APDUK MISSION STATEMENT - APDUK Constitution 2002

We aim to raise awareness and recognition of Auditory Processing Disorder as a disability, through educating both professionals and the public.

We aim to support research into APD, which will enable good diagnosis and treatment to be developed. We also support individual sufferers and parents/carers of individual sufferers, through self-help networks and internet forums.

APDUK Website and Online Support Groups

Since the last APDUK newsletter, we have started a new ‘Auditory Processing Disorder in the United Kingdom (APDUK)’ Facebook group, to support the needs of an increasing amount of people in the UK with Auditory Processing Disorder (APD). It is for parents of children with APD, adults with APD and teenagers with APD. It provides support, testing/diagnosis information and promotes better understanding of this disability, specifically support on living with APD, and other UK based APD related issues that members raise. You can join us here: https://www.facebook.com/groups/587199541354983/ The group is run in association with the voluntary organisation Auditory Processing Disorder in the United Kingdom (APDUK): http://www.apduk.org.uk/

We also have an ‘Adults with APD’ group on Facebook here https://www.facebook.com/groups/APDadults/ Also our Yahoo OldAPDs group for adults and parents with APD s still going strong here. https://groups.yahoo.com/neo/groups/OldAPDs/info There are also two independently organised groups for young people – Teens with Auditory Processing Disorder: https://www.facebook.com/groups/apdteens/ and one called Learning Disabilities: Online Support for College/University Students. https://www.facebook.com/groups/206543159541765/
Living with APD

At APDUK, we don't believe in trying therapy after therapy in the vain hope of a cure for APD because there is none. APD is for life. We do acknowledge the fact that there are therapies available, which, if appropriately chosen to work on a particular child’s individual needs, can give some measure of improvement in some cases. But every child is uniquely affected and what works for one child won’t necessarily help another and that any benefits might be temporary or limited. So the effects of APD will always remain, to varying degrees, in all sufferers. We therefore aim to address this by helping people to LIVE with their APD, to learn coping strategies and find ways around it. APD has many symptoms and can occur with differing severity and in association with any other disability/learning difficulties, all of which may negatively impact on APD and on each other. APD affects education, communication and socialisation. Children with APD will become adults with APD and they will have to rely on the development of their own individual coping strategies, using their own strengths and compensatory gifts and these can be helped greatly by provision of appropriate accommodations and, in some cases, assistive technology. It is all about knowing how APD affects you, how best to help yourself, how to self-advocate for your own needs and what accommodations will work best for you as a unique individual with APD and making it fit into your life, not take over your life. There is much more to a person than any disability.

Testing Centre Changes

APDUK’s aims include provision of accurate multi-disciplinary testing and recognition and support for APD all over the UK, for children and adults, along with the appropriate accommodations to help in school, in the workplace and adult education. Progress is slow in the area of diagnosis at the moment, in that the APD testing Centre at Great Ormond Street Hospital (GOSH) in London now only provides audiology testing for the diagnosis of APD, but they are using the tests developed in the UK by the Medical Research Council Institute of Hearing Research (MRC/IHR). Testing and referral criteria for GOSH are available in APDUK Newsletter 8. [http://www.tempapd.apduk.org.uk/newsletter.htm](http://www.tempapd.apduk.org.uk/newsletter.htm). Please email Dr Tony Sirimanna [sirimt@gosh.nhs.uk](mailto:sirimt@gosh.nhs.uk) for further information and check the GOSH website regularly for any changes to those criteria. Other sites are trialling the new tests and some offer testing - please contact ones local to you to find out if testing is available and if not maybe a request from you might make that possible, to meet public demand. [http://www.ihr.mrc.ac.uk/research/apd/IMAP_field_test_sites](http://www.ihr.mrc.ac.uk/research/apd/IMAP_field_test_sites). The only facility in the UK that offers that multi-disciplinary testing (via audiologists, a Speech and Language therapist and an Educational Psychologist), using a similar battery of audiology tests as GOSH, is the Royal National Throat, Nose and Ear Hospital in London. Please contact them for further information. [http://www.uclh.nhs.uk/OurServices/ServiceA-Z/ENTS/SLTENT/Pages/Home.aspx](http://www.uclh.nhs.uk/OurServices/ServiceA-Z/ENTS/SLTENT/Pages/Home.aspx)

Research, AGM and New Committee Members

APDUK support international research into APD in children and adults and hope to restart our online chats soon with Dr Damien Howard. We also hope to hold an online Annual General meeting in 2014 to appoint a new Executive Committee. Please email me at [apduknews@aol.com](mailto:apduknews@aol.com) if you can spare an hour now and then, we are looking for volunteers who have experience in administration, finance, marketing, web building, and fundraising, volunteers to take helpline calls (from home, at no cost to you)and people to help run the regional APDUK groups that we hope to set up, for in-person contact and support groups. You don’t have to have APD to volunteer or to join the committee – you just need to want to help people with APD. As always, thank you all for your continued support of APDUK - and of each other. © Alyson Mountjoy - Chair APDUK.

“When you have a disability, knowing that you are not defined by it is the sweetest feeling.” From ‘In My Dreams I Dance’ – Anne Wafula Strike

‘Alone we can do so little; together we can do so much.’ — Helen Keller
Page numbers are at the top right of each page

Page 1 - APDUK Mission Statement, APDUK Website and various support groups.

Page 2 - APDUK Chair’s Spring update by Alyson Mountjoy.

Page 3 - Contents Page.

PARENTS’ PAGES

Page 4 - ‘APD and Accents’ by ‘Veejayah.’

Pages 5-7 -‘Working with Jake’ by Renée Ramey.

Page 8 - Useful links page.

KIDS’ PAGES

Pages 9 to 10 - Drawing by Erin, puzzles & a suggested book for children with APD based on the author’s experiences as a child.

SUGGESTED BOOKS


TEENS/ADULTS PAGES

Page 12 to 13 - ‘APD Disorder Project’ by Bryan D Cox.

Pages 14 to 17 -‘How Does APD Affect Teenagers In Their Working Relationships?’ by Stephanie Kyle.

Page 18 - ‘Learning to Accept Yourself’ by ‘Anonymous.’

Pages 19 to 20 - ‘I Listen in Different Ways Than Others But I Am Not Mad, Bad or Dumb’ by Dr Damien Howard.

Pages 21 to 25 -‘The Importance Of Early Diagnosis Of APD’ by Alyson Mountjoy (based on Adults with APD Research); ALSO: ‘Seeing The Elephant’- Various Professional Approaches To Diagnosis’ by Alyson Mountjoy.

Page 26- 28 - ‘APD-related Tips for GP and Hospital Visits and Tips for Stress-free Gatherings’ by Alyson Mountjoy;

AND: Teenagers with APD page and interview tips for Employers page.

Page 29-32 - APDUK Alert Cards and posters.
An agency providing some regular hours of support for my daughter did not communicate with us when changing support workers. On one occasion a worker sent to support her had such a strong accent and unclear speech it was impossible for my daughter to understand what she was saying and extremely difficult for those without APD to understand her. When I spoke with the agency about accents and the difficulties it can cause people with APD they refused to use the word accent during any discussions or meetings with me and used the word 'tone' instead. The word 'tone' was subsequently also used by the social worker who did not support what I told her. She informed me that the agency were offended by the feedback I had given of enormous stress and difficulties being caused for my daughter when supported by a worker with a strong and unfamiliar accent. I wrote to the social worker and the agency about this matter in 2008.

‘Dear SW,
In my letter to you I wrote about the concerns I had for some aspects of the community support service being provided by the agency for my daughter. I understand from you that an example given about Sophie’s* communication difficulties and workers with strong accents may have been misapprehended as being discriminatory. This needs to be clarified to avoid any future issues, and possible awkwardness, when talking about accents and Sophie’s* communication difficulties. Sophie’s* needs are the priority in all of this.

I contacted the Disability and Race Teams at the Equality and Human Rights Commission (Tel. no. 0845 604 6610). Their advice is that in this particular case it is detrimental for workers that have unfamiliar accents to be used and using workers with familiar accents is a fair and reasonable adjustment to make to the service provided. They advised that changes to reflect this need should be made to the care plan; there ought to be appropriate measures in place; a consistency of care and that we should be consulted at every stage.

I also contacted the Lecturer in Language Pathology at the University of Sheffield, who carried out an auditory assessment on *Sophie in November 2003. The following is an extract from her advice given in August this year.

‘Sophie's* problem is not unusual with people who have auditory processing problems and /or language problems.

If you have auditory processing problems or language problems it takes you much longer to tune in to new accents and you may not be able to do this at all.

It is quite reasonable therefore to request an individual working with Sophie* on a one to one basis should have a similar accent to one she is used to.

People whose first language is not English will have different consonants as well as vowels and they tend to use their own form of the consonant when speaking English. They are unaware of the difference as we lose the ability to discriminate between sounds that are not in our native language by about 12 months old.

In addition the stress patterns and intonation patterns are different and Sophie* will use stress and intonation patterns to cue into the language meaning. She will be less able to adapt than a person with good auditory processing and language.

Tone of voice is quite different. Tone of voice reflects mood and attitude in people with normal left brain processing. Some people have less well developed left brain processing or as we get older we tend to lose some of this ability or it can be lost following an accident involving left brain injury. People with these difficulties may use inappropriate tone of voice.

