

Faculty Spotlight: Dr. Nancy Roizen

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Recommended Citation

Rudrapatna, Akshata and Gabe, Michael () "Faculty Spotlight: Dr. Nancy Roizen," *Discussions*: Vol. 16: Iss. 1, Article 1.

DOI: <https://doi.org/10.28953/2997-2582.1174>

Available at: <https://commons.case.edu/discussions/vol16/iss1/1>

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Faculty Spotlight

AN INTERVIEW WITH

Dr. Nancy Roizen

By Akshata Rudrapatna and Michael Gabe

Nancy Roizen, MD, is a Professor in the CWRU School of Medicine Department of Pediatrics and Director of the Division of Developmental and Behavioral Pediatrics and Psychology at University Hospitals Rainbow Babies & Children's Hospital.

This interview has been edited for length and clarity with Dr. Roizen's consent.

Q: What led you to be involved in the fields of medicine and pediatrics?

A: I wanted to do something interesting. There are two fields of developmental behavioral pediatrics. One is neurodevelopmental disabilities and one is developmental behavioral pediatrics. They started out on parallel paths. I started in neurodevelopmental disabilities and then moved in to developmental behavioral pediatrics because I was a resident at Hopkins, and in my second year of residency I was trying to figure out what to do with myself. They said, "Why don't you go to the Kennedy Institute?" because I was interested in neurology and genetics. So, I went over and was interviewed by the doctor who developed the field, and he said two things were wrong with me. First, that I was a woman and second, that I didn't go to an Ivy League school. But he had to take me because I was a resident at Hopkins. So that just gives you an idea of how much strong encouragement one received in that era. However, he became my biggest booster and my biggest supporter over time. So I went and did that.

Presently, I'm involved in looking at workforce issues basically. The way my research has evolved is after doing a year of fellowship at the Kennedy Institute, we moved to San Francisco, and I did another year of fellowship in behavioral pediatrics. Then I worked at UCSF Benioff Children's Hospital, and my boss said, "I want you to start a Down's Syndrome clinic," so I did that. And consequently, that's become sort of the focus of my career: looking at medical problems in Down's Syndrome. The other parts have been by collaborating with people who have big longitudinal NIH grants to



look at. So we then moved to the University of Chicago, and there was a Rena McCloud research program on congenital toxoplasmosis, so I worked with her. And then we moved to Syracuse where there was a research project on velocardiofacial syndrome, or 22.q.11.2 Syndrome, and I worked there with them. And then I came here.

"My sort of repeated message is the system doesn't take care of the patient population."

Q: What projects and research are you currently involved in?

A: Presently, I'm doing more workforce issues because small fields in pediatrics (subspecialties) have workforce issues; there aren't enough people going into them. So that would include developmental behavioral pediatrics, it would include rheumatology, it would include neurology, it would include nephrology. My sort of repeated message is the system doesn't take care of the patient population. Which means we have to get some data and publish.

So, in the nineties, I participated with the American Pediatric Center Workforce Survey, which we published a 2002 paper from. There was another survey that was done in 2015 and I was the representative of developmental behavioral pediatrics on this survey, and it actually got a lot of press. It's important to provide data that then compels people to push the NIH. It turns out maternal and child health is pretty supportive of

the things that we do. So, if you have some data, data helps.

Q: Is data everything?

A: Data's everything. Sometimes it doesn't say what you want it to say, sometimes there are surprises. But...

Q: Is it the most objective way?

A: It is. I'm sort of encouraging you to do a couple things: one is to collaborate with other people when you're thinking about doing research. Research is national, even international. If you join a network, try to work with a bunch of focused people.

The other thing is to be active in some national group that you are interested in. For example, I'm part of the Down's Syndrome medical interest group. When I started, there wasn't a lot of information about Down's Syndrome. When

"...if you had access to the autism navigator right away, three months later you were more likely to have an appointment or actually have achieved the educational medical referrals."

there's a lack of information, you get your patient population. You start collecting data and then answer questions or you listen to the parents' questions, and you figure out, "There's no answer to that question; I can answer that question if I collect enough data about it."

