

Podcast 6. Siobhan Brennan & Ketan Parmar “Autism and Learning Disabilities: Access to Healthcare Services

Hello and welcome once again to a ManCAD / British Academy of Audiology podcast. You might well know that ManCAD stands for Manchester Centre for Audiology and Deafness and that we are located at the University of Manchester in the UK.

I am Gabrielle (Gaby) Saunders. I'm a Senior Research Fellow at ManCAD and I moderate these podcasts.

We always try to address the topics pertinent to the practise of audiology but also want to make sure that they are relevant to researches and anyone interested in hearing and hearing loss. Some of them are specific COVID related issues and others are more general considerations in audiology.

We will record a new podcast each month each one will be about 20-30 minutes long and we will post the audio recording along with a transcript on our University of Manchester webpages.

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<http://research.bmh.manchester.ac.uk/ManCAD/Podcast/>

Today we have our first double bill; I am going to be chatting to Siobhan Brennan and Ketan Parmar.

Siobhan is a Clinician and Lecturer in Audiology at the University of Manchester who specialises in care for adults with hearing difficulties; Ketan is an optometrist who is studying for a PhD at Manchester.

Before they introduce themselves, today we will be discussing Autism and Learning Disabilities: Access to Healthcare Services.

Siobhan: I am split between the University of Manchester and clinical work. One of my specialisms for a long time now has been the audiological care for individuals with learning disabilities and I lead the Cognition and Hearing Service at Sheffield teaching hospitals.

Ketan: By profession a fully qualified optician since 2018 but am currently studying for a PhD at University of Manchester, which is investigating the links between autism and vision. Part of this project is also looking at how eye care examinations and eye care services could be made more accessible for autistic patients.

Gaby: That's going to be really interesting to give a different view on things as we usually only talk to audiologists.

We are going to discuss Autism and Learning Disabilities & Access to Healthcare Services but there's a lot to unpack here and a lot that comes to mind. First let's begin by talking about Autism verses Learning Disabilities. You specifically distinguish between them in the title. Are you saying that because up want to imply the considerations of the two are different, are they the same or what?

Siobhan: Frequently in clinic whenever I enquire about the cause of a person's learning disabilities I am told by carers "this person has autism" and it's presented as if that's a cause. Certainly, while there is a high coincidence of autism in individuals with learning difficulties, one is not a cause of the other; they are two separate issues. I think it's very important for us to bear that in mind. When I am talking about learning disabilities, I am talking specifically of an intellectual impairment in terms of the ability to understand new concepts, which has been present since childhood and the intellectual impairment is sufficient to affect that person's life. It does not include specific educational difficulties like dyslexia.

Gaby: Ketan if you would tell us a bit about autism but also whether or not everyone with autism has learning disabilities or if it's just a subset.

Ketan: I will start off with your first question. What is autism? Autism is a lifelong neuro developmental problem with its main impacts on sociability, communication and behaviour. A few examples in these areas, a socially and autistic person might have difficulty initiating a conversation or continuing it, understanding simple questions and instructions and expressing their emotions as well as understanding others emotions.

Communication wise an autistic person may lack eye contact, facial expressions during a conversation or may deliver speech unusually like very structured or song-like and may have difficulty interpreting nonverbal cues like eye signals. Behaviourally they may also repeat certain actions or movements, may have coordination issues, altered ability to copy actions through imitation, altered sensory reactivity. This altered sensory reactivity refers to either increased (hyper) or decreased (hypo) sensitivity to sensory input or sensory seeking behaviours.

Going to the second part. Autism in itself is not a learning disability, which is a very big misconception, unless it's specified on the person's diagnostic documents. An autistic person does not have an intellectual impairment. Behind that a third of all autistic individuals have a coexisting learning disability. Again, emphasising the point that autism is not a learning disability.

At this point, I will throw in two more figures: 1% of adults and just over 1.5% of children are autistic in the UK. 4-5 times as many men are diagnosed as autistic than females. It's long considered that many females are under diagnosed.

