AUTISM SPECTRUM DISORDER AND HEARING LOSS

A New Frontier of Clinical Care

Interview with Jolanta McCall and Glenn Rall

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Learn more about the AAA 2019 Marion Downs Lecture in Pediatric Audiology. Dr. Carroll speaks with two experts from the AAA Conference panel, Jolanta McCall, MA, MSc, and Glenn Rall, PhD, and discusses their work related to autism spectrum disorder and children with hearing loss.

The popular Marion Downs Lecture in Pediatric Audiology is one of the highlights of the American Academy of Audiology annual conference. The 2019 conference in Columbus, Ohio, will mark the 15th anniversary of the lecture series. To celebrate this landmark honoring the legacy of Marion Downs, the American Academy of Audiology Foundation (AAAF), with support from the Oticon Foundation, is pleased to host a presentation and panel of experts discussing autism spectrum disorder (ASD) and the clinical audiologist. The lecture will explore how the diagnosis may present in an audiologic clinic setting, current knowledge on the science of autism spectrum disorder, and strategies to assist pediatric patients and their families with the diagnosis.

I had the pleasure of interviewing two experts from our panel, Jolanta McCall, MA, MSc, and Glenn Rall, PhD, and discussing their work related to ASD and children with hearing loss. This discussion provides a preview of what is sure to be an engaging discussion at the Academy’s annual conference.

Originally from Krakow, Poland, McCall holds an MA as a qualified teacher of children with special needs, with a specialty in teaching deaf children. She moved to the United Kingdom in 1995 and obtained an MSc qualification in educational audiology. She is a former leader of the PAN-London Children's Audiology Services network, past secretary of the British Association of Educational Audiologists, and former chair of South East England Heads of Services and Schools for the Deaf consortium.

McCall has a national and international reputation, particularly for the development of innovative services. She was responsible for the development and establishment of the renowned Hummingbird Clinic—to date the only United Kingdom-based specialist clinic for hearing assessment for children with autism and additional special needs. She is a frequent speaker at conferences at home and abroad and has acted in an advisory capacity to the National Deaf Children’s Society in the development of U.K. Quality Standards for Early Years provision.

Rall earned a PhD from Vanderbilt University in microbiology and immunology. He has multiple academic and research appointments and holds the titles of professor, chief academic officer, and director of post-doctoral programs at the Fox Chase Cancer Center in Philadelphia.

Rall’s background as a researcher includes a focus on virus infections and immune responses within the brain. Because of his expertise in immunity in the brain, he was appointed to serve on the Autism Speaks Scientific Advisory Board from 2008 to 2014 and was honored as Autism Speaks Scientific Advisory Member of the Year in 2011. Rall is also a coauthor of the leading virology textbook *Principles of Virology*. He has served
on multiple National Institute of Health study sections and review panels.

**Brenna Carroll (BC):** Thank you for taking the time to answer these questions. As more children are diagnosed with ASD, audiologists are being asked to evaluate hearing as a component of care. Speaking for myself, I have many questions about the science behind the diagnosis of ASD and strategies to evaluate and treat children who may have unique sensitivities and needs.

Dr. Rall, what can you share about how your background in microbiology, immunology, and viral immunology research led to studying autism? And what can you share about the science of autism?

**Glenn Rall (GR):** My research has focused on virus infections and immune responses within the brain. One of the viruses my lab works on is measles virus. When the 1998 report was published suggesting that vaccination with the measles-mumps-rubella vaccine might contribute to autism, many of us in the field were called upon to evaluate this work and to determine if there were, in fact, any links. Of note, these additional studies unequivocally showed that there is no connection between vaccination (with any vaccine) and autism, though this concern remains prevalent among many parents of vaccine-aged children.

My lab does not work on autism directly, but I continue to stay updated on the science. It is a notably complex spectrum of disorders and causation for one type might not be applicable to another.