Some people may have greater perception of tone of voice than others and will notice minor subtleties in attitude or tiredness etc. which are not intentional on the part of the speaker.'

I hope you will agree that the needs explained above ought to be incorporated in an updated care plan for Sophie* as a matter of urgency.

Kind regards,
Ms X)

*I didn't receive a reply to my letter and there continued to be a strong reluctance to update the care plan as requested although some mention was eventually included. © Veejayah
Working with Jake – Renée Ramey ©

Jake has struggled with frustration for most of his life. When he was one, I figured it was typical one year old thing. When he was two, I figured he didn’t have enough words to express himself. When he was three, he continued to struggle to find the words to say what he was thinking and continued to become either aggressive or withdrawn over what appeared to be small things, hitting other kids or even himself. Often his frustration seemed to flare when I least expected it. When he turned four, his behavior deteriorated further. He was having full-on melt-down tantrums four or more times a day. These weren’t manipulative kinds of tantrums. They were clearly a result of his being completely overwhelmed with frustration and utterly unable to express what was wrong or how I could help. I would hold him and promise him we would figure it out, that it was going to be Ok. He started showing signs of having sensory integration issues as well. I took him in for an evaluation with Hillsboro school district, and he tested below the 7th percentile for both social and adaptive behaviors. We were all struggling, nearly all the time, everywhere we went. He started preschool at NWRESD in January.

We began searching for what was wrong and how to help him. We had his hearing tested. It is completely normal. We took him to a developmental pediatrician, who assured us he did not have autism or ADD. We took him to an Occupational Therapist who has been working on his sensory integration issues and fine motor skills. We had him tested by a Speech Therapist, but she determined that he was in the 50th percentile for his age, so we haven’t pursued any speech therapy. Recently, he has been participating in a social skills class and is doing very well sharing, taking turns, using his words. These are small classes of only five kids and two teachers: an Occupational Therapist and a Speech Therapist.

Since then, he’s gotten a lot better. In the past, he would never engage another child his own age without Mason to take the lead. If Mason wasn’t around, he wouldn’t say a word to another child anywhere. Nowadays, he can make friends his own age almost anywhere we go. Interactions with other children rarely end in tears and/or fighting over misunderstandings like they used to.

Still, he is often baffled when I say the simplest things. He will ask “What?” or “Huh?” over and over. He continues to refuse to participate in sports or activities unless his big brother is by his side, even though it is clear he would like to. He cries and says he can’t do what is being asked, when the activity is well within his abilities. My concern is that he will feel this way in school too, baffled by the simplest instruction and too uncomfortable to find the words to ask what he missed. He copes by imitating the other kids, but seems unsure and scared. It may not be at all obvious that he isn’t getting it and is struggling to keep up.

Continued on next page...

APDUK helpline

Our current UK helpline number for parents and adults with APD is 07815 995491. We hope to add more. Please refer to our website before you ring, in case this changes.
http://www.apduk.org.uk/ or email Aiy at apduknews@aol.com for updates.

We are listening!
www.apduk.org.uk
It is very likely that he has an Auditory Processing Disorder, which is unfortunately impossible to diagnose in a child as young as he is. In order to help him have a positive experience in school, I would like to provide you a description of what he is likely going through and what is likely hard for him so that you will be able to observe the subtle clues that he is feeling lost and can stop and give him the time to ask his questions or feel confident that he knows what is going on. He is entirely capable of doing all that will be asked of him. All that stands in his way is whether or not he thinks so.

The following bullet list is quoted directly from a book called “The Sound of Hope: Recognizing, Coping with and Treating Your Child’s Auditory Processing Disorder” by Lois Kam Hymann ©, page 17-19.

“In Preschool:

- A child with APD has a hard time following directions, especially when the directions are not part of a familiar routine and the child doesn’t have any visual cues such as pictures or familiar gestures from teachers to go with them. Many directions and questions posed by adults get a “Huh?” or “What?” and a baffled expression from the child.
- Forming sentences and building vocabulary comes more slowly and with a lot more difficulty than or the other boys and girls in class.
- The APD preschooler leaves sounds and syllables out of words or substitutes sounds that make what he or she says difficult for teachers and classmates to follow.
- The background noise of a busy preschool environment poses an increasing challenge to a child with APD. Loud situations become an irresistible distraction or a source of emotional upset. A conventionally noisy environment can prevent him or her from understanding what’s being explained, asked or said.
- The songs and rhymes that other children learn together and on their own are very hard for the child with APD to get the hang of. Riddles and jokes may make no sense to the child at all. The child increasingly relies on pictures, illustrations, gestures, and other visual information.
- Social communication and the beginnings of conversation with other girls and boys his or her age are full of misunderstandings and often lead to hurt feelings and fights.
- Complex language such as metaphors (“You little piggies will need to clean up this mess before snack time,” “Aren’t you a busy bee?”) and figurative verbal examples, (“We have enough food here to feed an army!” “Why, you’re covered with dirt from head to toe!”) are simply baffling to a child with APD.
- The kindergartner or primary school student with APD opts out of class discussions or appears lost and gives answers that are not on the topic at hand.”

“When we do the best we can, we never know what miracle is wrought in our life, or in the life of another.” Helen Keller

“The central struggle of parenthood is to let our hopes for our children outweigh our fears.” Ellen Goodman
What this means for working with Jake:

- Multistep directions are very hard. He will often only do the first or last thing you asked. This is disheartening and frustrating for him because he really wants to be good and do well. Try to limit the number of requests you give him at one time. Giving him low-key but steady positive feedback to let him know he’s on the right track helps a lot. He will work very hard for you. More than most kids, he doubts that he understands. Hearing that he’s getting things right gives him the confidence to hang in there and keep trying.

- If there is a lot of background noise or a lot going on, he is more likely to feel confused and afraid. He’ll want to escape the situation. He will withdraw emotionally, if it’s mild, or he will say he doesn’t want to do the activity anymore, or that he wants to go home. He might need a chance to sit someplace safe where there are no demands on his listening or comprehending abilities. I usually hold him in my lap till he gets the feel for what’s going on.

- Jake likes jokes, understands that you are supposed to laugh, but he usually doesn’t get it. I try to always offer to explain a joke to him, or ask him if knows what they mean, which helps slow things down for him and lets him know he’s not missing something important.

- He sometimes says what he doesn’t mean and is angry when he gets what he asked for. I don’t have any solutions for this other than showing him the choices if I can. For example, he said he wanted Frosted Miniwheats once, but at the time, his favorite cereal was Golden Grahams. On a hunch, I showed him both boxes and asked him to point to the one he wanted. He enunciated very clearly, “I. Want. Frosted. Miniwheats!” each time touching the Golden Grahams box.

- Sometimes, he will spend a lot of time struggling to find the right word, saying “ah, uh, um…” This is hard for the listener, and I know you will be busy. I don’t have a good solution for this other than being as patient as you are able.

- Sometimes, if he can’t find the word, he will talk around the word: instead of saying “light saber” he’ll say, “the thing that glows that swings around like this” leaving a lot for the listener to try to decipher.

- For Jake, playful teasing by adults or children baffles him. He can tell he isn’t getting it. For example, a coach at the sports camp made a mock-serious announcement that no child was allowed to go to his mother until the coach got a high-five from each kid. I applaud her effort to make sure she connected with each kid on the first day of camp. However, I could see Jake was picking up on the serious part but not the fact that she was joking. He didn’t get the intent. He was concerned that if he didn’t get the instructions right, he wouldn’t get to come to me. Small misunderstandings like this all day long pile up on him and leave him feeling unsure and scared.

- He is sensitive to facial expressions, and will check your expression to see if he’s doing Ok. A smile and encouraging nod goes a long way.

- If he’s feeling disconnected and unsure, he may not participate in a discussion or appear lost. That is a great sign that he needs some help catching up in his understanding, that something happened a little while ago that baffled him and he got behind trying to figure out where he went wrong.

“I put up a huge wall of denial. It was years before I was able to break through it... accepting that your child has a disability, especially one ... that cannot be seen or easily diagnosed, is one of the hardest things to come to terms with.”  

