

Guerrilla disability rock: Sloan Meek and his music

by [Jesse James DeConto](#) in the [April 1, 2015](#) issue



A JOYFUL SOUND: Sloan Meek (right) and guitarist Noah Goyette form the duo of Meek Noise. Photo by Meredith Macy.

“All right, Lee,” murmurs a robotic voice. “If you’re ready, take it away.”

The voice comes from a laptop affixed to Sloan Meek’s wheelchair. The 26-year-old has cerebral palsy and cannot speak. His longtime live-in caregiver, Wendy Lincicome, spends hours asking him questions in order to craft short speeches like this one, an introduction to a worship song Meek wrote with Lee Anderson, one of his part-time aides. A microphone over Meek’s wheelchair captures the sound from the laptop speakers. It also captures his own voice, in those moments when it’s able to fight its way from a body that won’t cooperate with his brain.

The song is called “I Am for You.” At Durham Presbyterian Church in North Carolina, Amanda Diekman has just preached a sermon on God’s abundant love in the midst of suffering. Now Anderson strums his guitar and sings: “I am the bread of life; when you’re hungry, I will fill you.”

For Meek to eat, Anderson and Lincicome have to place food in his mouth. These three, the Diekmans, and others live in Durham’s North Street Community, an intentional neighborhood of people with and without disabilities. Lincicome and

Meek's apartment there is outfitted with a harness on a ceiling track to move him from his bed to the bathroom and back again. To get him into the church this morning, volunteers installed portable metal wheelchair ramps on two separate sets of stairs.

Anderson reaches the song's chorus, "I am for you! I am for you!" Meek, though he can't articulate most of the words, joins in. It's not singing exactly, or at least it's not like any singing you've ever heard. It's more like a moan that captures the melody's dynamic movement without matching the notes or words precisely.

For the past couple of years, Meek has been on the circuit as a guest worship leader in Durham and Chapel Hill. "I Am for You" is his current big hit. Its title comes from a banner at a community center run by Reality Ministries, a Christian nonprofit that fosters relationships among people with and without disabilities. (Disclosure: my wife works there.) The lyrics riff on short devotionals given by Reality staff and volunteers:

I am the light of the world,
in the darkness, I am shining,
in the darkness I will lead you,
I am the good, good shepherd,
from the thieves I will protect you,
when you wander, I will seek you.

"The first time I heard Sloan and Lee do that song," says Susan McSwain, executive director at Reality Ministries, "I thought in that moment, 'What did I do to deserve to be a part of this?'" She finds Meek's singing more meaningful than "the greatest opera singer on the stage. . . . Even though we can't understand the words that he's singing, he's singing those words, I am absolutely sure of it."

People are often moved to tears when they hear Meek groaning along with these words, and all they can see is that he's stuck in a wheelchair and can't get the words out. They don't even know that he's blind and has frequent, life-threatening seizures. They don't know that he was in and out of a coma for four months at age 14, nor that most people with his condition are gone by age 20.

Three years ago, doctors misdiagnosed a case of pancreatitis. It was months before Meek finally got the treatment that helped his digestion, and he ended up with a pressure sore and a bone infection that might never heal. "He will always be on

antibiotics,” says his mother, Suzanne. “There’s nothing else we can do. They’re going to stop working at some point. People have no idea how really, really sick he is, but he’s a warrior.”

The words that sound from Meek’s speech software come from other people. He can’t say exactly what he feels, nor what “I Am for You” means to him. But when he sings his whole body writhes, like he’s trying to force the lyrics out. He smiles when you notice him, when you talk to him. He groans, seemingly in agreement, when someone talks about love, or Jesus, or the dignity of people with disabilities. When he sits by himself, he looks tired, bored—though his family and friends say he hears everything around him. It’s as if he perceives the world around him clearly, but the world doesn’t know it.

In 1999, the Special Olympics World Summer Games were held in Raleigh, and Meek was featured in a video. He was 11 and wore a green bandanna around his neck as he sat in his wheelchair. “People don’t know that I’m really cool,” he said, his synthetic voice then that of a child’s. “They don’t get it that I’m talking to them, but not with their regular language. I’m showing them my own. They think I won’t understand if they talk back to me.”

Meek’s language has long been music. Lacking eyesight or speech, he relates to people through hearing. When he was an infant, before his diagnosis, Suzanne noticed him trying to shout along as she sang. By the time he was 18 months old, Meek had figured out that he could get his mother to play his favorite jazz fusion album by refusing to do his physical therapy until she did. Home movies show Meek as a toddler banging on a plastic xylophone and singing along while James Taylor performed on Sesame Street. “He’s pretty much been obsessed with music since he was ten months old,” Suzanne says.

