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Autism News Network spreads the word about autism from those who know it best

By Leslie Cantu

cantul@musc.edu

Hector Salazar, right, works with William Murphy, center to edit some footage for the Autism News Network. The group meets every week.

Photo by Sarah Pack

Why would someone travel to Charleston from Georgetown, Beaufort or even Myrtle Beach every week just to meet in a small lunchroom for two hours and practice shooting and editing videos? There are surely places closer to home where the same skills could be learned. But for the people who come to MUSC week in and week out to create videos for the Autism News Network, the group is much more than a fun class.

"This group's been a lifesaver for me," says Scott Biehl, who drives down from Georgetown every Thursday to participate.

The group is actually a gathering of adults with autism who work together to create videos about living with the disorder, all the while improving their technical skills, practicing their social and executive functioning skills and even providing a sort of group therapy to one another.

The program is the brainchild of McLeod Frampton Gwynette, M.D., a child and adolescent psychiatrist in the Department of Psychiatry and Behavioral Sciences at MUSC. He originally thought it would focus on posting evidence-based information about autism to combat much of the misinformation found on social networks like Facebook.

But he knew his idea was missing something. The Autism News Network came alive when he realized that adults with autism would be best suited to write, produce and direct all the videos.

The original participants began meeting in January 2018. They were "noobs" — or newbies, in the words of one participant, who simply goes by CMagnus. They used basic video editing software available on iPads and shot entire videos from a single angle. Since then, however, the group has gained professional mentorship from Hector Salazar, who owns his own video production company in Charleston — MeanStream Studios.

Gwynette has expanded the program into a 12-week beginner course that meets Mondays and an advanced course that meets Thursdays "until I fall over," he says with a laugh. Or, adds Salazar, "Until they're employed and working somewhere, and they can't come here because they've got jobs."

Keeping jobs or staying in higher education isn't always easy for adults with autism. Biehl, who moved to Georgetown from upstate New York with his parents, says he had 40-some jobs in New York, each of which ended with him getting fired or walking out. "It wasn't fun. It felt like a treadmill of tragedy," he says. Bosses would tell him he was too slow or that he couldn't connect with customers.

"It's not true; it's just that ... I have horrific eye contact," he says.

Recent research suggests that the subcortical system of people with autism goes into overdrive when making eye contact, meaning eye contact becomes an uncomfortable sensation.

Biehl isn't alone in his troubles keeping a job. A University of Wisconsin-Madison study last year found that less than a quarter of its sample of mid-life adults with autism held either full- or part-time jobs on their own, without the support of a job coach. Most of the people in that study had lower-than-average IQs, but their difficulties keeping jobs had less to do with their intelligence and more to do with problems judging social situations, staying on task and adapting to

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changing work schedules or job requirements. They also needed more supervision than other employees and many had chronic health problems as well.

Gwynette saw this problem with his patients, too. He founded Project Rex 11 years ago to help children with autism and ADHD develop social skills and prepare for adulthood. Yet once people age out of the school system, many of their supports fall away.

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Some of his patients attempted college classes but couldn't pass because of problems with executive functioning – planning, paying attention, starting and following through on tasks and adapting to change. That's when Gwynette got the idea for the Autism News Network.

"These are people who are brilliant, and they can be doing so much more than they are. We're going to hopefully unlock all those amazing abilities," he says.

Every Thursday begins with a group check-in, as Gwynette asks each participant what's going on in his or her life.

Gwynette gently draws out each participant, encouraging the more reticent ones to share additional details.

He also offers praise. When one man shrugs off a discussion about the camera work he did in a previous session, Gwynette tells him, "I saw somebody really hanging in there, and you took direction from Hector like a champ."

Gwynette later says that participants sometimes tell him they're too anxious to continue with the program. He'll generally nudge them to continue; eventually, their confidence grows, and they begin to blossom.

Biehl says the group has made a huge difference in his life.

"I love it down here. I'm happy. I've made a lot of friends, actually through this group, and I'm starting to get back to socializing and living life," he says.

Ainsley Knight's confidence was on display for all to see when, at an autism conference, Gwynette showed one of the videos that featured her.

Knight was there with family, and "they said they almost cried" when they saw the video, she says, though she doesn't see why it would provoke such emotions.

Knight joined the Autism News Network because, as she says, she's never been afraid of the spotlight. She was in drama throughout her time at Bishop England High School.

Graduating, though, was a "nightmare." Her classmates couldn't stop talking about graduation in the month leading up to the big event, but she wanted nothing to do with it.

"I wanted to run out the doors and not get my diploma. As soon as I was walking on that stage, as soon as I got the diploma, I'm like, 'This is a big mistake,'" she says.

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"I love doing YouTube. I think it's more of a therapeutic thing for me," he says.

Murphy was diagnosed with Asperger's syndrome in the fifth grade. Asperger's doesn't officially exist as a diagnosis anymore; the American Psychiatric Association folded it into the umbrella "autism spectrum disorder" diagnosis in 2013. Many still use the term informally, however.

Murphy would like to become a director. Part of the reason he participates in the program is to get more hands-on experience. There's only so much you can learn from watching documentaries, he says. "I see it as a way to earn experience."

Two participants, Bobby Kalman and CMagnus, were diagnosed with ADHD, not autism, although CMagnus thinks he probably fits the criteria for autism.

Kalman says the group is "my happy place." He enjoys videography and photography.

During the group check-in, he shares that he scored a new camera and lens on eBay for a good price. Photography is a new hobby for him, and he's practicing by shooting photos of Charleston buildings and homes.

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Outside the group, he struggles with feeling like he's let his father down, because he hasn't been able to take over the family construction business as expected. While his sister is a dentist, he still lives at home. Part of the reason he comes to the group is to spread awareness through the Austim News Network to younger people with autism, explaining that they'll need support in the "real world."

"I've been out in the real world where people don't care if you have a disability or not," he says. "They don't care."

His support is his mom and the Autism News Network group. He loves it so much he comes for free, he says.

That's actually something Gwynette would like to change. He wants to be able to pay the participants. They show up and put in the time, he says, and earning a paycheck is a huge boost to any individual's self-esteem and self-worth.

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"I believe that God has blessed us with this program," Gwynette says. "It's something I feel strongly about, I pray about. I feel like He's got us on a mission to serve this community and beyond."

Autism News Network spreads word about developmental disability

Volunteers make a difference

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Network

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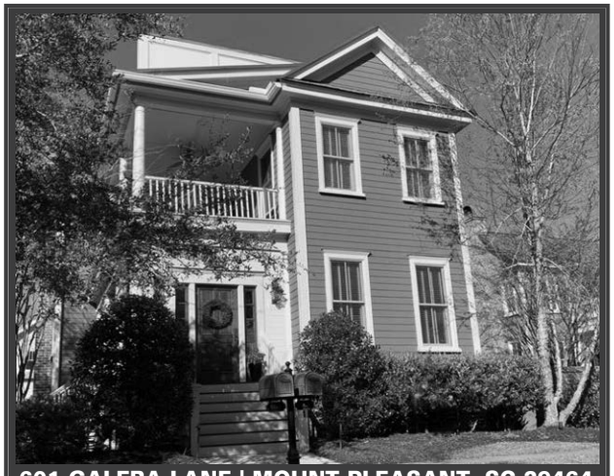

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