Anne Ford

Useful link: IPSEA - How to take Action

http://www.ipsea.org.uk/Apps/Content/html/?f
id=91

Next: Kids’ Pages ...
APD Related Links

APDUK website - [http://www.apduk.org.uk/](http://www.apduk.org.uk/)


Legal Support

IPSEA - for free advocacy advice - [http://www.ipsea.org.uk/](http://www.ipsea.org.uk/)


Learning Styles

I Think in Pictures, You Teach in Words: The Gifted Visual Spatial Learner, by Lesley Sword [http://talentdevelop.com/articles/ITIPYTIW.html](http://talentdevelop.com/articles/ITIPYTIW.html)

APDUK’s Working Model for Learning Styles - [www.templearningstyles.apduk.org.uk](http://www.templearningstyles.apduk.org.uk)

Other learning styles information - [http://www.bcps.org/offices/lis/models/tips/styles.html](http://www.bcps.org/offices/lis/models/tips/styles.html)


Common Difficulties That May Accompany APD


Sensory Processing Disorder - [http://spdlife.org/symptoms/index.html](http://spdlife.org/symptoms/index.html)

Research

Cite U Like Audiology and Auditory Processing Disorder - library of 824 articles - [http://www.citeulike.org/group/12655/order/year](http://www.citeulike.org/group/12655/order/year)

International dyslexia symposium 2012 - the downloads from the final days presentations relating to APD related dyslexia (auditory dyslexia) [http://www.oxfordkobe.com/program.html](http://www.oxfordkobe.com/program.html)

8th cranial nerve- damage here is one of the causes of APD, but other areas of the brain might be affected - [http://voices.yahoo.com/understanding-central-auditory-processing-disorders-453302.html](http://voices.yahoo.com/understanding-central-auditory-processing-disorders-453302.html)

Medical Research Council Institute of Hearing Research leaflets on APD – in conjunction with APDUK [http://www.ihr.mrc.ac.uk/research/apd/APD_documents](http://www.ihr.mrc.ac.uk/research/apd/APD_documents)

Research Council Institute of Hearing Research participating sites for APD testing - please note, not all of these sites test for APD at the moment but if they are local to you it might be worth you contacting them [http://www.ihr.mrc.ac.uk/research/apd/IMAP_field_test_sites](http://www.ihr.mrc.ac.uk/research/apd/IMAP_field_test_sites)


Family Disability Support Groups

Contact a Family [http://www.cafamily.org.uk/](http://www.cafamily.org.uk/)

Useful Free Programs


Free word processing programs


Libre Office [https://www.libreoffice.org/](https://www.libreoffice.org/)
Please send us a painting, a drawing or a story for our next newsletter to apduknews@aol.com

Print this page, then colour in the picture and find the answers!

Find 2 rabbits that look similar!

Maximize Your Abilities - Living with CAPD: Central Auditory Processing Disorder
by Christopher Rawlins
Max has had CAPD (Central Auditory Processing Disorder) since he was a young boy. He struggled with his disability when trying to learn, understand language and socialize with other kids. Will Max be able to overcome his disability and succeed in life? This story is based on the author’s actual experience living with Central Auditory Processing Disorder.
Thank you to Erin aged 6 for this lovely drawing of the Easter Bunny and to her Mum, Donna, for sending it to us!

Erin is a twin and APD makes school difficult for her.

Her brother Dean aged 11 also has APD. He copes well at school, but he doesn’t like APD as it ‘makes his speech mixed up.’

How does having APD make you feel? It’s good to talk to someone about it!

Please send your drawings to apduknews@aol.com

Solve this flower maze puzzle to help the bee to get to the centre of the flower!
SUGGESTED BOOKS

BOOK REVIEWS

The Gifts of Imperfection: Let Go of Who You Think You’re Supposed to Be and Embrace Who You Are by Brené Brown

“This is about vulnerability, courage, worthiness, and shame. I have found this book very useful in my journey through multiple disabilities, including APD, as it meets head on some of the issues I run into daily and presents a new way of looking at life and circumstances.”
© Hannah Crossett

Living with a Learning Disability by Barbara Cordoni

“Barbara Cordoni bases her book on both pioneering a learning disability center at a university in the U.S. and also on raising a son with a learning disability. She speaks of the importance of providing a learning disabled person feedback so that person can more ably navigate the environment of the non-learning disabled, and also of acceptance and the dependence a person with a learning disability may feel.”
© Anonymous Reader

NEW APD BOOK – AUTHORS WITH APD

Don’t You Get It? Living With Auditory Learning Disabilities: A Guide for Parents and Professionals ©Authors
This new book was written by three experts in the field, led by educator and speech-language pathologist Dr. Jay Lucker, along with Dr. Loraine Alderman, a school psychologist, and Harvey Edell, a former teacher. All three co-authors have APD. Read more at http://special-ism.com/dont-you-get-it-living-with-auditory-learning-disabilities/#A

OUT SOON – AUTHOR WITH APD

Encountering the Edge: What People Told Me Before They Died
The career memoir of Karen Kaplan, an adult with APD - Here is an extract below...

“This is how I describe dealing with auditory processing disorder in my job as a hospice chaplain. Anyone who wants more information about the book can email me at karenbookmankaplan@gmail.com or see my blog, http://offbeatcompassion.com. The book is expected to be available on April 15th 2014, and can be pre-ordered about one month prior to that via Pen-L.com (the publisher) or Amazon. This is an excerpt from the book:

“….When I am with friends in a restaurant, the conversations at the other tables, the sounds of dishes being washed, background music, and especially the sounds of coffee makers, all compete to make hearing my friends a fatiguing enterprise. This is probably what it is like for a person communicating in a second language that they do not know very well. When I am seeing patients in nursing homes, which are full of noise, and sometimes the patients speak softly to boot, I have to do what I can to steer the patient out of the common areas and into her room or some quiet nook.

“I also have to contend with the problem of my auditory processing disorder with my colleagues, the hospice staff. If an air conditioner is rattling away at a meeting, I have to concentrate very hard to understand what they are saying. If the door is open and the copier is chugging away, same effect. No matter how closely I concentrate, I can guarantee you I will miss a certain percentage of what is said. Or when a social worker and I are standing in a hallway to discuss a patient, and I hear a car going by through an open window, I will miss some of what she is saying until the sound of the car fades away. Even if I forewarn my colleagues and friends, they often forget about the problem or misunderstand it and think I am partially deaf. Moreover, my processing of speech in a noisy place takes longer, and so I confuse and annoy people with my slow reaction time. A fellow chaplain once told me that talking to me is like when a newscaster on TV says something to another one at a different location, and there is a brief delay before the latter hears what is said, and then finally responds. And so now you know why I revere and seek quiet, or at least am grateful when I can hear one thing at a time, be it a conversation, a piece of music, a colleague’s report, or the change in a patient’s breathing from labored to relaxed and steady. I listen, and as I encounter each new patient, I wonder, like an explorer of new worlds, what unique features will come my way.”
© Karen Kaplan

PLEASE SEND US YOUR SUGGESTED BOOKS - apduknews@aol.com
Auditory Processing Disorder:

A Complex and Misunderstood Problem

By Bryan D Cox ©

Imagine that you are around 14 years old and you have APD, while school day in and out you have classmates around you that tap their pencil and whisper to their buddies right beside you and you can’t really hear the teacher… Sounds like a regular high school day right? Well now add that to the APD now you have a pencil tapping sound echoing around the room, the whispers sound as if they are amplified by triple of what they originally were and the teacher is seemingly whispering to you!

That’s just in the classroom; now imagine being on the bus normally, noisy right? Add APD to that now, you have around 30 people shouting and music from iPods blaring and the bus music at a decent level of noise, Well there is this little thing called Auditory Hypersensitivity that’s caused by APD; if around 15 people being seemingly quiet is very disturbing, a bus…would be literally like a Nightmare on your ears!

APD Is an Acronym for Auditory Processing Disorder.

Below is a Graphical Diagram in which having APD are common symptoms:

- Auditory Hypersensitivity
- Auditory Overloading
- Poor auditory memory
- Hearing difficulty against background noise and
  Slowness in processing spoken information
Now that you have some idea of what APD is and some common symptoms, I will give you an example of what it is like from the perspective of someone with the disorder.

That someone is a high school student by the name of Kyle.

Kyle’s Journal: Week One.

Today was the end of my first week of school. The building is quite large and the atmosphere is very noisy, and I found myself very disoriented with everything going on around me. I barely even noticed the bell. First period was hectic; the heater was making a cranking sound, and this was only one of the small classroom noises that seemed to drown everything out. Did anyone else have trouble concentrating? It seemed like I was the only one.

Week Two.

This week I had my first test. The information was simple, but I just didn’t get the information in class. The teacher thought that I just didn’t care enough to study harder. I got a 60. If that wasn’t disappointing enough, my teacher assigned homework out of the book, but I couldn’t hear what page it was on. Her lips moved, but it seemed she was mumbling. The bell rang and I got rushed out of class.

Week Three.

I got called down to the office about my low grades. They wondered why I wasn’t doing most of my work. When I tried to tell them I couldn’t hear or understand what my assignments were, they didn’t get what I was trying to tell them. They just saw a student with excuses.

Week Four.

One of my teachers assigned a big project. It was due in...how many months was that? I don’t know...didn’t I write it down? And oh yeah, it will be 65 percent of my grade. Just what I need. I don’t know the format of the project, and I need to ask the teacher. However, I have no time after class in the rush to get to my next class.

Week Five.

I’m going to have to see the guidance counselor this week. It seems no matter what I do, my grades just won’t get any higher. It seems everyone else in the class is doing fine except me. The school counselor has already set up a meeting with my parents to discuss solutions. It seems that when I try to study for anything, the information just gets jumbled. I don’t know what I will do but I hope this ends well. This can’t get any worse...right?

Week Six.

It’s been five years since I found out I have APD. It wasn’t me, I wasn’t just some stupid teenager or lazy student who didn’t care about his grades. I had a disorder. That’s why I couldn’t process the information I was given. That’s why I wasn’t able to study right. That’s the reason why I barely passed my first year of high school. That’s why it felt like no matter what I did, I couldn’t do it right. Just because I have a disorder doesn’t mean I’m stupid. It doesn’t mean I’m not hardworking. It just means I have to work harder than everyone else. Every day is a struggle, but I’m up for it. I look like I’m your average student, but I’m different. But that’s ok, knowing is half the battle. I just wish I had known sooner. In our class of 20 I was the only one with APD.

