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Deciphering autism

Alumni approach research from many angles

By Diana Bean '81

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Associate Professor of Psychology Jennifer Gillis '99, MA '02, PhD '06, left, and research scientist and licensed psychologist Rachel Cavalari, MS '09, PhD '12, work at the Institute for Child Development on the Binghamton campus.

In 2002, the number was 1 in 150. In 2008, it was 1 in 88. Last spring, the gap narrowed further — to 1 in 68. Those are the numbers of children with autism, as reported by the Centers for Disease Control and Prevention.

"Today, you'd be hard pressed to find somebody who doesn't know somebody who is affected by autism in one way or another," says Michael Rosanoff '04, director of public health research for Autism Speaks, an advocacy organization.

Autism spectrum disorder is a general term covering a variety of disorders rooted in early brain development. People on the autism spectrum have varying degrees of difficulties with social interaction, verbal and nonverbal communication, and may exhibit repetitive behaviors. Some have intellectual disabilities, while others may excel at math, music or art.

As autism touches more of us, Binghamton University alumni are, in turn, having an impact on autism research — in both traditional and unexpected ways.

Meet four with very different résumés: an artist, a communicator and a team of faculty researchers.

Debra Swack: artist

While Debra Swack '80 was earning a bachelor's in studio art at Binghamton University, she learned photography and printmaking, studied painting with Angelo Ippolito and creative writing with Heather McHugh and Milton Kessler. Then she looked at the job market, did an about-face and got a degree in computer science.

The two disciplines turned out to be a perfect match for Swack, who is a new-media artist and a technical writer/software tester for the SUNY Research Foundation.

Her art is digital and sometimes interactive. She uses sound, animation, photography, video and more. “As technology became more affordable, I started buying hardware and software and teaching myself how to use and modify it to make art that became increasingly science related,” she says.

In 2007, her installation *The Emotions (after Charles Darwin)* caught the attention of Ava Britt, then a scientific assistant at the Brain Mind Institute in Switzerland. *The Emotions* uses four videos of four faces, each expressing a particular emotion: happiness, anger, surprise and sadness. The animated faces in the videos are created from photographs. Britt found Swack’s work in the Rhizome art collection on the New Museum’s website during a search for photos of facial expressions for use in research on how the human brain processes emotion.

The idea was to have subjects with and without autism look at the faces while undergoing functional magnetic resonance imaging. What set Swack’s photos apart, Britt says, is that they were candid; the subjects did not know they
were being photographed. Photographs in similar experiments were staged.

“I felt it would be more useful to investigate the brain’s response to images of genuine facial expressions, rather than phony ones,” Britt says.

Swack’s installation was inspired by more than 100 years of emotion research, beginning with Charles Darwin’s assertion, in his book *The Expression of Emotions in Man and Animals* (1872), that certain facial expressions are universal and that the emotions they express are rooted in biology.

To prepare for the experiment, Swack edited her photos to make them as uniform as possible to reduce visual distractions. “I centered the eyes in each frame and cropped each face from chin to brow for maximum emotional effect,” she says. A small red cross was placed between the eyes of the faces in the photos to give subjects something to focus on while in the MRI scanner. That’s because researchers discovered that autistic people sometimes focus somewhere other than on the eyes.

Before their collaboration, Swack knew little about autism.

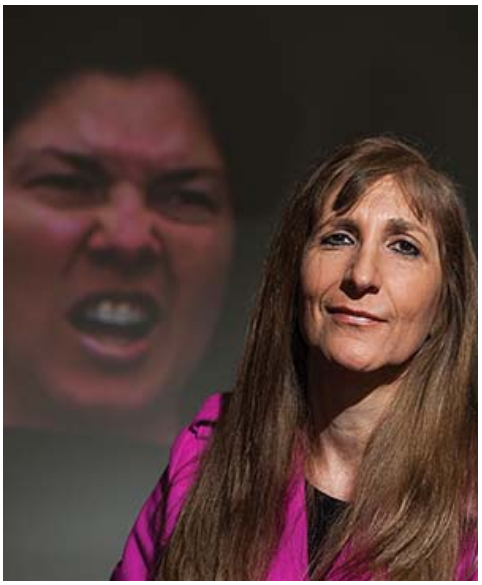
“Working with the Brain Mind Institute gave me a better understanding of how people with autism relate within a social context and the difficulties they face in an environment of confusing emotional cues,” Swack says. “This greatly affects their social and interpersonal skills, both in reading the often-subtle emotions of others and being able to communicate their own emotions to others.”

In the end, the very thing that attracted Britt to Swack’s photos proved to be the experiment’s undoing: The facial expressions in the candid shots were too subtle to be scientifically useful.