The adults are in the same position. There's no information about adults with Down's Syndrome because they weren't living that long several decades ago. So this group has put itself under Dr. Capone's leadership, from Hopkins, who has systematically gone through and looked at all the data that we have in adults with Down's Syndrome. Now, Kate Meyers is there someplace. She's our fellow I pulled in, and she mainly did most of the work on looking at hearing loss, which is another thing I've been involved with.

In our RAD (Rainbow Autism Diagnostic) clinic, which is for kids who were 48 months of age or less where there's a question of autism, we have an autism navigator, a social worker who helps people after their kid gets diagnosed with autism. Of course she's helpful, but how do you really know, right? You do a study.

And you have to consider the money. We had Medicaid and non-Medicaid patients who were diagnosed with autism. We randomized them to have face-to-face contact with the autism navigator immediately on the diagnosis and then again three months later. So, did it make a difference? Because, they both got a pretty standardized report and recommendation list, okay. Yeah. It did make a difference. Sure we had pretty small numbers, but you use all your resources. My brother-in-law is a statistician. So at Thanksgiving I approached him several years ago, "Okay, Richard, how can I do this with my small numbers?" And he's like, "This is how you do it."

So I thank you Richard. And, um, and what we found was what we expected to find, even with those small numbers. Which was that if you had access to the autism navigator right away, three months later you were more likely to have an appointment or actually have achieved the educational medical referrals. If you didn't, you were less likely to. Okay, so that's not shocking, but now you have data to look at.

We also asked if there was no difference if there was or wasn't Medicaid. We expected that the people with Medicaid would say that it was helpful. And I think the people not on Medicaid were already heading down the road. They already knew they needed to have something and that they had some gotten services. Whereas the people who had Medicaid were sort of like "there's a problem but we have no idea what to do." That was a surprise. There's very...there's not a lot of literature that says that something helps people who have Medicaid.

Q: We notice that you've done some work with cerebral palsy, can you tell us about that?

A: There's the science and then there's the story, right? This cerebral palsy work was done by a

wonderful researcher by the name of Karin Nelson who's a pediatric epidemiologist at NIH. She did groundbreaking work in cerebral palsy, where she looked at the data from a longitudinal study starting in the 60s featuring individuals (same individuals across time) born from pregnancies. She did two things: (1) she did something directly related to magnesium sulfate, and (2) she came to the conclusion that cerebral palsy was not mainly birth trauma, but that these were babies already compromised because of various reasons (e.g., intrauterine stroke), and may (not) have had a difficult delivery. It wasn't a traumatic delivery that was the etiology, it was usually something that was happening in utero. And yes, it could've been a traumatic delivery in 10% or 5% or 8% of the cases, but it wasn't. And you know that, don't you?

"There's not a lot of places that can service the whole spectrum of assisted technology needs that you have in kids with cerebral palsy."

But if I'd asked that of a medical student 10 years ago, they would've been like, "traumatic injury" or "traumatic delivery". So, not only did she come to this conclusion in the 90s, but she also noticed that the mothers who had received magnesium sulfate for their hypertension had preeclampsia. But those babies whose mothers had received magnesium sulfate were less likely to have CP. She thought there should be a controlled study, randomized, and prospective, looking at giving moms magnesium sulfate when they went into premature labor and to see if there was cerebral palsy. And so she connected with UCP (United Cerebral Palsy) and they connected Bob Mittendorf, who was an epidemiologist and an OBGYN at the University of Chicago. In that area, there weren't many academics. The University of Chicago had a nursery with one of the highest percentages of premature pregnancies in the country. That always surprised me, but we lived on the south side of Chicago, and that is a very impoverished area, so it shouldn't have. So anyways, he started a randomized, controlled

treatment with magnesium sulfate, and I did the follow-ups on these kids. The numbers ended up indicating that it was helpful in preventing cerebral palsy. But there are two stories behind it. They were finding, at least, that there were more deaths in the treatment group than in the non-treatment group. But was that because they were giving them too high a dose or was that because it was just a "pick of the draw," or that they were too vulnerable? Mark Seigler would talk to all the parents about this and the OBGYNs were not happy. Magnesium sulfate had been the treatment for preeclampsia, so that created a political kerfuffle. We'll just go "dot, dot, dot" on how that worked out. Dr Mittendorf moved to pediatrics and out of OBGYN and "dot, dot, dot." It was very disillusioning for me; you come with an answer where maybe it's wrong, but maybe it's right.