Works Cited
www.soundskills.co.nz/Auditory%20Processing%20Disorder.html
www.ncapd.org, Dr Jay R. Lucker, Ed.D, CCC-A, SLP, FAAA
How Does APD Affect Teenagers In Their Working Relationships?

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[ An Extract]

This is an extract taken from the full dissertation by Stephanie Kyle. Please note that all the references are linked to her Bibliography, Research and Appendices which are included in the full document (available from the APDUK website here:

http://www.tempresources.apduk.org.uk/teenageapd.htm

How Does APD Affect Working Relationships With Friends?

One of the main effects of APD is that the ears hear things but the brain doesn’t understand these sounds. Imagine playing “Chinese whispers”, a game where a message is passed on from one person to another and usually ends up nothing like the original sentence. Every sentence that a person with APD hears is like Chinese whispers but backwards and where time replaces each person in the game. The message is completely jumbled and confusing. They may believe they hear something like “Are you going to the four-metre spa?” [9] This happens when the brain struggles to label correctly. Sometimes, the more time that passes, the clearer the phrase becomes and they may then believe they heard “Are you something to tutor something more”. The person with APD would obliviously use a procedure called “auditory closure” which is the ability to fill in the missing pieces when parts of a message are not heard or understood, relying on higher-level language and reasoning skills as well as contextual cues [10].

If you have ever assembled a jigsaw puzzle, you know it is much easier if you have a picture to refer to or if you know of what the final assembly is supposed to represent. A similar principle applies to auditory closure abilities. It is far easier to fill in the missing pieces of a message when you have a general idea of what the message is and a good vocabulary from which to choose likely candidates. Sometimes a person with APD can “guess” what the missing words are although; sometimes the words they choose aren’t always the right ones. This proves difficult with every single sentence of every day, however it is even more so when making new friends either at school or college. The inability to interpret words and understand what is being said, people with APD may appear “disinterested” [12], “not very bright” [11] [12] and “rude” [11] [13].

When approaching people to initiate conversation and become acquaintances, at school and college, this is normally in a noisy corridor or recreation area. The inability to filter out background noise makes it difficult to hear what is being said. Auditory closure will probably be used however the noisier it is; the harder it becomes to join a conversation with an understanding of what the topic is. The person with APD could possibly be ridiculed for coming out with something random and off topic and feel very left out. [14] [15] [16] This then results in low self esteem, and nearly all of these teens will lose confidence and end up feeling insecure; they will repeatedly encounter moments of despair [17] – another reason why people will not want to befriend them.

Even before conversing with others, people will make a judgement of an individual with APD for a number of reasons. Due to difficulties in the classroom, a person with APD will have to catch up a lot outside of school/college therefore; they will be assigned the stereotype of being a “nerd” or “teacher’s pet”. Unfortunately, those who are classified as being a nerd are most likely to be at the risk of being bullied. Also, APD affects some people in their speech as the brain cannot interpret the words that are being spoken and will distort the way they are presented [4] [18] [19]. These people will also be a bullying target. This means that it will be even more difficult to make friends as others do not want to be friends with those who are bullied as they fear that they will also then be targeted. Also, if other people have low esteem themselves, they like to see other people being bullied and are more likely to join in rather than offer a helping hand.

Time spent studying at home or during free periods at school or college means there is a lot less time for socializing and friends. Friends may feel like the person with APD is ignoring them or avoiding them and even
friendships made become strained and due to time restraints, pressure is placed on the relationship and friends grow apart. Because the brain fails to filter out background noise on a regular basis, someone with APD is most likely to be startled easily and these noises will be stored in the long term memory. The thing that created the noise will be forever associated with fear hence, the majority of APD sufferers will also have an unusual phobia or phobias relating to the noise. For example, a girl was startled by a flushing toilet cistern and so every time she came across a similar noise, experienced fear. This escalated into Corporophobia (the phobia of toilets in general). Many APD sufferers develop Claustrophobia also. Possible friends will be put off by the fact that people with APD have crazy phobias. They come across as weird and are again ridiculed. People think they are “psychos” and “idiots” but they just do not understand the problems relating to the condition and do not want to try to understand.

How Does APD Affect Working Relationships With Educators?

An intense curriculum at GCSE and A Level means there is a lot of information to take in for all students in a class. The increasing pressure of attaining satisfactory grades requires remembering and understanding this information. Even the simplest of tasks are a challenge for those with APD. One way of making coping with APD easier is to liaise in short sentences using only key words as the less words there are in a sentence, the less there is to cause confusion. Teachers cannot do this in a lesson as there is the rest of the class to consider. This usually concludes with the unsuccessful use of auditory closure or the teenager with APD missing out information completely and leaves them confused and distressed. Sometimes, when auditory closure does work in these circumstances, in the amount of time it takes the brain to process the information, the student has missed the following sentence.

With new technologies, teaching tools such as interactive whiteboards are the main focus of the lesson. The only problem is, the teacher will have to face it in order to scribe or manipulate the board hence their face is away from view and their voice is projected in the opposite direction to the student. Because APD can cause a processing delay, to an individual with the condition, there can be a constant lag like when a television picture is out of sync with the sound. This can be especially confusing and often nothing at all is understood when this occurs, so some people decide to learn to lip-read to a certain extent to ease this effect. Also, if a person affected by the condition thinks they hear either the word “spoon” or “goon”, if they are watching the lip movements of the speaker, they can distinguish which word is being said. This process cannot be carried out properly in a classroom situation if the teacher is not facing the student or is walking around the room.

Teachers nowadays also tend to use PowerPoint presentations to provide information but quickly move onto the next slide before a teenager with APD can read through and understand the contents of it. Again, due to the processing delay, this becomes a problem.

In some teenagers, their activity levels may increase because they have to burn up much more energy than average teens in order to pay attention and understand what is being taught in school or college. Other teenagers with APD exhibit lower-than-normal activity levels (hypo activity). These pupils do not act up in the classroom; in fact, they appear to be either passive, lethargic or reserved. Often parents report that their children are very fatigued after school. They are expending a significant amount of energy just trying to receive auditory information in a meaningful manner as well as the brain burning a lot of energy in concentration and constant studying. They are then very tired in lessons and some teachers who don’t understand how APD affects a student’s learning may see them as being “lazy” or “not paying attention”. If work is not completed during lesson time when information was given out, teachers may expect all pupils to complete the work at home. The part of the condition that prevents sound discrimination also interferes when reading and memorising. Someone with APD will struggle to read as the brain treats the thinking and reading voice in their head as a separate sound and when there is background noise, this becomes a problem. It can take a number of attempts at reading the same passage to fully comprehend the context it is written in and by the time they have got to the bottom of the page, all knowledge of the previous section has been forgotten. It can take people with APD up to ten times longer to understand the work and complete the tasks involved. This further lowers the self esteem of APD sufferers and consequently reduces the time for them to work on relationships with friends and family.
Problems can arise in exams because although teenagers with APD are entitled to up to 25% extra time in their exams [32], this time isn’t always enough. They can read exam questions wrong several times or have difficulty interpreting the questions, especially if there is background noise such as pencils scribbling, pages turning etc. [32] [33]

The above can cause conflict in relationships with teachers and tutors as the student may come to dislike the teacher for expecting such a lot of work from them which will not be much to another student. This impedes on both their school and home life and can put pressure on other relationships.

The fact that teens with APD are often classified as under-achievers by their teachers [25] does not ease the bridge between teacher and student. It is harder to build a healthy working relationship also, when the teacher does not understand the condition as the student can get angry and frustrated.

Some teens that are having trouble coping with their auditory world “act up because of extreme frustration and confusion [2]. This could be because they feel like nobody understands how they feel and how much of a struggle their life is [28], it could be because the frustration with not being able to do things like others builds up and they just want to be normal [20] or it could be for many other things. A teacher will get angry if a child always forgets what to do or forgets their homework or does a completely different piece of work because they thought the teacher said page XX instead of page XY [29]. Even though the teacher will be aware of the condition, more likely than not, they will snap at the child at some point.

Teenagers are already fairly sensitive at this time in their lives and with the added stress, some teens will have a meltdown and a large number will become cynical, argumentative and even aggressive because of the distress the condition is a causing them [8] [30]. They get easily flustered and frustrated when they cannot accomplish something simple like “normal” people can [25]. This can also cause conflict between a teacher and a student as the teacher will not appreciate a teen “playing up” in their lesson.

Disputes with a teacher can also occur when an APD sufferer is positive that the teacher taught the wrong thing. The Central Auditory Nervous System is vast and is also responsible for functions such as attention and converting working memory to short term and then long term storage [31]; however, this is where the condition of APD transpires. This effects the auditory memory conversions in a way that the brain remembers exactly half way through the process of “unravelling what is being said” which is not always correct. This in effect actually alters the auditory memory.

Problems can arise when this happens as an APD sufferer can be absolutely certain they heard one thing when actually this never happened. They can then be accused of lying and this can ignite arguments between teacher and student as well as is social life.

The short term memory is used to process a conversation rather than remember what you have heard. The result of this is that often students with APD will leave a lesson or lecture with no recognition of what they have just been taught as they have not had much extra short term memory available for storage [12]. They will have to do lots of revision after the lesson to keep up with the rest of the class taking up the majority of their time [5].

