**NOTES - PLEASE DO NOT SEND THIS PAGE**

This letter is for you to adapt and send to your local Clinical Commissioning Group/CCG (England) or Local Health Board/NHS Trust (Wales) which decides on the health service provision in your area. You can also send it separately to the CEO of your nearest hospital that provides hearing services/ENT/audiology, also to your, MP, GP, local Council Leader/Councillor, audiologist etc. Please see the links below to find the email for the CGGs in England, LHBs/NHS Trusts in Wales, your MPs (and your Welsh Assembly/Senedd Member if you live in Wales).

It's quicker to send via email (and it won’t cost you anything). Please copy and paste the text into the body of the email; attachments will probably end up in their "spam" folder. Please include your home postal address in an email to an MP. Also make sure to adapt the parts highlighted in yellow to your situation, and remove any unused yellow highlighted text choices before sending (and don’t send this notes page).

**LINKS**

A list of all local Clinical Commissioning Groups/CCGs in England

<https://www.england.nhs.uk/ccg-details/>

A list of all Local Health Boards/NHS Trusts in Wales

<https://tinyurl.com/2p8r68ph>

Search for your MP’s parliamentary email address

<https://www.parliament.uk/get-involved/contact-an-mp-or-lord/contact-your-mp/>

Search for your Welsh Assembly/Senedd Member’s email address

<https://senedd.wales/find-a-member-of-the-senedd/>

**Your home address**

**Date**

Dear [Mr/Mrs/Ms SURNAME]

I wish to draw your attention to the lack of local provision of testing for the condition Auditory Processing Disorder/APD. As [the parent of a child/ an adult] suspected of having this condition I was appalled to find that full testing is not available locally.

You may not have heard of APD, but it is not rare. Recent international research has indicated that APD is thought to be present in 5% to 7% of children (some sources say up to 10% or 1 in 10) and in over 20% of adults. The amount increases steeply in children who have additional learning difficulties, with up to 40% of those children also having Auditory Processing deficits. By comparison, according to the WHO in 2019, Autism/ASD is thought to affect only 1 in 160 children worldwide (affecting only 1.1% of children in the UK) yet Autism receives widespread diagnosis and support and APD deserves the same level of provision. It is also now believed that all those with Autism have some measure of APD.

*[Add as appropriate:* The nearest NHS testing centre where I can access full testing for this condition is in [London/Cardiff] which is prohibitive to me.

[*Add as appropriate:* I have therefore had to travel to [London/Cardiff] to [have my child tested/be tested] [on the NHS/privately] [incurring travel costs and/or overnight accommodation] when local testing should have been available to me, causing added stress/distress and expense to me/my child.

The following pages contain relevant information from APD Support UK about this condition and the minimal current testing provision UK-wide. I draw your attention to the facts relating to this situation and the reasons why local testing provision is needed, also the reasons why screening is unnecessary and cannot provide a valid diagnosis. Please read “About APD” here. <https://apdsupportuk.yolasite.com/about-apd.php>

 As you will see from the information provided, the percentage of individuals potentially affected in this area, and the implications for health, mental health, education and work, all demand your urgent action. Ours is not an isolated issue and a substantial section of the population in this area is being failed. This is a problem that will grow exponentially with greater awareness. So, more patients in your area will be affected and it will become an ongoing problem unless addressed. There is therefore an evidenced need for local provision of specialist APD testing.

APD diagnosis can only be made by an APD experienced and qualified specialist consultant in audiovestibular medicine. Basic screening, even if provided, is not an acceptable level of testing; it is unreliable, and it cannot lead to a conclusive diagnosis. Specialist testing is essential. Professionals that are aware of the specialist testing centres often refuse to refer out-of-area. Or they insist that a child has local screening before making a referral for specialist testing. But this is pointless because screening is part of the specialist testing battery anyway; the difference is that when used at a specialist testing centre, it is interpreted by an experienced, qualified consultant. At screening centres, children are being told they don’t have APD and refused a referral to a specialist testing centre which parents then have to pay for, and their child is found to be severely affected - not because they paid but because they received the necessary additional testing that screening centres cannot provide and are not qualified or experienced enough to use. This makes a diagnosis based just on screening invalid

Parents/patients are being refused a referral for specialist testing based on inaccurate information. They are told that screening leads to a valid diagnosis, or that it is all that is available. Or they believe that APD doesn’t exist, or that nothing is available. Patients are being refused accurate testing for other invalid reasons too. All of this wastes valuable time in which children have more gaps in their education, lose their self-esteem and confidence, and fall further behind their peers. Similarly, adults have more stress at work, lose their job or find it harder to gain employment. CCGs and LHBs must inform professionals in their area of the facts about APD, provide specialist testing, and advise professionals to refer their patients there. The facts about APD and the issues that exist around recognition and referral can be found in the APD Support UK guide for professionals. <https://apdsupportuk.yolasite.com/professionals.php>

Under the principles of the NHS Constitution, I would therefore like to request local provision for the diagnosis of APD to be provided at my local hospital [name], for both children and adults to the testing standard provided by centres on the APD Support UK testing centres list, and the replacement of existing screening centres with those providing specialist testing. <https://apdsupportuk.yolasite.com/about-apd.php>

I would also like you to raise the issue of lack of national full APD testing provision with the relevant bodies at both local and national level, on my behalf and on behalf of the hundreds of thousands of potential sufferers of APD in the UK who are denied access to a valid diagnosis.

