnose APD. Diagnosis is essential; it is not just about education and every child is UNIQUELY affected. It isn't simply a question of having it or not. Appropriate and adequate support (at school, at work, for life) depends on accurate diagnosis.

RECOMMENDED NHS TESTING CENTRES IN ENGLAND

- Great Ormond Street Hospital, London/GOSH for children age 7-16, headed by Prof. Doris-Eva. **N.B. GOSH are now only accepting referrals for children living within the M25 area (Outer and Inner London).**

<http://www.gosh.nhs.uk/medical-information/auditory-processing-disorder>

<http://www.gosh.nhs.uk/parents-and-visitors/coming-hospital/how-get-referred>

Please check with the individual centres regarding testing age, unless specified.

- There is also a multidisciplinary APD service for children at the Nuffield Hearing and Speech Centre. Dr Spyridakou sees those patients.

<https://www.uclh.nhs.uk/OurServices/ServiceA-Z/ENTS/NUFF/Pages/APD.aspx>

- UCLH: for adults/children over 16 and headed by Dr Doris-Eva Bamiou.

<https://www.uclh.nhs.uk/OURSERVICES/CONSULTANTS/Pages/DrDoris-EvaBamiou.aspx>

RECOMMENDED NHS TESTING CENTRES IN WALES

The Hearing Institute based at UHW Cardiff - for children age 7 plus. (*They also test children 16 plus and adults). The consultant is Dr Rajenderkumar.

*With just one clinic a month, following several months' wait for an initial consultation and basic hearing test, it can then take a further 6 months before an appointment there for APD testing.

Welsh Hearing Institute (Audiology) University Hospital of Wales Heath Park CARDIFF CF14 4XW

Tel; 029 2074 3474 / 07807 457952

Email; audmed@hotmail.co.uk

<http://www.cardiffandvaleuhb.wales.nhs.uk/audiology>

Please note: None of these centres will now test children with autism.

RECOMMENDED PRIVATE TESTING CENTRES IN ENGLAND

- Southampton University has a private, 2-tier, multi-discipline children's service. Level 1 merely includes screening, assessments to see if APD is likely, Level 2 provides the testing to confirm it. The team is headed by Dr Nicci Campbell who is the current Chair of BSA APD Interest Group. She is a key author of BSA APD guidelines and its position statement. They also offer dyslexia screening at Level 1. * Both Level 1 and Level 2 testing are recommended unless decided by the consultant.
<http://ais.southampton.ac.uk/auditory-processing-disorder/>

N.B. Due to increased demand, Southampton University is now only taking referrals from those living in Hampshire, Wiltshire, Dorset, West Sussex and Isle of Wight.

- Private APD testing for children is available too at the London Hearing and Balance Centre. Contact them and ask about APD testing with Dr Doris-Eva Bamiou.

Address: 70 Grafton Way, Kings Cross, London W1T 5DT

NEW Phone: 020 740 5555

NEW Fax: 020 740 5555

Email: c.bishop@lhabc.co.uk

- Also, there is a private children's service at The Portland Hospital that provides full testing. **Unfortunately, this service is also currently not taking new referrals; please contact them to keep checking – this may change with the expected addition of a new consultant.** <http://www.theportlandclinic.com/mdepartment/audiology/>

TESTING IN SCOTLAND AND N.I: there is currently no full testing service provided.

WHY I RECOMMEND NOT TO GO ANYWHERE NOT LISTED ABOVE

Other places, including NHS hospitals and private organisations and charities, may offer 'testing' which may just be basic assessment not diagnosis, and which can result in limited and, in some cases, unreliable and incomplete results and generic recommendations. This is virtually useless when children are affected uniquely and have various other conditions impacting on the APD and vice versa. Children with (sometimes severe) APD have been missed by some of these assessments, and later diagnosed at GOSH. It is for parents to decide whether locality is preferred over quality of testing and the experience of the audiologists. Personally, I would not advise that you go anywhere else until standardised testing is available UK-wide, (unless your child does not meet the current criteria). If you are unhappy with this situation, please contact your local health board or commissioning group and MP to request that

standardised testing is provided locally. It is your right as a parent or adult with APD to do so.