Gaby: What are the barriers to health care access for people with autism and learning disabilities then?

Ketan: Just some general thoughts about barriers to accessing health care for autistic people. Autistic individuals are generally more likely to develop more health issues and have poorer physical and mental health. Various reports and studies have highlighted that there are significant barriers to accessing health care services for autistic people. These are different to the barriers you would expect for non-autistic people. There are few services in the UK which are adapted to be autism friendly, so that's thinking about the clinic setting, the flow of the appointments, awareness about autism of the service providers which is at present poor. Autistic individuals can have some of their health concerns unfortunately just dismissed as being a result of autism. The altered sensory reactivity, which I mentioned earlier, can result in various sensory experiences. These can have significant impacts on the ability of an autistic person to physically access a healthcare setting. That's thinking about the layout of the clinic, how it's decorated, the sounds there, the noise levels, the smells, the temperature etc.

Siobhan: Further to that I would add that in terms of some of the barriers to individuals with learning disabilities there is lots of evidence that there is quite low rates of self-report of difficulties within that population and low identification of hearing issues particularly by carers. So overshadowing frequently occurs. This is where a carer or health care worker or a referrer indeed will attribute an individual's lack of communication or lack of responses to sounds to their learning disabilities as opposed to considering there may be a hearing loss.

Gaby: So it's differentiating between their hearing loss and their other conditions as well. That makes it pretty hard. There are clearly major barriers to these populations.

Since I think most people who listen to these podcasts are likely to be people with an interest in hearing, I would like to know more about how hearing loss fits into this from the perspective of how many people there are with learning disabilities and hearing loss, and autism and hearing loss. Is it more than in the general population? But also from a diagnostic service provision perspective.

In terms of prevalence of hearing loss among people with learning disabilities and autism. Is that different from the general population?

Siobhan: It certainly is. Certainly, in individuals with intellectual disability the prevalence, like anything, varies across studies. The estimate most commonly used is that between 30-40% of individuals with learning disabilities are thought to have a hearing loss but that could be an underestimation as a lot of these prevalence figures come from the Special Olympics. The athletes in the Special Olympics generally tend to be very healthy, also tend to have milder learning disabilities on the whole than the wider population and so the prevalence of hearing loss may be greater again.

In individuals with autism, in terms of the prevalence of hearing loss, that is thought to be closer to that of the wider population but that varies across studies and with age as well. One of the risks sometimes is that for autistic individuals a factor that frequently drives the referral is perhaps a hypersensitivity to sound that is causing concern. Something that needs to be borne in mind is that that does not rule out the possibility of a coincident hearing loss as well and so a test of thresholds should be included as a minimum in the assessment.

Also, I think in terms of the diagnostic and service provision there needs to be an awful lot more flexibility whenever it comes to possible assessment of individuals with learning disabilities. For example, in a specialist service, generally speaking, about 75% of individuals with learning disabilities in a specialist service can have hearing assessed using behavioural methods of some type. So that means about ¼ may need some form of electrophysiology but only a very small number may need hearing assessment under general anaesthetic. Locally, for instance, we have found this to be less than 3% of those we would see would we need to consider under general anaesthetic and I think that returns to some of the barriers. I think that there is a general misconception that hearing assessment is not feasible within this population when that's simply not true.

Gaby: You sort of touched on this just now. The complications of differentiating hearing loss from sensory issues and maybe it pops over into vision loss as well, I don't know. Do you want to expand a bit on that? It sounds complex.

Siobhan: There are many referrals in because of concern with someone's relationship with sound. We work closely with our hearing therapist to talk about sensory sensitivities but in terms of the impact that could potentially have on the hearing assessment, that's certainly a factor and there can be some anxiety for autistic people when they come to have a hearing assessment that they may be exposed to loud sounds within the clinic. I think there has to be some reassurances put in place.

Gaby: Ketan, as an optometrist, can you tell us about the issues you encounter with the vision side of things and how they likely overlap with hearing testing and evaluation.