“I was disappointed,” Britt says. “Attempting to understand something as complex as human emotion by our current scientific methods has its limitations, but we do our best.”

Swack used what she learned to refine *The Emotions,* which has been presented at conferences and museums around the world. Yet it remains a work in progress, evolving along with the science that informs it.

“Art and science are similar in a lot of ways. Both make keen observations about our world, its cultural values, processes and systems,” she says. “The goal of both is to reveal truths through observation and experience about the world that we live in.”



About Debra Swack’s art

Debra Swack ’80 writes about *The Emotions* in an essay titled “Re-Program My Mind,” published by MIT Press in 2013 for Leonardo Electronic Almanac (volume 19, issue 4), the journal of the International Society for the Arts, Sciences and Technology. Find it at leoalmanac.org

Her most recent work is *Cloud Mapping Project,* an immersive installation and soundscape about all manifestations of the cloud, from arts to technology, including surveillance. It will be published in an upcoming issue of *Leonardo Electronic Almanac* and exhibited at Banff Centre for the Arts in Alberta, Canada, in 2015. Swack’s Animal Patterning Project was part of the Alumni Art Show at the Binghamton University Art Museum in fall 2014.

Michael Rosanoff: Science communicator

Michael Rosanoff ’04 talks, blogs and tweets about autism research. As director of global public health research for Autism Speaks, he has traveled to 30 countries in the past six years to appear at conferences, give interviews and meet with policy makers.

What gives him the most satisfaction, though, is an experience like this: “I once had a dad of a child with autism say it was the first time since high school that he understood a science lecture. You could tell he was excited about it — it seemed to unlock something that made him hopeful for the future of his child.”

The ability to share research is as important as the research itself, Rosanoff says. “That’s what excites me about being a science communicator.”

Autism Speaks is a nonprofit organization, founded in 2005, that focuses on awareness, fundraising, science and advocacy. Rosanoff was hired in 2007.

Parents of children with autism can feel bombarded by the increasing number of studies, theories, treatments and interventions that attempt to address the many manifestations of autism. Making sense of all that information and knowing how to use it can be overwhelming — and these are parents who have experienced "overwhelmed" on a rarified level.

"What good is the work that we do if we can't explain it to the families that we're trying to help?" Rosanoff asks.

"My job is to be critical of research papers by looking at the design and strength, understanding limitations and coming up with a take-home message for families or policy makers who want to know, 'Where does this research fit in with the bigger picture and what does it mean specifically?'"

Rosanoff earned a bachelor's degree in integrative neuroscience, formerly known as psychobiology. ("Any time I had to say that word it left an awkward silence," he says.) Coursework provided the scientific foundation for what he does today, he says, but it was his work as a research assistant that taught him the process of science, from discovery to delivery.

"I learned the basics of study design, grant writing, data collection and analysis by working as a research assistant in a lab. That's also where I got my first exposure to science communication, presenting at a Society for Neuroscience conference 10 years ago.

"I owe a lot to Terrence Deak [professor of psychology]. He was a great influence on my life as a student at Binghamton and my career," Rosanoff says.

It's all in the delivery

All scientists are communicators, says Michael Rosanoff '04. But some are better at it than others. Case in point: Distinguished Professor of Anthropology Randall McGuire and his buried cities and lost tribes class — Rosanoff's favorite. "That man is a skilled science communicator," he says. "Anybody who comes to the first class dressed as Indiana Jones has my full attention. Maybe it was his approach that also got me excited about communicating science. He was passionate about what he did but made it accessible to the incoming freshmen who hadn't had a formal lecture class before. He really engaged students in a way only he could do in a big lecture environment."

But it was Distinguished Professor David Sloan Wilson's class in evolution and human affairs that prompted Rosanoff to think about health at the population level, and he later earned a master's in public health epidemiology from Columbia University.

When he joined Autism Speaks, Rosanoff helped create the Global Autism Public Health Initiative. Its goals are to raise awareness, increase access to services and support international research.

"Seven years later, we are working with experts in more than 65 countries to discover the best ways to deliver autism detection and intervention that are culturally sensitive and feasible, especially in resource-poor countries," he says.

"The most important thing is never to go in expecting to know what will work in any given country." For instance, it can be an ethical tightrope when there is no safety net of services. "You can't identify kids with autism without providing help to those families," Rosanoff says.

There's excitement in Rosanoff's voice when he talks about the future.

"Today it's not just about scientific discovery, it's about the science of making those discoveries accessible and turning them into real-world solutions," he says. It's also about uniting stakeholders — families, government officials and affiliated professionals — to work toward a common goal.

"It's easier said than done. I'm learning that lesson every day at Autism Speaks."