Please read the new GOSH criteria for England and other UK countries; they are quite specific and can be found in the files section of my website, along with a lot of APD information and articles for parents, teenagers and adults. **N.B. GOSH are now only accepting referrals for children living within the M25 area (Outer and Inner London).**

HOW TO GET A REFERRAL FOR TESTING

To start with, your child needs a hearing test at around the time the referral is requested - it has to be within 3 months before referral and a referral cannot be sent until after the child turns 7. The symptoms of hearing loss and glue ear are similar to APD and need to be ruled out first. It is difficult to test for APD with hearing loss and usually cannot be done during an NHS appointment due to time constraints. Glue ear needs to be treated before testing can take place; they would not, and should not, test a child with glue ear because results are skewed by the intermittent hearing loss that accompanies glue ear.

If the hearing test shows no hearing loss and glue ear, then you can request a referral. To meet GOSH criteria, you will FIRST need a report from a SALT, Ed Psych or Paediatrician stating that APD is suspected. There are other professionals that are accepted (**please contact the centre you want to be referred to, for their criteria**). Any other suspected conditions and speech and language issues MUST be diagnosed before referral; they won't test a child with hearing loss, glue ear, severe autism or ADHD or language impairment, which can lead to child being unable to respond appropriately to testing. **PLEASE NOTE: Most of the recommended testing centres will not currently test a child with autism, please contact them to check concerning co-existing conditions before getting a referral sent. Please don't have a referral sent in the hope that it will be added to the waiting list: it will simply be rejected and you will have wasted valuable time.**

Other recommended testing centres may not have the same strict criteria but, like GOSH, may not be able to test if a child cannot respond appropriately to questions asked during testing, due to other conditions/SLI. No-one should test children with glue ear/hearing loss because the results will not be accurate, so don't let them try to persuade you otherwise. A hearing test is advised before seeking referral as an adult.

Request a referral from your GP or audiologist, asking them to send all reports, and I would also read and take along the one page "What is APD" sheet from the files section. You will also find most of your questions answered by the document "APD and its implications". N.B. They may not consider a referral without professional suspicion of APD and all appropriate reports being sent with it. Please contact them to check.

WHAT FULL APD TESTING SHOULD INCLUDE

I have been advised that there are sadly no national APD testing guidelines at present. Check they don't just use a SCANC or SCAN3 screening or only Feather Squadron, these are assessment tools and will not provide full APD testing alone or be able to provide a diagnosis alone. There should be more than just one or two APD tests. Most eminent audiologists agree that there should be a full test battery approach but the practice varies from one service to another. Different individual assessments plus tests may be used, but the areas of auditory processing tested should be roughly the same as GOSH, and selected based on the problems that each child has and the presentation, also considering the other issues the child has. Not all children will need all the tests that can be used; it will depend on what type of APD difficulties seem to be causing a problem.

This is what GOSH provides (it can take up to 4 hours in total for your visit). Other testing centres provide a similar, full range of testing which can take 1.5 to 2 hours of testing alone. They may have a consultation appointment and make a further appointment for the testing.

PLEASE NOTE: Most of the recommended testing centres will not currently test a child with autism, please contact them to check before referral.

TYPICAL GOSH TESTING APPOINTMENT N.B. GOSH are now only accepting referrals for children living within the M25 area (Outer and Inner London).

This is an example of the standard of testing and the process that you should expect to receive at any of the recommended testing centres, although they might all vary slightly.

- First, they take a detailed and comprehensive history (this part takes at least an hour), looking at problems that the child has, parents' concerns, teachers' concerns, speech and language issues, cognitive issues, reading, written work, memory issues, other diagnoses e.g. ASD, ADHD, learning difficulties. Visual problems, current educational environment and support, pre, peri and post- natal problems, developmental milestones, past history of middle ear, neurological and other mendicant problems, ear problems etc. plus family history.
- Then there is an examination of ears, general examination, and an observation of speech quality.
- Tests are selected based on suspicions raised in the above. They should test from this list, as applicable:
- Tests of peripheral auditory function

- Cochlear feedback pathway
- Ability to hear degraded speech
- Ability to hear speech in noise (if needed in quiet)
- Spatial processing
- Binaural resolution
- Temporal processing
- Auditory pattern sequencing

They can request other tests that are relevant e.g. Electrophysiology (ABR, corticals) and MRI, if applicable. The audiologist has to have sufficient knowledge to interpret these, understand the losses or conditions that may affect the outcome of each test, and if there are other issues e.g. Language issues, how that might affect the test results and interpretation. The audiologist also needs to have a very broad understanding of intervention available and find the most suitable to help the child.