This constant revision can cause more problems as if the student has misunderstood the material in the first place and then constantly revised the wrong information, they will become frustrated and this could possibly lead to blaming the teacher as there is nowhere else to address anger.

It is not always definite that an educator will be local - some will be from other countries; some will simply be from a different city in the region. APD makes understanding speech a complex process, let alone when the person speaking has a foreign accent. An inability to adapt to a wide variety of speaking styles and enunciations [8] can make understanding people from a different area incredibly difficult and can put stress on an existing or potential relationship as failure to differentiate what is being said can make a conversation awkward. People with APD will possibly have to ask for repetitions numerous amounts of times [31] and the other in conversation may become frustrated. Awkward encounters like these may urge students with APD to avoid particular teachers as the last time they conversed, they felt embarrassed. This would then severely affect the relationship.

Equally, a positive aspect of APD in educational surroundings is that because teenagers diagnosed with APD struggle to express themselves clearly through the use of speech and communication [4][7], their artistic skills are enhanced and a lot of talent is displayed in creative subjects such as art and music [34][35][20]. These are the subjects that APD sufferers normally excel in as well as mathematics in which not much vocabulary is used – just figures.

A common field with an educator will enable opportunities for conversation and the start of a working relationship. Feelings and ideas can be presented through music or art and a teacher specific to this subject can understand and appreciate what is meant without the use of words if necessary. This connection can make
a teenager feel respected and accepted and it can build up their confidence knowing they have a teacher who they can rely on. This obviously has a very positive affect on a working relationship and the teenager themself.

**How Does APD Affect Working Relationships With Employers?**

Around the ages 15-16, a vast amount of teenagers decide to take up a part time job to earn a little extra money and/or to gain some experience for the future. The first issue for someone with APD is trying to find an employer that is willing to take in someone with special needs. It is unfortunate but true that many people go for jobs and their CV will be more than acceptable, but the minute they inform an employer of a disability in any form, they are no longer required.

The fear of losing a job because of a disability can be very pressurising and stressful and this can result in a poorer performance in the work place. Poor performance means there is more of a chance of being made redundant and the vicious circle repeats. This can either go one of two ways; the employer – employee relationship could be non existent as both may feel that any encounters would be awkward. It could also be that the employer appears friendly and the relationship would be strong as the employer wants his APD member of staff to feel comfortable and supported. There is also the risk of this relationship being built on patronisation and discriminatory.

There are certain jobs that will be more taxing than others due to memory issues and constant background noise such as waitressing, babysitting, telesales and customer services etc. [39] Defective memory and memory alterations play a huge part in making these jobs an almost impossible task [12] [38].

Again, the main physical element of APD concerns the Central Auditory Nervous System (CANS) and its inability to "label" sounds. A similar dysfunction initiating with the same cause is that the CANS also fails to recognise tone [25]. The result of this is that people with APD can feel like everyone is speaking to them harshly and will take everything literally [36] [12] [37]. Teenagers are known for their mood swings so when the above obstacle is also applied, emotions run riot and leaves them very agitated. Humour with colleagues cannot be carried out successfully as a person with APD cannot understand the sarcasm/intention [37] of the joke and are often referred to as gullible for thinking they were being serious.

This can cause a lot of problems in every day life but it is particularly distressing in a work environment where there is a hierarchy of authority. Here there is a high chance of being told what you are doing incorrectly and as tone cannot be sensed, teenagers in this situation will become upset and easily perturbed – possibly even aggressive [17]. Professional relationships with employers could be volatile and may result in dismissal if it reaches this extent.

**In Conclusion**

To answer my original question “How Does APD Affect Teenagers in Their Working Relationships?” I say dramatically.

There is no cure for Auditory Processing Disorder. People learn to adapt to life with the condition, in order to attempt to fit in, in different ways.

APD will affect the lives of every single person that is diagnosed with it as well as anyone relating to them and everybody they become involved with, from friends and family to their dentist. Some people believe that it doesn’t affect them one bit, some are even convinced that they don’t have a problem. I think this is because they have incorporated APD into their lives and various methods of dealing with it so this is all they have ever known; therefore, to themselves and their family, they are normal. It is only when you have a “bad day” where you are on the verge of a mental breakdown that you realise just how much it does impact your life in every little detail. As the mixed responses from the survey and supporting articles show, every factor of daily routine is controlled by aspects of the condition. Simple things that may seem insignificant to other people are of huge importance to APD sufferers. One example of a method for managing to get through the day is the use of Post-it Notes to remind you to do something, such as have breakfast - even a task that obvious can easily be lost when the CANS attempts to do too many things.

The majority of my research comes from my survey responses however I strongly believe that these people are the only ones who can really judge whether APD affects them or not. After all, they are the ones who have to cope with it on a daily basis.

I know exactly what these people go through to try and be normal, to try and fit in, to be discriminated against, have a bad day, how much extra work is needed to be even close to keeping up with everyone else and how much APD has changed their lives in positive and negative ways. I know this because I was diagnosed with APD in 2007 after my mum battled for a very long time to have my condition diagnosed once and for all.

So, “How Does APD Affect Teenagers In Their Working Relationships?”

An unbelievable amount!

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Lessons from Learning to Accept Yourself

ANONYMOUS

1. *The only person with the power to decide who you are is you.* Don't give away the decision or you lose your power over your life.
2. *Don't let APD or any other difference in ability have the privilege of defining who you are.* I made that mistake and retreated into living through what I wrote instead of living in reality. There's more to you than what you can and cannot do.
3. *We all have the power to transform the world around us with our actions or inactions.* In looking back, if I could tell a younger me anything I would advise myself to act to change my circumstances by talking to a trusted authority figure or speaking up for myself.
4. *Be present and feel.* People notice when you're not feeling when you should. Meanwhile, if you don't react for a long enough time, here's what happens:
   a. You will experience the reality that bad feelings cannot be suppressed without the good feelings being suppressed, too. This can reach the point that feelings just don't make sense anymore when they pop out unexpectedly and are often times inappropriate to the situation at hand:
   b. Your heart will get so full of emotions that it's hard to function in life because you hurt and feelings you share don't seem genuine or understandable anymore.
5. *Coping mechanisms for life become exposed as either healthy or not, but reality never really goes away.* You will face life eventually so plan ahead and prepare.
6. *Counseling can help you realize the power you have and give you tools for facing life.*
7. *Engage in self-care.* This means, do things you enjoy doing to enjoy doing it. Be kind to and supportive of yourself. In short, be patient with yourself and with your mistakes. You don't deserve mistreatment even from yourself.
8. *Be your own advocate.* After all, no one but you can be you.

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**COMING UP NEXT:** 'I Listen In Different Ways Than Others, But I Am Not Mad, Bad Or Dumb'.

**THEN:** Adults with APD Research – The benefits of early diagnosis.

*“Anyone can give up; it’s the easiest thing in the world to do. But to hold it together when everyone else would understand if you fell apart, that’s true strength.”*  
Christopher Reeves

*Do you have any tips for teenagers or adults with APD that you want to share – any strategies that may have helped you or a story or poem about your life? Or anything APD related that you would like us to post tips about? If so, please email Aly at apduknews@aol.com*
People with normal hearing, who have good auditory and verbal skills, generally assume that others reach an understanding of what is said the same way as they do – by relying mainly on auditory skills. However, people with listening difficulties often understand what has been said in quite different ways. Because they cannot rely on their auditory skills they develop other non-auditory strategies to supplement the information that they can hear. These skills are most effective when dealing with familiar people in known situations, where the listener can use an existing framework of knowledge, or build one ahead of time, to guide their understanding. So already knowing about what is being talked about or pre-learning about what will be talked about in the future are often important ways to better understand what is said.

Familiarity with people, processes and with situations helps those with listening problems, because they can better anticipate what will be said and thus compensate for their listening difficulties. Many of these ways of listening rely more on thinking about and integrating what is seen, or has been seen in the past, with what is being heard.

‘Thinking-listening’ requires more mental effort so people tire more quickly than others in intensive listening situations. They may listen for a time, tire, then ‘tune-out’ and stop trying to listen. Also, people who rely on ‘thinking-listening’ skills generally need a break after listening for a time. Much of the thinking that helps understating may actually happen after something has been heard - processing known information to integrate with what has just been heard. If people don’t get enough processing time after listening, they may get frustrated and/or understanding less. Also having some recovery time after intensive listening is important. Some quiet time to recover at the end of a day of heavy ‘thinking-listening demands’ is usually needed. Two people, one with good auditory skills and another who relies more on ‘thinking-listening’ skills, will leave a long listening session feeling very different. The person with good auditory skills may be relaxed and comfortable and keen to socialise. The person who has been working harder to understand what has been said may be exhausted and desperately in need of some quiet time without conversation. It is common that children with listening problems arrive home from school ready to have a tantrum from the pent up emotions and frustration of having worked so hard trying to listen at school. Similarly, an older person with listening problems may blow up at their partner when they try to keep talking to them on the way home from a social gathering, after they have become mentally exhausted from trying so hard to listen.

Continued on the next page…

WHAT’S YOUR STORY?
If you would like to share your experiences of living with APD please email your story to Aly apduknews@aol.com
Copyright will remain with you and it can be printed anonymously.