Most researchers in the field now believe that the disorder is established during gestation and not post-natally, but the relative contributions of genetic and non-genetic (e.g., environmental) factors remain incomplete. Certainly, if there is a genetic component (as many believe, myself included), it is, again, complex. It surely is not that a mutation in a single gene that triggers the disorder. Rather, it appears that disruption of synapse pruning or
communication during brain development, which is controlled by many gene products, might be involved.

**BC:** Ms. McCall, your background is also very interesting. I understand that you began your career teaching children with special needs and today you are the chief executive of the Seashell Trust in the United Kingdom. How did you wind up on this path? What can you share about the Seashell Trust with Americans who may be unfamiliar with the organization?

**Jolanta McCall (JM):** My career pathway is quite unusual. I qualified as a teacher and teacher of the deaf (TOD) 29 years ago and started work as a ToD in Poland before taking leadership positions in the United Kingdom. I always worked with children with disabilities, including sensory impairments and complex needs.

I also hold an MSc qualification in educational audiology and trained in different modes of communication including PECS (Picture Exchange Communication System), Makaton, and BSL (British Sign Language) level 1. Positive outcomes and the well-being of children, young people, and their families is the silver thread through all my work.

I have always been interested in early intervention and complex needs children, with a special place for integrated care pathways and a holistic approach to assessment and habilitation of disabled children.

I was responsible for the development and establishment of the well-known Hummingbird Clinic—to date the only United Kingdom-based specialist hearing assessment clinic for children with autism and complex needs. I will talk about this in my presentation at the Academy’s 2019 annual conference.

My new role as CEO and principal at Seashell Trust gives me an opportunity to channel my skills and knowledge toward enabling children and young people with complex needs to communicate well, achieve their potential, live independent lives, and make their own life choices.

Seashell Trust is a national charity that operates family and outreach services, a school, a college, plus residential homes for children and young people with the most complex needs. All of our pupils have severe or profound learning and communication difficulties relating to one or more conditions including autism, multisensory impairment, hearing loss, visual impairment, complex physical disabilities, and medical needs.

Our students learn effective communication strategies, including speech, signing, objects of reference, PECS, intensive interaction, and the use of technology to meet their individual needs.
Children and young people are referred to us when local special schools are not able to meet their needs. We offer an extended curriculum, including after-school clubs and focus on the development of daily living skills.

Our vision is to reach families and professionals beyond Seashell by providing specialist training in autism and multisensory integration (MSI). We have close links with local health, social care, and education providers.

You can see why I was attracted to the CEO role. It ticks all my interest boxes and I’m delighted and proud to lead this organization.

**BC:** The Seashell Trust sounds like the perfect fit for you. Can you share a little about how specifically, ASD and hearing loss in particular became two of your champion causes?

**JM:** My interest in hearing assessment of autistic and complex needs children developed from practical and financial necessity. At one point in my career, I took on the leadership of pediatric audiology, and our waiting list for special needs clinics was enormous. This is partly because, on average, it took us between 8 to 11 appointments to arrive at a diagnosis.

I watched growing parental anxieties with every appointment they attended, and much of the time we were not able to provide answers to them. We sometimes had to recommend auditory brainstem response testing under general anesthetic, which didn’t go down very well with parents.

It was time to find a different solution and think outside the box. I was lucky enough to be surrounded by enthusiastic, committed, and brave pediatric audiologists who were determined to find a solution. We started with a big dream and worked out details as we progressed.

**BC:** What do you feel are important variables for audiologists to consider when working with patients with ASD?

**GR:** I think two misconceptions are pervasive among clinicians. First, to call a patient “autistic” is nearly as unhelpful as saying he or she has “cancer.” Just as the site of cancer is a major indicator of prognosis and treatment; likewise, the nature of the patient’s autism will be a crucial variable for how to interact with that child (or adult), and perhaps, what supportive options will work best.

Second, autism is not “just” a cognitive disorder—it affects the gastrointestinal tract, sleep, etc., so the disorder is often much broader than the neurological phenotype.

