

TO THE DIRECTOR OF EDUCATION/HEAD OF ALN/SEN (or equivalent education officer)

(Please forward this email to the relevant senior Education officer).

Dear Sir/Madam

In June/July 2021, a request for information was sent to all the Local Authorities/LAs in England and Wales. This was sent by representatives of APD Support UK, the only voluntary organisation that supports children/young people, families, and adults affected by Auditory Processing Disorder/APD in the UK. This request concerned provision for children with APD while also providing LAs with accurate information about the disorder. The emails were sent using the email addresses provided on the local government websites, several of which were found to be incorrect.

I would like to thank those who took the time to respond. Sadly, most of the LAs did not respond to this request and Freedom of Information requests were subsequently made. Formal complaints were sent to those that failed to reply, or even acknowledge our request.

APD Support UK response

APD Support UK would like to make some recommendations based on the replies that we received. Due to the final number of responses involved, and the varied content of the replies, it is not possible to send an individual reply to each LA, so this response will be sent to all. These were the results of the questions we asked.

Do you have a policy supporting APD? If so, could you please refer us to it on your website, or send us a copy?

Regarding a policy supporting APD, it has become apparent that the majority of LAs in England and Wales do not have one, or feel it necessary. Some LAs asked for our support in developing a policy. It is hoped that all LAs would consider developing an APD policy or adapt their existing policy with regard to the required provision described in this email.

Do you have a Sensory Support team, Hearing Impaired/Hi team or Teacher of the Deaf, or equivalent?

All the LAs that replied have informed us that they have a Sensory Support team, Hearing Impaired/Hi team or Teacher of the Deaf, or equivalent. However, their reported knowledge of (and involvement with) children with APD is mostly limited or non-existent. Either they exclude APD or do not provide support, unless there is an additional diagnosis of hearing loss/impairment. The LA that produced the policy referenced above recognises APD as a hearing impairment. That so many other LAs do not accept this view is of particular concern, especially considering that APD is now recognised as a hearing disorder by the 2021 World Health Organisation (WHO) "Report on Hearing" in section 1.3.3 page 37. As such APD should fall under the remit of each LA's sensory team or equivalent and receive ongoing, appropriate support, regardless of whether hearing is impaired.

<https://www.who.int/publications/i/item/world-report-on-hearing>

Another issue lies in that the few LAs that do provide support for APD only provide the same generic support as is provided for HI children. The LA that produced the policy referenced above recognise that APD, although a hearing impairment, requires a separate policy and differentiated support. APD does not affect hearing or cause hearing loss. Therefore, strategies for hearing loss are neither appropriate nor adequate for children with APD. APD affects each child uniquely and they will normally have a different number and variety of other unrelated conditions which means that they each need tailored support. It is therefore a recommendation by APD Support UK that any Sensory Support team, Hearing Impaired/Hi team or Teacher of the Deaf (or equivalent) should receive training on the nature of APD*, its implications in an education setting and strategies to fully support a learner with APD** be provided, also that support is provided for APD by that team LA-wide as soon as possible. This is in the best interests of children with APD and for LAs wishing to avoid litigation for contravening the Equality Act 2010 and Education Act 2011. Please be advised that failure to support

APD, a medical condition that also qualifies as a disability, might also be considered to be disability discrimination. APD is not in itself a learning difficulty/disability, but it directly affects communication. As a result, APD can have significant impact on learning. The law dictates that an LA cannot refuse to recognise or support a child with APD for that reason, and because it is a medical condition.

*Please see the document "About APD" here <https://apdsupportuk.yolasite.com/parents.php>

**Also "APD in the classroom" and "APD in tests and exams" here.
<https://apdsupportuk.yolasite.com/parents.php>

If so, do they (the Sensory Support team, Hearing Impaired/Hi team or Teacher of the Deaf, or equivalent) follow NatSIP guidelines regarding the support of APD within the school setting?

Many LAs said that they follow NatSIP guidelines regarding the support of APD within the school setting; however, a lot of them fail to understand what APD support entails. Further, many LAs stated that they did not follow NatSIP guidelines where the young person did not also have a diagnosis of hearing loss, which might be considered unlawful. It is therefore essential that accurate information on APD and how to support it is disseminated to all schools in your designated area to ensure legal compliance and best practice, and to avoid potential complaints and legal proceedings against schools and LAs for breaches of the relevant legislation, and to ensure DDA compliance. (see* and ** above) as per the Equality Act 2010 and Education Act 2011.

When recommendations are made by a professional for a learner-with APD, do you provide and support any recommended equipment, e.g., FM systems?

We have found that some LAs do provide FM systems/assistive listening technology to children with APD, although these are few.

N.B. A worrying trend is developing among some LAs who are imposing a listening test on children whose parents are requesting assistive technology to see whether the learner needs it. If they did not need it, it would not have been recommended by the specialist consultant in audiovestibular medicine that diagnosed the child with APD. This arbitrary test has caused additional distress to the learners and their parents, also resulting in an unnecessary delay in provision of this vital technology, and usually resulting in refusal to provide the device/s requested. As stated above, it is a legal obligation for schools to implement the recommendations made by the diagnosing specialist for a learner with APD (and all other conditions) with regard to provision of reasonable adjustments. Unless the person administering the test and deciding on whether the learner needs it is a specialist consultant in audiovestibular medicine with experience in formally diagnosing APD, they are not qualified to make that decision. Parents whose child has been put in this situation may wish to make a formal complaint to the LA and/or inform the diagnosing specialist whose professional medical diagnosis and recommendations have been questioned and disregarded, with a view to possible litigation against the LA and/or individual staff members involved. I don't believe that the LA would seek to question a specialist recommendation for another medical condition in such a way. APD Support UK therefore recommends that such unnecessary tests should be not be used by any LA.