Dr Damien Howard is an Australian psychologist who has specialised in the psycho-social outcomes of listening problems (hearing loss and auditory processing problems). He is available for internet based consultations and can be contacted here: damien@phoenixconsulting.com.au

Adults with APD Research
The Adults with APD Research project with Dr Damien Howard, on which many ground-breaking articles for our newsletters have been based, will recommence in 2014 via online chats for adults. Details will be posted on our adult forums. Please take part! All in formation is used anonymously. Email for details. apduknews@aol.com
Having a familiar topic being talked about and/or a familiar person listened to helps make people’s thinking-listening skills most effective. When people have their own ‘framework of knowledge’ about what is talked about there is less need to think constantly. So there may be a preference to mostly engage with familiar people and avoid strangers - see the Adults with APD research article ‘The trouble with Strangers’, in APDUK newsletter 2.

Also it is easier to cope with listening when there are routines or when someone has control over what will happen. Being ‘bossy’ is one way to cope with listening problems. A teacher told a story about a student with listening problems who coped by being bossy.

Helen used to hassle him all the time about, "What's happening next? What are we doing next?" Finally he said to her, "Look, here's my timetable, just keep that under your desk and then you'll know what's happening." That was fine for about a week until one day he was running overtime in one lesson, and Helen came up and said, "Timetable says we should be doing maths now." He said, "Yeah, we'll get to that. Don't worry about it." She said, "No. Hey, you all, pack up, we're doing maths now." She then organised the rest of the group to pack up and go on to maths. Helen took control to maintain his plans. When the teacher didn’t follow routine, she acted to take control of the situation herself. She was seeking predictability. For people who have listening problems, predictability is often important. It reduces the need to listen in order to know what to do. If they know what is going to happen they are able to prepare themselves to cope. One way of creating predictability is to control social dynamics (be bossy) and so better manage listening demands.

When it is challenging to listen - for example, when it is noisy, or the topic is unfamiliar, or there are limited visual cues, then people with listening problems have to work harder. They may get more stressed or may respond by avoiding the situation or by being more bossy. These challenges are mostly invisible to those with good listening skills, so these kinds of responses by those with listening problems may be perplexing and irritating. Those displaying them are liable to be seen negatively as 'mad, bad or dumb'. Those with listening problems see these judgments, since being visually astute is a common compensatory strategy that is developed. When repeated over many years with different people those with listening problems may come to believe these judgments about themselves. After all, they so many people believing the same thing about them can't be a coincidence. While it isn't a coincidence, the judgments are not true. Understanding the processes that prompt these inaccurate judgments is important to avoid others beliefs becoming self-fulfilling.

This is important for both those with listening problems and those around them. Those with listening problems will mostly not realise how the challenges of listening have contributed to who they are. They are liable to think that they must be not be as smart as others because they struggle understanding what others grasp easily. They usually do not know they are working much harder than others in getting to understanding what has been said. Or, they may feel confused and ashamed when they don't understand what has been said as well as others do. They often don't understand why they experience the frustration and stress they do, or may try to avoid, tune out or boss others in certain situations. Understanding what is happening is often an important step for people to cope with situations better, feel less self-critical about themselves and to protect themselves from the potential toxic effects of other people’s judgments.

Understanding these processes is also important for those who live with, are friends of, or work with those with listening problems. Understanding what people with listening problems experience - and why they do certain things - helps establish more co-operative and positive relationships. It is especially important for parents to help children to deal with their feelings about others’ judgments and it is often necessary to act as an advocate with some teachers who may make destructive judgments about kids being 'mad, bad or dumb'
THE IMPORTANCE OF EARLY DIAGNOSIS OF APD
© Alyson Mountjoy, Chair APDUK (apduknews@aol.com)

The experiences that we have in our formative years play a large part in how we progress in our future lives. So too the support that we receive, or that is denied to us, will have an impact on our education and socio-psychological development as individuals. This is particularly true for those with disabilities, such as APD.

The poll below was posted on 4 online APD forums in order to get an idea of whether adults with APD felt that earlier diagnosis would have made a difference to their lives.

QUESTION: Do you think that earlier diagnosis of your APD would have helped you in your life?

The results are collated below.

<table>
<thead>
<tr>
<th>Index</th>
<th>Responses</th>
<th>Percentage of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Yes definitely</td>
<td>70%</td>
</tr>
<tr>
<td>B</td>
<td>Not sure</td>
<td>12%</td>
</tr>
<tr>
<td>C</td>
<td>Definitely not</td>
<td>2%</td>
</tr>
<tr>
<td>D</td>
<td>I don’t have a diagnosis</td>
<td>2%</td>
</tr>
<tr>
<td>E</td>
<td>I don’t want a diagnosis</td>
<td>2%</td>
</tr>
<tr>
<td>F</td>
<td>I was diagnosed early in life and had very little support</td>
<td>7%</td>
</tr>
<tr>
<td>G</td>
<td>I was diagnosed early in life and had a lot of support</td>
<td>5%</td>
</tr>
</tbody>
</table>

The general consensus then, of the people who responded, is that 70% of them, (over two thirds of the people who voted), felt that early diagnosis of their APD would definitely have helped them in their lives.

On a diagram it looks like this:

From research already undertaken over the years with adults with APD, by APDUK in association with Dr Damien Howard, this is the response that I would have expected to see. In real terms, this highlights the importance of early diagnosis of APD. If we hope to achieve better outcomes for children and adults, we need to provide early diagnosis, support, therapy (if appropriate) accommodations and validation - in addition to advice on developing their own unique coping strategies.
Alternative responses

In addition to the standard poll responses, adults with APD were invited to give alternative responses of their own if what was listed didn’t apply to them - some of these are listed with the participants’ permission. One response was:

‘Whether a diagnosis early in life would have helped or not I think would have depended on how it was handled emotionally by my family and friends, and how the diagnosis was acted upon.’

A very important point to consider. Having a diagnosis alone is great for validating that you are not making it up, that you do have a debilitating disability that affects you in school socially, at home and on into work and further education. It affects your ability to get work, it impacts on every aspect of your life. BUT if nothing is done to help a child with APD, if no support is put in place, then that diagnosis is virtually worthless to that child. One contributor stated:

‘I was diagnosed early and found that self-support was the only support I needed’.

Another adult said:

‘It may be different now, but I don’t think an early diagnosis of APD would have helped me at all because the available treatments at the time were useless to detrimental. (My sister was diagnosed, so I saw first-hand).’

It is true that years ago there was very little that could be done and after diagnosis, even with family support, there were few programs or therapies available. Even now they offer little help, if any, at least now the option is there to aid improvement for some people for whom therapy is suitable. Then, as now, having APD means living with it and getting around it, but as a child, if you have acknowledgement of your APD, family support, someone to help you develop coping strategies - maybe a family member who has been through it and who can tell you how they cope, and that it isn’t your fault - all that is invaluable.

Family support or denial?

‘It (APD) is strongly dominant on my dad's side and the way that side of my family raises kids and communicates was way more effective as 'treatment' and also life skills (i.e. talking to kids in appropriate adult language, checking for comprehension, taking kid's attempts at communication seriously even when they are pre-verbal all of which models a communication method that leaves us able to communicate well with those with weak language skills and the hard of hearing.) There has been one kid per generation who doesn't really talk until age 3 or 4 and the general response is 'Oh, s/he is just like so & so' (shrug & keep treating them like a normal kid) until said kid is 4 in which case the statement turns to a hope that they will be talking in time to start kindergarten.’

‘It may be different now, but I don’t think an early diagnosis of APD would have helped me at all because the available treatments at the time were useless to detrimental. (My sister was diagnosed, so I saw first-hand).’

‘It (APD) is strongly dominant on my dad's side and the way that side of my family raises kids and communicates was way more effective as 'treatment' and also life skills (i.e. talking to kids in appropriate adult language, checking for comprehension, taking kid's attempts at communication seriously even when they are pre-verbal all of which models a communication method that leaves us able to communicate well with those with weak language skills and the hard of hearing.) There has been one kid per generation who doesn't really talk until age 3 or 4 and the general response is 'Oh, s/he is just like so & so' (shrug & keep treating them like a normal kid) until said kid is 4 in which case the statement turns to a hope that they will be talking in time to start kindergarten.’