Ketan: Adding to what Siobhan said before I come to that, as well as the hypersensitivity, we have also to keep in mind autistic individuals who maybe be hyposensitive. We may find that some of our autistic patients don't respond to tests in a way that we expect. They may not exhibit symptoms to certain findings in a way we would expect, might not react to pain in the same way. If we are looking at one side of sensitivity, being too sensitive, we have to also consider the other side.

Going back to your question about vision testing. A lot of the generic considerations can be applied across all schools of healthcare. So ensuring the patient is expecting what you are going to do, thinking about how close you are to the patient, making sure that the patient is keeping up with what you are saying, just being alert to the fact that the patient isn't becoming stressed or overwhelmed by what you are doing or what you are saying. All professionals can apply these basic principles, which are largely part of basic patient care, across all schools. For individuals with autism and I guess with learning disabilities too, if these basic points are not covered it can be quite detrimental to the ability of that person and the willingness of that person to want to continue to access those services.

Gaby: So do you have any general advice on how that can be managed?

Ketan: There is lots of advice available but, like I said, the basic points are generic can be applied across all schools and whenever I mention now all the considerations, if there are any listeners who want to look

further they will find more specific things and maybe to their clinics and their clinical settings. The main aim of a lot of the considerations is to reduce the negative emotional responses associated with the consultation and visiting the clinic, so that might be worry, stress, anxiety, fear, but also to reduce the sensory experiences, which could impact the flow of the consultation too.

I will cover some points briefly.

First area is communication: Communication is important for all of our patients so they know why they are seeing us, what we're doing and what the outcomes are. For an autistic person there are more specific considerations. Now we should provide an electronic means of communication for our patients. Now most of our services are accessible via telephone and telephone only usually, but for autistic people it can be anxiety inducing having to communicate with a stranger in person but especially over a phone and many autistic people avoid using the phone and this can actually lead to a limitation to accessing healthcare services. So if an autistic person is able to contact the clinic by email or text or via an online portal that will actually facilitate use of those services. Similarly, professionals should use as many visual aids as possible during the consultation. Again, just to make sure that the patient is fully understanding what you are telling them and prepared for what's to come so again there is not that sudden spike in anxiety. We should use specific questioning because some autistic people can take our questioning quite literally. If we are not clear with what the test involves and what we are expecting from the patient that again can lead to the patient feeling confused and again making them feel anxious or worried that they might respond in a way or may not understand the test properly which could jeopardise the outcome of the examination. Again we should make our communication extremely clear when giving information to the patient but make sure you are not giving long reams because you need to ensure your patient is keeping up with what you are saying and processing what you are saying. It's also vitally important to try and give some written advice to our autistic patients so they can go away and in their own time and own space, process the outcomes. If it's not possible to write down the outcomes during the examination, why not just offer to send a report either in the post or electronically.

Now, looking at the appointment as a whole, we should maybe offer if possible appointments at quieter times of the day to autistic patients. That might be the case also for patients with learning disabilities considering the sensory issues. If you are inviting the patient to the clinic at a busy time of day where there is going to be lots of people, lots of movement, lots of sounds; that can result in lots of sensory issues, anxiety and that can have an impact on the consultation before it's even began. Perhaps offer longer appointments slots; just keeping in mind that you might need to be aware of the patient becoming overwhelmed or stressed during the appointment, they may need some breaks, they may need more explanation, may need more time to complete the tests because of just understanding what needs doing.

Very basic point is just to make the patient feel comfortable. That's part of all our basic training. Just to introduce yourself, explain what you are doing to do, let them settle into the consultation environment, have some general chit chat too and last thing I will mention is to try to see the patient as best as possible on time. For autistic people they can be quite precise and accurate and can turn up at the clinic way in advance of their appointment so they are ready for you to see them on time. Now as a healthcare professional, I am sure Siobhan will agree with this, most of the time, we don't see our patients at the given time, we either see them earlier or later. But it's just important that we let our patients know about that; either when they book in at the desk or when they are in the waiting area. Don't just give throw away comments "I will be as quick as possible" or "I'll be 2 minutes"; because it will be the autistic patient who's on the edge of their seat counting those 2 minutes. If you don't see them within that time, again for them, it can set off a load of anxieties and worries; have I been missed; have I been forgotten about, will I not have my concerns looked into today etc. etc. Those are some of the possible considerations that can be kept in mind by our professionals.