**JM:** It starts with the pre-appointment clinic preparation, which includes gathering information from parents and teachers about a child’s likes and dislikes, the way they communicate, their favorite toys and music, and the best time of the day for them to come to the clinic. It helps to get parents involved in this preparation, asking them to read a social story as many times as possible before the appointment. The social story explains what’s going to happen during the appointment and what to expect.
Prepare the physical environment, i.e., the clinic room. Have all the toys and equipment ready and easy to reach; prepare the audio and visual resources. Have a visual timetable available, with “now” and “next” prompt cards to help to lead into the next part of testing.

And then comes clinical testing beyond warble tones, using a bandpass-filtered signal from the child’s favorite tunes/songs used in the VRA. Don’t forget to involve parents in your clinical testing, sending them some homework, so next time you will work together even better. Evaluate the session; learn from each session.

BC: Along those lines, do you have insights into the variables that audiologists should consider when working with families who have a child with ASD?

JM: There is only one principle to follow. Parents are experts in their children; they know them best. Make parents equal partners in your audiology clinic.

BC: To both of you, what, in your opinion, do you think is the biggest misconception about autism as it relates to your areas of expertise? Dr. Rall, what do you think is the biggest scientific misconception, and Ms. McCall, what is the biggest clinical misconception?

GR: Oh, this one’s easy. I still think that if you ask many parents “What do you know about autism?”, the vast majority will mention vaccines somewhere in the conversation. Even though the scientific community has soundly ruled out any role for vaccines in autism, it remains a prevalent concern in the public. Addressing this challenge will be a major component of my lecture.

JM: I think we tend to have low expectations for non-routine children, using the argument that children with autism or complex needs are difficult to test. They are not; it is we who need to work harder to reach these children, making time to learn about their individual expectations.

There are many adaptations to testing and clinic preparation that can be made without huge expense. Tailoring the stimulus and the reinforcers was done without any equipment beyond what is routinely available in an audiology clinic in National Health Service (NHS).

BC: What do you both see as the future of ASD research? What do you consider the biggest unknowns?

JM: It appears that there are not many recent published studies on autism and hearing loss. Practitioners tend to conduct their audits and studies in the comfort of their department. Most studies are focused on communication, social skills, interfering behavior, school-readiness skills, or cognitive skills. We definitely need more studies in the area of auditory functions in autistic children.

GR: My particular advocacy on the Autism Speaks Board was for more inquiry into immune elements in autism. In addition to terrifying many parents, the categorically false vaccine report also stymied research into autism and immunity—many scientists just felt that the field was too “radioactive” to pursue, and so, relative to other sub-fields in autism such as genetics or behavioral modulation, immune correlates fell behind.

Beyond my own interests, I think a major challenge will be for the field to determine if autism is truly a spectrum (that is, gradations along a continuum) or many different disorders with some clinical similarities that are then grouped into “autism spectrum disorders.” If the latter is true, as I suspect, these various conditions could have entirely different etiologies. Thus, when we talk about research in autism, we will need to be very precise about which type, exactly, we are studying.

BC: Before we conclude, do you have imparting “clinical pearls of wisdom” for our readers?

JM: To get the most out of your time with every child, it is important to consider the needs of each child in their entirety, from their journey into the hospital up until they make their way home.

GR: I completely agree. I would reiterate that—as every child is different—even child with autism is also different. These kids may have some unique additional challenges and fears. Communication and partnership with the parent and a greater awareness of the child, I suspect, will be catalysts for a good clinician–patient–parent interaction.

BC: Thank you both for your time and thoughtfulness in answering these questions. I look forward to the presentation and panel discussion at AAA 2019, on March 29, 9:00-11:00 am, in Columbus, Ohio. It is sure to be a fascinating addition to the Marion Downs Lecture in Pediatric Audiology series.

Brenna Carroll, AuD, is a clinical audiologist at Swedish Medical Group in Seattle, Washington. She is also the chair of the AAA Foundation Board of Trustees.