Most families accept their children with APD and try their best to help them, advocate for them and push to help them get the support they need. They do whatever they can. But there are situations - too many cases, even today - when family and friends refuse to accept the diagnosis, even going so far as to pretend there is nothing wrong. There are several reasons for this. It might be because they don’t wish to accept that there is a child in their family that is less than perfect in their eyes, or they might suspect there is a genetic cause and they don’t want to be held responsible, blamed or stigmatised – or maybe they don’t want their child to be stigmatised or ‘labelled’. To some people, what other people think is everything, even more important than helping their child. Other parents may not want to have to go to the trouble of getting help organised in school and some parents just don’t care. Others may even have gone along with the school’s suggestion that there was something that their child needed help with, but don’t see it as their responsibility to push for support for their child. Some parents don’t even tell their child that they have APD, so they go for years not knowing why they struggle, feel stupid, and can’t understand what is going on around them. But they do know they are different. Acknowledgement and people’s acceptance of APD, ongoing family support and understanding are therefore as important as the diagnosis – in fact, even more so.
**Disability or behaviour problem?**

Even worse, there are also those few parents who just focus on their child’s behaviour and refuse to acknowledge or make any allowances for the enormous frustration, stress and anxiety that a child with APD has to put up with daily. All children need rules and boundaries - that is not in question. But the child with APD needs more patience and understanding in order to make sense of rules. They can be punished for venting their frustrations when they come home from school, where they think they are safe and because they can no longer hold it in. They need peace and quiet and they need ‘down time’ after a busy, stressful day. They need to relax and play before attempting homework – which should always be appropriate, manageable and differentiated to match their capabilities (and those stipulations can and should be put into their IEP). They might be punished for not conforming to rules that they don’t even understand; having different rules at home and at school and at someone else’s home - this upsets their need for consistency. Pushing them to act and appear ‘normal’ at noisy family gatherings, when processing is harder and the child would rather be at home in a quiet place away from the hustle and bustle that isolates them can be an unrealistic expectation to make of that child. It isn’t just a case of being difficult or anti-social; the brain needs to rest when it is saturated and those with APD can suffer from sensory overload and, like an overloaded computer, they need to ‘reboot’ for the next day’s efforts. Even as teenagers and beyond, they are expected to observe social niceties that they are unable to reconcile with their search for peace and solitude when they cannot make sense of people talking all around them.

Ignoring APD won’t make it go away; it will only make their child’s life even more intolerable and even make their child’s behaviour worse - a self-fulfilling prophecy where the parent assumes they were right all along. But at what cost to their child?

**Noticing APD as an adult**

There are those adults who don’t realise that there is a reason for the difficulties that they have suffered all their lives. Maybe APD was not known about when they were young, or effects were mild and they masked their difficulties so well with natural coping strategies that they didn’t notice anything was wrong, till later in life. When vision and hearing start to diminish in some slight way, as they do as we get older, that is the time that people often notice difficulties. Their natural coping strategies fail to work as well and what was maybe only a minor hindrance throughout their life now becomes a bigger problem. For those that are aware that they have APD, at this time their APD appears to be worse – it may be because of coping strategies failing to cope as well, or it could be something else – the start of some deterioration in brain capacity due to dementia, or some other illness. It can be a worrying time – but in all cases it should always be checked out by hearing tests, vision tests and specialist consultation if those avenues fail to give answers. Things may also appear worse at times or tiredness, illness or stress. If an adult chooses to, they can also then seek APD testing. Also for adults without suspicion of their having APD, when their own child is diagnosed they might realise that there might be a genetic component at work in their family, which is often the case, and they can see themselves in that child. The penny drops and suddenly the adult realises that they too might have APD. They can then also seek testing, should they choose to pursue it.

‘Estimates from around the world suggest between 5 and 10 per cent of children have APD to some degree.’
- APD web page of Great Ormond Street Hospital, London.
http://www.gosh.nhs.uk/medical-conditions/search-for-medical-conditions/auditory-processing-disorder/auditory-processing-disorder-information/
To test or not to test?

Many adults in these situations choose not to seek testing – after all they have managed all their lives without a diagnosis. They may not want it to be known, it may be from fear that that their family and friends will not understand or be sympathetic, so they decide to just dismiss it as part of the natural ageing process. But there is always the thought that maybe they could have succeeded more in life had they known. There is the prospect of validation if they always thought that there was ‘something’ there. It is not their fault and a diagnosis can prove that. Usually APD doesn’t exist in isolation- they probably have other difficulties that they might now wish to investigate, ones that they might know about that were masking the APD or they might have been misdiagnosed before APD was known about. Either way, it isn’t too late. With a diagnosis of APD (and anything else going on) and appropriate reasonable accommodations, adult education might now be an option, or pursuing a change of career etc. It is a very personal decision with many individual reasons for and against. But at least today, the testing option is available to them. As one group member posted:

‘I was diagnosed with APD when I was 50. What a difference it might have made to my life if it had even been a recognised handicap when I was in school. What a difference it might have made had it been diagnosed, whilst I was in work, when I first got up the courage to try to make a noise about the problem and the recognition had already reached these shores. Instead of that I have gone through life with the stigma of being ‘strange’ and a reputation for ‘always getting it wrong’ and learnt it better that I totally avoid social contact!’

The past meets the future

When those that are adults now were children themselves, APD was less known – we still struggle to have it recognised today. Imagine how much worse it must have been for those people who were more than mildly affected and who suffered badly from the effects of APD. Even now, if the school or education authority will not accept a diagnosis or provide support and accommodations, from lack of funding or disinterest or whatever reason, the child is no better off than they were before – knowing that they need help and why they need help, yet still nothing is being done; but to me not probably knowing what is wrong is even worse for a child’s self-esteem. But the result is the same. The child is still lost, isolated, rejected, struggling and more often than not blames himself/herself. They take it all on board and the pressure can be crippling for a child or teenager – unbearable. That is too much to put onto any child. They NEED support, recognition, accommodations and help to understand APD and develop their own coping strategies.

There are adults all over the world that have done it alone; adults that have developed coping mechanisms and have succeeded despite all odds. There are also those for whose their life was avoidably ruined by ignorance and disaffection, by the absence of the basic human right to be listened to, receive help for their disability and to gain access to an appropriate education. These adults have difficulty in getting qualifications, in finding suitable careers, in gaining and maintaining employment and relationships. There are those that are socially isolated, have low self-esteem and poor self-confidence. Many may suffer with mental health issues such as anxiety and depression. Most, if not all of them, will have other co-existing conditions to deal with, in addition to their APD. They need continual, tailored support, as do children, with provision of early, accurate, full diagnosis and help for all their difficulties. We must provide it, for our child and future generations, to make sure that no more children with APD are left to fend for them. Who knows what they might achieve with the right support!
SEEING THE ELEPHANT’
VARIOUS PROFESSIONAL APPROACHES TO DIAGNOSIS

Alyson Mountjoy, Chair APDUK

Who to go to first...

When seeking any diagnosis, it is always recommended to seek the appropriate professional for the task, which in APD is an audiologist. This is because each professional will only see the condition from their own perspective, as they are trained to do and if you speak to the wrong professional first, you may get an inaccurate diagnosis, a misdiagnosis, simply because they will focus on what they know; the symptoms that will match the conditions they are familiar with. They can only diagnose what they know and will do that. For example, the apparent inattentiveness of a child with APD will appear to an Educational Psychologist as ADD, if the child is also very active, maybe a sensory seeker, they may diagnose ADHD – the important aspect of inefficient auditory processing will be missed (and maybe also that the child might have Sensory Processing Disorder). Similarly if your child has communication difficulties which are very bad due to extremely poor auditory processing, you may get a diagnosis of Autism. Just like in the worldwide tale of the blind men and the elephant – one version is below:

Six blind men were asked to decide what an elephant looked like by feeling different parts of the elephant’s body. The blind man who felt its leg said the elephant looked like a pillar; the one who felt the tail said the elephant looked like a rope; the one who felt the trunk said the elephant looked like a tree branch; the one who felt the ear said the elephant looked like a hand fan; the one who felt the belly said the elephant looked like a wall; and the one who felt the tusk said the elephant looked like a solid pipe. A king explains to them: All of you are right. But every one of you is telling it differently because each of you touched a different part of the elephant. But the elephant has ALL the features!

Where to go next...

Each man said what they believed be true, but they were still wrong. Therefore there needs to be wider recognition of APD and knowledge of who to refer to. Similarly, like each part of the elephant, APD does not exist alone and all that remains after APD has been diagnosed by an audiologist needs to be identified, ideally by a multi-disciplinary team of specialists, or by one at a time if that is all that is available. Only then will you get the full picture, truly ‘see the elephant’ as a whole and get a full and accurate set of diagnoses for your child!

‘The day the child realizes that all adults are imperfect, he becomes an adolescent; the day he forgives them, he becomes an adult; the day he forgives himself, he becomes wise.’
Alden Nowlan

NEXT: ‘APD-related Tips for GP and Hospital Visits’
THEN: ‘Tips for Reducing Stress at Social Gatherings’
APD TIPS FOR PARENTS AND ADULTS

APD-related tips for visits to your GP or hospital appointment

© Alyson Mountjoy, Chair APDUK

A visit to your GP, Accident and Emergency department or hospital appointment can be a stressful and worrying experience without the added stresses of coping with APD. These tips can help take some of the stress out of your visit. They can also be used if you are accompanying a child.

1. When booking an appointment at your doctor’s surgery, request a longer appointment than normal each time, to allow time for delayed processing/communication issues.
2. Tell the receptionist that with APD they may need to come and get you if you don’t respond when they call your name (due to background noise/blocking out sound).
3. Make notes beforehand of anything you need to tell the doctor/consultant – symptoms, any deterioration/improvements, worries about your illness/condition, side effects from medication etc. This avoids worrying when you get there about word recall problems/forgetting something. Keep it in your hand to remember to give it to the doctor/consultant when you get into the consulting room.
4. Ask that APD and any communication difficulties be noted in your file /your child’s so all medical staff will be made aware of this – on your first visit you can take notes with you. This can include things like speaking while facing you to allow for lip-reading, making eye contact, speaking clearly, giving you time to process speech and to formulate responses etc. allowing for word recall difficulties, also whether you would prefer follow-up contact by email/letter and not by phone – whatever would help you best.
5. In the consulting room, ask the doctor/consultant to write down anything important that they need you to remember, or if you feel is appropriate, you can ask to take a family member/friend without APD to go in with you when you are talking to your doctor/consultant, so that they can make notes. This also helps if the doctor/consultant has an unfamiliar accent or speak very fast etc.
6. Ask for any leaflets/hand-outs/websites about your illness/condition so that you can read up on it later.
7. If your doctor/consultant will not comply with these requests, perhaps it would be better to register with a more disability-friendly doctor or request to see another consultant!