Gaby: Those all make sense; they are almost common sense if you think about it. If you are going to bear all these in mind, you would need to know upfront that someone was autistic. Does that tend to follow their clinic notes wherever they go?

Ketan: It's interesting that you mention that because it's paramount for our services and clinics to ask our patients in advance if they have any accessibility needs. That's a perfect point where our patients can come forward and tell us: I'm autistic; or this patient has a learning disability; I am sensitive to lights; I am sensitive to sounds; I am hyper/hypo sensitive to x,y and z so it allows the practitioner and clinics to prepare for this in advance to think about those adaptations so they are not put on the spot. It has a two way advantage actually as it also and shows the patient that as a clinic and service we are willing to adapt to make them feel more comfortable.

Siobhan: I would add to that slightly to raise the question of the soundproof room. These are spaces that not the whole population is familiar with. How someone is going to react to a soundproof space is really interesting because it varies so much from person to person. It's worth making that person aware of the fact that they are going to be in a sound treated space and for them to be thinking through how they might experience that.

Ketan: If I can add back to what Siobhan has just said. There are some things that we just have to do. Some tests that are conducted in a particular way and you cannot flex from that apart from giving lots of information in advance and making the patient feel comfortable etc. I know for autistic patients, if we could send them information in advance, and I am sure it applies to patients with learning disability too, if we could send a document with pictures of the room, of the tests, some explanation, may be even some videos. They could go through that and watch in advance and they will be a bit more prepared about what's to happen. It reduces the capacity required to deal with that. For the clinic staff if they were to have some form of basic autism training, like access to their local trusts, that would also give them some awareness of the factors that would affect an autistic person but also in relation to that clinic and service, so they can think about adaptations and changes. Some good news is that soon it's going to be mandatory for clinic staff to have autism training, so that's in the pipeline.

Gaby: I was going to ask what the NHS perspective is on this. Are there guidelines and do they have priorities for these populations?

Siobhan: Absolutely. This is very much a priority for the NHS. Both autism and learning disabilities are highlighted in the NHS long term plan published in 2019 and there is also a number of recent publications which support a focus for these populations. Public Health England published a key document entitled "Improving the Health and Wellbeing of People with Learning Disabilities" in 2015. There is also the National Learning Disabilities Mortality Review Programme, which publishes a report every year and aims to make improvements for people with learning disabilities and yes, in terms of that mandatory training, for Health & Social Care and Dept. of Health is going to be introducing that. It's training for health and social care in working with both autistic people and individuals with learning disabilities.

Gaby: That's really good to hear. I'm going to ask one more question. I think generally when people think of learning disability and autism, the paediatric population jumps to mind and obviously these things don't go away when you reach adulthood so what are special considerations or issues you think adults with learning disabilities encounter that we might be forgetting about because of this mind-set that it's a paediatric issue.

Siobhan: I think one of the factors that I would say is that there does seem to be a greater deal of funding and resource and support around children's services; and the fact that the care scenario that somebody may be in is likely to change over time. As opposed to living with family, somebody may live in residential care, being cared for by professionals and that care can be very different. Certainly one of the things that we have observed and has been reported, is that fact that the cause of intellectual disabilities is not known for a significant percentage of those seen by a service. Therefore, how you should adapt your care will be limited a little in as much as the cause of somebody's intellectual disability is not known for some. Whereas with children a much greater percentage it may be known because there is more investigation that goes on at that point, so the numbers whenever we get to adulthood who are not know will hopefully decrease over time.