Yours sincerely

 [Your name]

SOME FACTS ABOUT APD

* APD is a neurological condition affecting the way that sound, including speech, is processed by the brain. It is a lifelong, debilitating and often isolating condition that can be considered a communication disorder, a sensory disorder, and also a hearing disorder. For most sufferers (depending on severity), it also comes under the classification of a disability as it impacts every aspect of daily life, and it is persistent and ongoing.
* APD does NOT affect hearing or cause hearing loss, only the way the brain processes what it hears (although it can also exist in individuals with hearing loss). But without the interpretation of sound by the brain, what we hear is just noise. APD is recognised as a hearing disorder by the 2021 World Health Organisation (WHO) "Report on Hearing” in section 1.3.3 page 37 <https://www.who.int/publications/i/item/world-report-on-hearing>
* APD is not itself a learning difficulty, it is a medical condition, but because of its effects on communication, auditory memory etc. it can be severely detrimental to learning. E.g., one type of APD affecting phonics acquisition and management can lead to some children developing auditory dyslexia, for which it is the primary cause in an estimated 70& io cases.
* APD affects each sufferer uniquely and is worsened in the presence of background noise, such as a busy classroom or workplace.
* APD can affect all aspects of a person’s life, including access to an appropriate education, work and benefits, and having effects on both communication and relationships.
* APD can be inherited, congenital, or be caused by head trauma from any cause, epilepsy, development problems in utero, certain conditions and illnesses, in childhood or as an adult (this list is not exhaustive).
* APD is a stand-alone condition, but it never exists in isolation; there can be any number of other co-morbid yet unrelated conditions and difficulties which impact on their APD-related difficulties and vice versa, compounding all the sufferer’s difficulties and leading (for many children and adults) to stress, anxiety, depression, social isolation and numerous other additional issues.
* There is no cure for APD, just development of appropriate coping strategies; Each sufferer, as well as developing personal coping strategies needs provision of lifelong, individually tailored support, and reasonable adjustments (including assistive technology) at school and in the workplace which are often very hard to secure even though they are a legal obligation.
* APD is classed as an invisible disability, but it has remained hidden long enough.

CURRENT UK DIAGNOSIS PROVISION

Please consider the following, concerning the current level of provision:

* Children from England can be tested as The Nuffield Hearing and Speech Centre in London on the NHS if their local health board/clinical commissioning group will fund it (even though parents/patients some have to fight for a referral despite NHS Patient Choice giving them the legal right to be tested where they choose). Certain centres in England will also test patients from Wales. GOSH only tests children from within the M25 area only and Fullwood in Preston accepts only local children. The Hearing Institute in Cardiff Hospitals provides the only APD testing centre for the whole of Wales and they hold just one clinic a month for both. Adult NHS provision is just one clinic, the London Hearing and Balance Centre, for England/Wales or the one in Cardiff for Wales. There is currently no testing provision at all for APD in Scotland or Northern Ireland.
* So, there are just five NHS testing centres in the UK, only three are for children and most have restricted access, and two for adults. They are the only centres that provide the necessary standard of testing to identify the unique profile of difficulties that affect each sufferer, all with rapidly growing waiting lists. There is just a handful of private centres that do the same. The current provision falls far short of what is needed.
* Full testing has been available in the UK since 2004 when a test battery of an agreed standard was first implemented at Great Ormond Street Hospital and has been used ever since. GOSH was the only testing centre in England for many years and so few have been added since. No hospital or clinic can do the job efficiently without the proper tests and training and it is unconscionable that any hospital should provide anything less. It leaves the hospitals, local health Boards and Commissioning Groups all over the UK open to complaints and litigation
* It is said that there is no ‘gold standard’ in APD testing; that might be true, and that in itself is nothing for the NHS to be proud of. It is also an excuse not to provide the full range of testing that already exists. Yet the centres that provide full testing manage to deliver the best that can be provided, and that is what every APD sufferer deserves. all over the UK.
* It is also vital on providing specialist testing, that each hospital publicises APD as an accepted hearing condition so that schools will support children with this condition. Many local authorities and schools are refusing to acknowledge an APD diagnosis, implement the specialist recommendations or even support a child with a diagnosis of APD without hearing loss and even then, they just support the hearing loss, which is discriminatory and therefore unlawful.

LEGISLATION

In England, the Action Plan on Hearing Loss was jointly published in March 2015 by NHS England and the Department of Health, in partnership with a wide range of stakeholders. It sets out the case for taking action on the rising prevalence and personal, social and economic costs of uncorrected hearing loss, and the variation in access and quality of services experienced by those with hearing loss, including those who have substantial hearing problems in noise (auditory neuropathy spectrum disorders) or more complex hearing problems. [https://www.england.nhs.uk/…/03/act-plan-hearing-lossupd.pdf](https://www.england.nhs.uk/wp-content/uploads/2015/03/act-plan-hearing-lossupd.pdf)"

The Department for Health considers that the Action Plan on Hearing Loss is adequate to cover APD provision in the UK, yet this action plan is about hearing loss, it does not even mention APD at all, let alone make provision for it. Hearing loss alone is covered.

The Welsh Assembly also considers that one testing centre for the whole of Wales is adequate. It is not. Scotland and Northern Ireland don’t even recognise or test for APD**.**

FURTHER INFORMATION

For further information on Auditory Processing Disorder and links to support:

* APD Support UK <https://apdsupportuk.yolasite.com/>.
* “About APD” <https://apdsupportuk.yolasite.com/about-apd.php>
* “APD testing centres” <https://apdsupportuk.yolasite.com/about-apd.php>
* <https://www.frontiersin.org/articles/10.3389/fneur.2021.607907/full?&utm_source=Email_to_authors_&utm_medium=Email&utm_content=T1_11.5e1_author&utm_campaign=Email_publication&field=&journalName=Frontiers_in_Neurology&id=607907>
* “An APD Guide for medical professionals” and “APD referral process” <https://apdsupportuk.yolasite.com/professionals.php>
* Contact: apd.support.uk@aol.co.uk