5 TOP TIPS FOR STRESS FREE FAMILY GATHERINGS © Alyson Mountjoy, Chair APDUK

1. Unless it is a party at which people are dancing, ask your host/hostess to turn down music so that you can process the conversation;
2. At a dinner party or meal, make sure you are seated next to someone who know and whose voice patterns are familiar to you and ask for music to be turned down/off;
3. Take frequent breaks from all the noise (trips to the solitude of the bathroom/garden/kitchen/outside the venue;
4. At a family/ friend’s meal, offer to help in the kitchen to get you out of the main party area for a while;
5. Don’t be embarrassed if you have to leave early because of the noise - your host/hostess will probably be glad you took the time to attend!

NEXT: Teenagers with APD information sheet.
THEN: Tips for Employers on How to carry out an APD friendly interview.

“Don’t wait until everything is just right. It will never be perfect. There will always be challenges, obstacles and less than perfect conditions. So what. Get started now. With each step you take, you will grow stronger and stronger, more and more skilled, more and more self-confident and more and more successful. “Mark Victor Hansen
Auditory Processing Disorder (APD) is a neurological listening disability. APD is a lifelong disability and requires lifelong support from family, peers, friends, and interim support from teachers and employers, etc. APD can include multiple issues, all of which can have varying degrees of severity, and no two individuals who have APD are the same. There is no cure for APD. Living with APD can be difficult at any age, and especially during the teenage years when children become more self-aware and hormones can pose additional problems.

Auditory Processing Disorder is a disability causing problems processing all sounds that the ears hear. Issues can include problems processing the gaps between sounds, having processing problems with low levels of background noise, poor auditory memory, poor sequencing skills and abilities, working memory issues especially stress related, word recall problems, problems following conversations, following multiple verbal instructions, problems repeating unfamiliar words / names, problems with reading aloud.

Living with APD can be very isolating especially for children who have APD, they need to know that they are not only one who has APD, understand it, learn coping strategies and learn to self-advocate. According to the Medical Research Council 10% of the child population has some degree of APD. Each individual who has APD needs to understand the limitations APD imposes on them and develop the alternative compensating skills and abilities they are able to develop and use to work around their problems; and the specific compensating skills and abilities individuals develop will depend on their neurological and genetic strengths and weaknesses.

Understanding the alternative compensating abilities and skills each individual who has APD is able to use is probably the most important part of living with APD. As both the individual who has APD and all those who live and work around them need to understand and be prepared to use the preferred alternative types of communication and information presentation, to enable effective integration and cooperation. Providing the wrong type of support can be as detrimental as having no support at all. This creates the perception that the specific APD related problems are not being understood, and that all of the offers of support and remediation are a waste of time and effort, because the support offered and provided does not match the individual’s actual support needs.

Most people who have APD develop good lip reading skills, sometimes unknowingly, and learn to read the body language of others to help fill in the auditory communication gaps caused by the bit we miss or fail to process. It also has to be remembered that although there might be commonalities between people with APD, each sufferer is affected differently and with varying severity, has unique strengths and coping strategies and might also have additional co-morbid difficulties that impact negatively on them, making their APD difficulties harder to manage.

APD can also affect acquisition of speech in some people, for the same reason. ALL of these difficulties are worse when a sufferer is ill, tired or stressed, while the brain is focused on remedying these situations and their natural coping strategies can fail at these times making all symptoms of APD present as worsened.

APD can also be inconsistent and variable in its effects from day to day and even within a day. Stress, tiredness or illness can also make it far harder for them to process and their difficulties will be much harder to cope with at those times. Frustration is common, but this is not a behaviour problem, rather it should be seen as a cry for help.

APD is a complex and far-reaching disability which affects all aspects of a person’s life, not only in education, but also communication and socialisation - from school to workplace problems, with difficulties in communicating with family and friends, choice of suitable careers, enjoyment of hobbies and leisure time – in fact, everywhere and with everyone. Each person with APD will therefore need individually tailored support and accommodations, throughout their life.

If adequate and appropriate support is not already in place by the time the suffer reaches their teenage years, which are a particularly difficult time for them, problems like disaffection, depression, substance abuse can arise, in an attempt by the sufferer to regain control of their life. This can be avoided if vital, individually tailored support is in place. We must ensure that we ‘get it right’ - first time, every time. Additional Information can be found here:

**APDUK website:** [http://www.apduk.org.uk/](http://www.apduk.org.uk/)

**APDUK IEP ideas:** [http://www.tempinformationsheets.apduk.org.uk/iep_page.htm](http://www.tempinformationsheets.apduk.org.uk/iep_page.htm)

**APDUK newsletter:** [http://www.tempapd.apduk.org.uk/newsletter.htm](http://www.tempapd.apduk.org.uk/newsletter.htm) including articles written by parents, Adults and teenagers with APD and supportive professionals.


**Medical Research Council:** [http://www.ihr.mrc.ac.uk/research/apd](http://www.ihr.mrc.ac.uk/research/apd)
When interviewing an applicant with APD (or any communication difficulties) please follow these guidelines in order to give them equal access to the interviewing process.

1. On arrival, give the applicant a list of the questions you will be asking, with spaces provided for their notes and a pen.
2. Also provide space for them to list any questions they might have and any reasonable accommodations they might need in order to fulfil the duties of the post applied for.
3. Allow them a short period to process the questions and make their notes for each one. Some applicants will need more time than others and this should be allowed.
4. Allow the applicant time to also rehearse their replies.
5. If the applicant has difficulties with reading/writing the questions could be recorded and provided to them in that format also.
6. In the interview, always face the applicant and seat them not too great a distance from you so that they can read your lips and body language, if they need to.
7. If more than one person is interviewing, make it clear before you start if you are going to be taking turns in asking questions and then allow time for the applicant to become accustomed to the change in speaker.
8. Each interviewer should chat to the applicant for a short while, to allow them to get used to their speech pattern/accents. If possible, they should be interviewed by someone without a strong regional accent, unless it is the same as their own - this is because unfamiliar voices and accents can cause great problems in processing/comprehension for people with APD and puts them at a disadvantage from the start.
9. Make sure that all interviewees speak clearly, pausing between long phrases to allow for delayed processing. Questions might need to be repeated or rephrased, to meet the preference of each applicant if they have not processed it clearly.
10. Allow plenty of time for the applicant to reply, allowing for delayed processing and word retrieval issues. Remind them that they can read from the notes that they made earlier.
11. Offer to inform the applicant about the outcome of the interview by the method of their choice. In writing is usually preferred - by email, or by letter – because a lot of people with APD have problems using the telephone (because of processing speech when there is degraded sound quality). Some applicants without this problem might still prefer a phone call, so all methods should be offered, but I would recommend also sending a letter as reinforcement, in case an applicant has not fully processed all that was said (in case they might not have grasped the details).

NOTE - With reasonable and appropriate accommodations, a person with APD is as capable of fulfilling their duties as any other employee with the same experience and qualifications, so please do not hold their APD against them when appointing a successful candidate – to do so is disability discrimination according the Disability Discrimination Act 2010.

APDUK © ALERT CARDS – SHEET 1 - You can print these cards on vertical business cards – these are the fronts of the cards. Print these first.

APD ALERT CARD
I have Auditory Processing Disorder (APD). My hearing is fine, but sometimes I can’t understand everything I hear. It isn’t my fault.

Auditory Processing Disorder in the United Kingdom ©(APDUK)
APDUK © ALERT CARDS – SHEET 2 – Turn over the cards you have printed, SHEET 1, and print these on the back. They can then be laminated.

**APD - HOW TO HELP**
Get my attention before you talk and face me when you speak.
Talk to me somewhere quiet.
Speak clearly.
Please repeat things if I don’t understand, or say them in another way.
Please give me time to answer; be patient.
Please don’t interrupt me when I speak or I might forget what I want to say.
Write all instructions down.

THANK YOU!
Have you heard about

Auditory Processing Disorder/APD?

*Do you have problems understanding what you hear, even if you have been told that your hearing is good?  
*Do background noise and/or crowds make this worse?  
*Do people think you don’t listen to them?  
*Do you have problems following spoken instructions?  
*Do you have reading/spelling problems?

If so, you might have Auditory Processing Disorder/APD.  
(These difficulties might not all be present).

WHAT IS APD?

Auditory Processing Disorder (APD) is not a problem with hearing, but with the way sound is processed by the brain. This can be diagnosed by trained specialists but will not show up on normal hearing tests. Those with APD can appear unable to hear but may have perfect hearing, although it can also co-exist with hearing loss. APD can exist alone or with any other learning difficulties or disabilities. It is a major cause of dyslexia. APD is for life but coping strategies can help, as can support at school, at home and at work.

CONTACT

Auditory Processing Disorder in the United Kingdom/APDUK

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Chair: Alyson Mountjoy apduknews@aol.com

Helpline: 07815 995491

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