Ketan: I completely agree with everything Siobhan has covered. There is a lot more attention to autism and learning disabilities in children populations. Around 1% of adults in the UK and just over 1.5% of children in the UK are autistic. There's a difference in that number. Why is that? Many autistic individuals are diagnosed when they are in adulthood. But it's the adults without learning disabilities who are regularly overlooked and this has been found through surveys as well like the National Audit Office. It may be just because that type of learning disabilities are there or just that autistic individuals without learning disabilities do lead their own lives but people don't recognise those underlying factors which impact them on a day to day basis.

Siobhan: There was one study that suggested that only 20% of adults with learning disabilities are known to learning disability services and that's because the majority of individuals with learning disability have mild learning disabilities and therefore who could benefit from support but are perhaps unaware of the fact; that support applies to them and could be beneficial for them.

Gaby: That's what I was thinking because they would, as a child, you would have a parent seeking help for you. If you were not willing to self-advocate for yourself you could easily disappear off the radar sort of thing.

Ketan: Healthcare providers and professionals may not be aware or may not have a good level of knowledge about these special populations. But they are not always to blame either because you don't regularly receive autism specific training as part of your degree qualification or post graduate training and that has been found in a survey by the National Audit Office with GP's and so that awareness needs bulking up there. I can give my own personal experience. The first time I saw an autistic patient, I felt really out of my depth because you know it's not a learning disability so you cannot be patronising or childlike to the patient. What are those sort of specific changes should you make? I had to learn that on the job with the patient telling me; can you repeat that, can you tell me in smaller chunks, can you give me a break so I can process what you are saying. Can I just have a minute because I am feeling a bit overwhelmed. If there was just a bit more focus on autism without learning disabilities even at a training level, undergraduate level that would actually send professionals into their practice a lot more equipped.

Siobhan: Couldn't agree more with the requirement for training at the point where people are doing their initial training as well as it now being introduced to healthcare staff who are already in services but also at that point where they are learning generally. They are both really important populations to be learning about and as I say because of that need for I would argue there is a very strong need in terms of adult services for individuals with learning disabilities and how their needs differ very much to those of children and how adults should be seen as adults. There is a risk as well of too much attribution of adults with learning disabilities occasionally seen in a paediatric manner. There have been reports of adults with learning disabilities being seen by paediatric services, which is very unfortunate. It really needs some focus.

Gaby: Sounds like education to a certain extent, common sense and awareness are the key things to think about. Thank you both very much. That was really interesting and we could all keep learning about the topic.

All it remains for me to do is say thank you for your time and sharing your thoughts.

Thank you. If the audience have any follow up questions, feedback or share ideas for future topics please contact me. You can send me an email. Gabrielle.Saunders@manchester.ac.uk

I hope you enjoyed this discussion and are going to come back to the next podcast. Until then farewell and stay well.

References:

From Ketan:

Here is a list of useful online resources for healthcare providers when considering autism-friendly services and environments.

- AASPIRE have provided online resources and a toolkit for healthcare providers so they may provide a more “autism-friendly” service <https://autismandhealth.org>
- NICE have provided checklists for autism-friendly environments <https://www.nice.org.uk/guidance/cg142/resources/endorsed-resource-checklist-for-autismfriendly-environments-2016-2665557037>
- The Autism Dividend report provides evidence-based recommendations on support, services and healthcare provision for autistic individuals <https://www.asdinfoales.co.uk/resource/autism-dividend-report.pdf>
- The Westminster Commission on Autism: A spectrum of obstacles https://westminsterautismcommission.files.wordpress.com/2016/03/ar1011_ncg-autism-report-july-2016.pdf
- Autism@Manchester: Films to increase autism awareness <http://www.autism.manchester.ac.uk/research/projects/autism-awareness-films/>

From Siobhan:

https://www.england.nhs.uk/wp-content/uploads/2020/08/v1.17_Improvement_Standards_added_note.pdf

<https://www.gov.uk/government/collections/reasonable-adjustments-for-people-with-a-learning-disability>

https://www.ndti.org.uk/uploads/files/IHaL_2011_healthinequalitysocialcare_guidance_final.pdf

<https://www.ndti.org.uk/our-work/areas-of-work/learning-disability/>