RESULTS/REPORT

The test results are usually explained in person on the day or as soon as is possible afterwards. Make sure you understand what the results mean, the specialist should take time to explain it and you have a right to be told, in plain English, what the results mean for your child or yourself, plus the diagnosis. A report should be sent to you later with the test findings; make sure you request one or it may just be sent to the person that referred you. Other testing centres mentioned above may vary in their format but should be expected to provide efficient, complete testing, an explanation and a report. I cannot say about the process of those not mentioned above because at present they vary widely and most places provide testing that is just assessments, or one or two tests where more are needed, which is unfortunately not better than nothing and patients should not have to just accept what they can get.

If seeking private testing, I would personally you to specifically ask whether you are paying for full APD testing to the level and standard provided at GOSH; also, if what they provide qualifies as an audiological diagnosis of APD. Get it in writing before you pay. You should also be provided with a full explanation, diagnosis and report after testing.

N.B. It is up to parents to make sure that they get what they think they are paying for or being referred for, whenever they seek APD testing and diagnosis for their child, either privately or otherwise. You are within your rights to complain (and ask for a refund, if private) if you feel that you have been misled. You can also make a complaint

to them, report them to the GMC, or here. Check that they are on the register here: <http://www.hcpc-uk.org/check/> (audiologists are apparently listed under Clinical Scientists). If they are on the register, and they acted inappropriately, or were rude/dismissive to you or your child, failed to explain the diagnosis fully or with care, or took money under false pretences, report them and ask for them to be removed from the register.

DIAGNOSIS/REPORT

Check the report when you receive it; it should say whether the child has been given a diagnosis of APD/Auditory Processing Disorder (which means that there is enough evidence of 2 or more separate difficulties of qualifying severity to merit that APD diagnosis). But if it says that there are auditory processing difficulties, that may mean that there is NOT enough evidence of 2 or more separate difficulties of qualifying severity to merit an APD diagnosis or that they cannot say it is APD (*I would ring and ask why). It might just give a diagnosis of Spatial Processing Disorder which is a stand-alone diagnosis of that one specific APD difficulty. If that was the only difficulty found of qualifying severity, that is not a diagnosis of APD (which needs 2 or more) but Spatial Processing Disorder plus one or more other difficulties of qualifying severity would merit a full APD diagnosis.

(*Other testing centres apart from those mentioned above may not be able to give a diagnosis of APD/Auditory Processing Disorder if they have no consultant to verify the results. The report may then say auditory processing difficulties even if the child has APD, but that might not be the case, so contact them to check). Some places clearly state that what they are giving is not a valid APD diagnosis.

The report should always include the tests used and scores given (if they don't, ask for them). Also in their report should be clearly-explained, tailored recommendations based on your child's test results, not a generic handout. Be mindful of what the report tells you: it might affect your child's support and/or EHC Plan application/statement/benefits claims. It needs to be clear and complete. (I would personally recommend that any child with APD struggling at school needs an EHCP).

CONTACTS

For any questions on referral, testing and diagnosis.

Dr Doris-Eva Bamiou, GOSH and UCLH

Dr Nicci Campbell in Southampton, Chair BSA Auditory Processing Disorder SIG

SUPPORT AND FURTHER INFORMATION

On my website <http://apdsupportuk.yolasite.com> there are plenty of APD-related articles, handouts and useful hints and tips (for parents and those with APD of all

ages), including my APD presentation for you to use, along with accompanying notes and A4 posters, plus APD alert cards with designs for children, teenagers and adults.

There is also a list of all my current APD support groups for parents, also for teenagers and adults with APD, both UK and international.

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<https://apdsupportuk.yolasite.com/>