Jennifer Gillis and Rachel Cavalari: Researchers test treatments

Associate Professor of Psychology Jennifer Gillis '99, MA '02, PhD '06, was a Binghamton University undergraduate trying to settle on a career path when she went to the Science Library to read about autism interventions conducted by researchers.

She was not impressed. Specifically, she was surprised at the lack of empirical data to support the claims of efficacy for so many of the interventions.

"I realized that people can say they are doing all these wonderful interventions for children with autism, ... but it's important to go to the research literature and ask, 'Do the findings hold up scientifically?'" Gillis says. "So I decided I wanted to learn what good science is and how to conduct scientifically sound experiments. I wanted to learn how to read and interpret science, communicate it to others and use it to inform evidence-based interventions for individuals with autism spectrum disorder."

In 2005, Rachel Cavalari, MS '09, PhD '12, had completed her bachelor's degree and was working at an agency that provided support services for children with autism. She received training, along with conflicting advice. "Why are some case managers telling me to do applied behavior analysis while others are suggesting hypnotherapy?" she wondered.

She started reading about autism interventions and concluded: “If we have something supported by science, why aren’t we using it?”

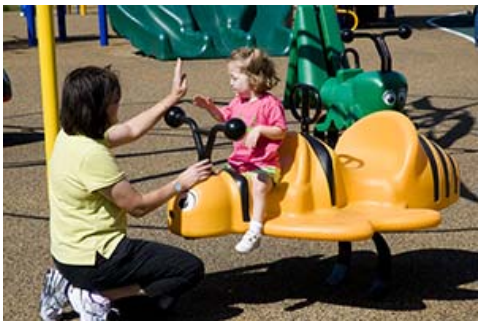
Today, Gillis is associate director of the Institute for Child Development at Binghamton University, and Cavalari is a research scientist and licensed psychologist at the Institute. Together they are collaborating on how to improve training and intervention methods for people who teach and care for those with autism. And they are doing the science that will tell them, and others, if their methods really work.

“There are over 400 interventions advertised for children with autism spectrum disorder. And only a handful have empirical support,” Gillis says.

As a faculty member at Auburn University, Gillis had completed a study of a new intervention that teaches parents how to help their child initiate social interactions with someone they don’t know well. For example, a family who liked tailgate parties at football games wanted their child to be able to do some of what the other kids were doing, like cheering or chatting about the game.

Parents were taught to help the child start a conversation by practicing saying “I’m excited for the game” or “who’s your favorite player?” The goal was for the parents to provide encouragement during the outing but not to hold the child’s hand and tell him or her what to say, because that doesn’t create a natural interaction between the child and the friend.

The next step was to see how much training parents actually needed to be able to master the intervention.



About the Institute for Child Development

Raymond Romanczyk, distinguished service professor of psychology at Binghamton University, founded the Institute for Child Development in 1974. The Institute offers diagnostic evaluations and assessments, early intervention programs, preschool through school-age programs, afterschool programs, research opportunities and degree programs in psychology (an undergraduate track in applied behavior analysis and a doctoral program in clinical psychology).

Typical behavioral-skills training includes instruction (me telling you), modeling (me showing you), role-playing and rehearsal. Research literature suggests that sometimes those steps can be truncated.

“Parents are always busy, and we want to have something that would give us the most bang for the buck,” Gillis says. “This is where the science came in.”

Parents were split into groups; some received instruction and modeling, followed by role-playing and rehearsal. Others did role-playing and rehearsal first. The outcome showed that those who started with role-playing and rehearsal acquired the skills at a faster rate compared to the other group and so did not need to spend additional time on instruction and modeling.

The next step is to see if practitioners can be trained to effectively teach the intervention to parents, rather than relying on researchers. That will help Gillis with another research project on what she calls “practice gaps.”

That’s when a procedure vetted by research doesn’t quite account for the “messiness” of work in the field, leaving the practitioner wondering, “How do I know what to do for this individual, given his or her specific circumstances?”

Cavalari remembers having those questions. “Some of the children I worked with were aggressive and some just had social deficits. Both can be equally difficult to work with for different reasons. How do I protect a child who gets upset from trying to hurt themselves versus how do I get them to continue a conversation with a friend on the playground without me becoming too deeply involved?”

Having solid answers and strategies supported by science is empowering, she says, but they’re of no use if they’re not shared. That is one of the reasons she came to the Institute for Child Development.

“As researchers here, you can be on the front line of helping move something forward and see it working. “We do the evidence-based research, we do evidence-based applications. We also are on the forefront of disseminating that information,” Cavalari says. “And I think being a part of both sides keeps us humbled and reminded of how we have to keep that loop intact.”

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