Q: What challenges or barriers confront cerebral palsy and neurodevelopmental research and treatment in the medical field?

A: There's a lot of challenges. Specifically with cerebral palsy compared to other developmental diseases. The children are so varied that it's so hard to have a double-blind controlled study. You have kids with a mild hemiplegia, you have kids with coreathitroids cerebral palsy, you have kids with quadriplegia, and you have kids with different comorbidities, vision problems, hearing problems, orthopedic problems. So they're not as uniform. When I talk with people who do research in cerebral palsy, that is one of the things that they struggle with.

The treatment is also complex. So you have botox, intrathecal baclofen, to help with spasticity. You have other medications that help with spasticity, but not a lot. You're trying to compensate so that people can function, so you have wheelchairs. When you're treating children, you have a little wheel chair. All these things are expensive. There's not a lot of places that can service the whole spectrum of assisted technology needs that you have in kids with cerebral palsy. So here in town we have our complex care person, Rich Roseburg, who services kids with motor problems so they usually have a trach or a G-tube. Nationally, so if we're talking about systems (kid, treatment,

technology), they're developing now centers of complex care, which is what Rich Roseburg does, the goal of which is to keep these kids out of the hospital and in school. And so people are supportive of developing these, as this small percentage of kids account for a big chunk of admissions because of surgical needs or infection.

The good news is that systems are motivated to support these centers because they're thought to save money. So they need one of these, right? But they are not so easy to do, because not all these kids are the same.

Q: What do you see as the future of cerebral palsy research and the potential for treatment?

A: The future research? With cerebral palsy, you want to do more prevention. Circling back, initially prevention was making it so that there wasn't birth damage. Of course, it's not a bad idea, but it didn't have an impact. There was a lot of focus on monitoring kids during labor, and trying to time the delivery so that if they were getting into any difficulties (e.g. brain damage)... but hasn't born the fruit from what you'd expect, in part because, remember what we said, the damage is already done.

So what can you do? You can go back and go through healthy pregnancies, preventing things like toxoplasmosis, preventing CMV, and doing better with prevention, with delivery, and with neonatal care. Of the kids with cerebral palsy, premature kids are a big chunk of them. A big chunk is the kids who are full-term; that group is more likely to have had traumatic deliveries, so they're trying to treat them with cooling and other things immediately after birth. And then do better with helping people be functional with technology.

Q: Do you have any advice to students who are interested in work or research in this area?

A: I think you want to find a mentor. Good mentoring is a wonderful, rare commodity. See if you can attach yourself to a longitudinal study. There was one student at the University of Chicago who went to Columbia to pursue psychiatry. He was wonderful. When he arrived at Columbia, my perception was

that he was able to attach himself to a study that had gone on for several years, and was finishing. I was able to watch his career as his publications were coming out. And the next thing I knew, he was at NIH, at the head of something in psychiatry at the NIMH, and was a national expert in that. Do that kind of thing: attach yourself, collaborate, find something that you're passionate about. When our fellows come in, I encourage them to think about questions that they're passionate about. Especially at the beginning, it's easy to give up on things, so if you have some passion about it. I keep saying this to the fellows, "You have to get it done. You have to get it done." You've already put a huge amount of time and effort into this, so you don't want that to go to waste. And two, as soon as you move out of your fellowship and you go onto your job, you're not going to have the time to do it. If you think you're busy now, just wait until you stop your job. You're going to have to learn new things and get up to speed. Be sure to publish it and collaborate with people. Where can you connect? And the other thing is that there's national databases now. It's sort of an interesting phenomenon. We have all these people thinking, "Can we get your patients to sign on to our database?" It's just like we have database fatigue.

But I'm technology-challenged. But it's not clear to me that it's so easy in general. But it happens. Pay attention to your patients. Listen to them. "I don't know the answer to this question, but I'll look it up." And if there isn't an answer, maybe you can develop the answer.

A Selection of Dr. Roizen's Work

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