Would the LA expect the educational setting to provide and support FM systems?

In most cases LAs would expect the educational establishments/schools to provide assistive listening technology. Sadly, it is the experience of most parents' that schools refuse citing lack of funding. However, it falls to the LA to provide top-up funding where the school does not have sufficient funds for the necessary equipment. Please be advised that it is a legal obligation for educational establishments/schools to implement the recommendations made by the diagnosing specialist for a learner with APD (and all other conditions) with regard to provision of reasonable adjustments, including purchase of and support for recommended equipment, e.g., FM systems/assisted listening devices (ALDs). These are vital to ensure that a child with APD and other difficulties can efficiently access the National Curriculum to the same level as their peers, and receive an appropriate education, as per the Equality Act 2010 and Education Act 2011. All LAs should make all schools in their area aware of their legal obligation, in their own interests and that of their learners. LAs should

ensure that schools in their area are aware of their legal obligation with regard to the appropriate legislation i.e., the Equality Act 2010 and Education Act 2011.

Would you like to consider adding APD Support UK to your local offer?

For those LAs who have agreed to add APD Support UK to their local offer, a short description has been included below this email. This piece can also be used to signpost parents to APD information and support.

Additional points

Identification and diagnosis

It also became obvious from the responses received that many LAs are unaware that children potentially suffering from APD need specialist testing at one of the few testing centres available in the UK, or the need to signpost parents promptly to seek appropriate testing for their child whenever APD is suspected. Schools in their area are likely to also maintain that view. Only specialist testing can rule it out, and as a medical condition of neurological origin and an invisible disability, it can be hard to identify. Parents need to be believed when they raise issues with the school and LAs need to set an example by informing schools of the appropriate pathway so that they can signpost parents appropriately.

In Wales, there is only one specialist centre for APD testing for children or adults. It is based at The Hearing Institute, University Hospital for Wales at The Heath in Cardiff. It is the only specialist centre for APD in the whole of Wales and should anywhere else claim to provide APD testing/assessment, they would just offer basic screening which does not lead to an accurate diagnosis and can miss even the most severe APD.

The appropriate process for any child suspected of APD is as follows, and must be passed on to all schools in your area to advise any parent whose child is suspected of having APD:

Schools should advise the child's parents to ask their GP referral for a hearing test. It is a misconception that a child with APD will have poor hearing, and APD can exist in the presence of perfect hearing or hearing loss, but this should be ruled out as it excludes a child from NHS APD testing. If there is no problem with their hearing (no hearing loss, glue ear, or grommets present) they should be referred immediately by their GP, or audiologist, to Dr Deepak Rajinderkumar at The Hearing Institute, UHW at The Heath in Cardiff. They should not be referred to a local hospital to ENT or to a paediatrician for APD testing. Only a consultant in audiovestibular medicine is qualified to diagnose APD. APD is a medical condition which can only be diagnosed or ruled out by a specialist. In Wales, that is only Dr Rajinderkumar. If you wish to refer to an outside agency for education support, please make sure you also make recommending that parents seek a referral for APD testing a priority. Each child with APD will need tailored support depending on their unique APD presentation and other comorbid conditions. Generic support for all will not help them.

If the child has hearing loss, glue ear, or grommets present, they will need to be seen privately for APD testing at one of the private specialist centres on our "APD testing centres document here, of which there are none in Wales. <https://apdsupportuk.yolasite.com/about-apd.php>

Parents should also be reminded to check that their child meets the other criteria on the list for the testing centre, or they must seek private testing. Every day lost is detrimental to the education and wellbeing of a child with APD.

It is advisable that any child suspected of having APD should be supported as if they had it from the first suspicion. That support must be amended accordingly when the school is given a copy of the diagnosis report. There are recommendations in "APD in the classroom" here.

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

It is imperative that any existing policy for APD support and advice to schools should be amended to reflect the need for the proper referral process, appropriate diagnosis pathway and tailored support.

A guide to APD can be found on our "About APD" web page which includes signs and symptoms of APD from an early age, other FAQs and misconceptions about APD explained.

<https://apdsupportuk.yolasite.com/about-apd.php>

Please also encourage schools to share our websites with the parents in your area for them to seek accurate information and online support and our guide to the testing process.

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

In conclusion, we are still collating the data on the LA responses which will be added to our website. This information will be made public anonymously, and any parent wishing to know the responses made by their LA will be advised to contact you direct. The anonymised data will also be shared with the research team of a project being undertaken at Great Ormond Street Hospital.

Many thanks for your time in reading this, and in anticipation of your ongoing support for children with APD.

Yours sincerely

Alyson Mountjoy, Chair APD Support UK

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

Suggested text for local offer.

Auditory Processing Disorder/APD is a medical condition of neurological origin affecting the way the brain processes sound and speech. APD is not itself a learning difficulty, but due to its effects on communication it can have a lifelong impact on learning, work and relationships. APD Support UK is the only organisation providing UK-wide support to individuals and families affected by this disabling condition. Their website has information on child and adult diagnosis at the specialist testing centres and links to support groups for parents /families and adults with APD. It also contains free, printable information about APD, coping strategies/management, strategies for support at school, home and work, plus current research projects and more.

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

Contact: apd.support.uk@aol.co.uk