Another home video finds him sitting on one aunt’s lap as another aunt plays piano and the family sings “Angels We Have Heard on High.” The song’s “Glorias” are the sort of simple, swelling lyrics that invite Meek’s voice—much like “I Am for You” or Leonard Cohen’s “Hallelujah,” another favorite of Meek’s. Long, sustained notes give his voice a chance to resonate with another’s.

“There are times when our voices will blend together,” says Anderson, “and you can’t tell whose voice is whose, just like any good harmony.” As a religion student at UNC-Chapel Hill, Anderson volunteered as Meek’s “buddy” at Reality’s Tuesday night

gatherings.

“When the music started, I just kneeled down next to him, and we just started singing,” says Anderson. “I don’t want to romanticize disability too much or over-spiritualize it, but I remember thinking, man, that must be such a beautiful sound to God.” Before Anderson became one of Meek’s paid respite workers, the two sang together—and Anderson began to see how he might write a song for his friend to sing.

“Externally, it probably looks like I was just writing the song,” Anderson says. “But we were there together. I wouldn’t have written the song without Sloan. I’ve sung with him enough that I know where he likes to hang out, likes to dig in. We were physically together as the song was happening. It felt like we were doing something together. I know that he’s a creative soul. When you’re in a creative space with another creative person, it’s one of those things I can’t really put my finger on.”

Reality Ministries grew from the ashes of conflict. In 2007, theological differences led to the entire Durham-Chapel Hill staff of the evangelical group Young Life being fired or resigning. Jeff McSwain—Susan’s husband—was the leader, and he had been promoting what he called the “Gospel of All-Along Belonging,” the idea that Christian conversion can come after acceptance into a community of grace, not only before. The group had already been building a ministry for people with disabilities, so it formed Reality to focus on this work. The goal was to blur the lines between servants and served by spotlighting the image of God in each participant.

Around that same time, Meek moved into Lincicome’s home in Durham, funded by a Medicaid program that helps keep people with disabilities out of more institutional settings. Lincicome had worked as Meek’s part-time caregiver for five years of his childhood. Later he lived in a group home, and Lincicome acted as a big sister, visiting him and going along on family vacations. It took three years for her to secure funding to foster him in her home, but now Medicaid provides not only her salary but also respite-care pay for Anderson.

It also allows for a “community networking” budget. This enables Noah Goyette, who met Meek while working at his group home, to take him out into Durham to do volunteer work. “He loves music; he loves socializing; he loves food,” says Goyette, a social work student and a musician. “He wants to be surrounded by compassionate, open-minded, enthusiastic people. . . . We were looking to make his

life outside his home to really be about him. I was able to be his sidekick in his whole new life.”

Meek began to find his voice as a performer at an annual Reality talent show in 2008. He read an “Ode to Reality” he had written, naming many of the friends he had met there and all the gifts they bring. One of his closing lines signaled what was to come: “My favorite thing is when we sing.” A year later, he and Goyette sang the Beatles’ “Let It Be” from that stage.

“At Reality, he never worries if he can do it or not. He goes for it,” Lincicome says. “He’s just confident to be himself and to get up on a stage and perform. He knows that with everyone around him, he’s going to get a standing ovation from all his friends.”

In turn, Meek has become an ambassador for Reality, singing in local churches and at events at Duke Divinity School and elsewhere. Alex Furriness, a 22-year-old North Street neighbor with Down syndrome, sometimes travels with Meek and Anderson as a sort of roadie. Meek also met his girlfriend Janie Desmond at the Reality Center six years ago. Desmond has a milder case of cerebral palsy and is able to attend the University of North Carolina at Greensboro, but she has lived in the North Street Community during school breaks.

“We all get by with a little help from our friends,” says Meek, in one of his prerecorded speeches for Durham high school students. “I love living my big dream of being a rock star.”

Anderson’s father Fil, a longtime Young Life colleague of the McSwains, heard “I Am for You” for the first time at Meek’s birthday party last year. “I just thought, oh, this is dreadful,” he says. But soon “it became in a way the most beautiful music I’ve ever heard. People have always known it’s a good thing to help people with special needs. But it’s terribly sad to me that when the stories of Jesus are told, there doesn’t seem to be a consideration that maybe Jesus was getting something out of the relationships, too. To me it’s inescapable: everyone has gifts to offer. It thrills me to see [Meek] being my son’s teacher.”

Twice a week, Meek and Goyette play music at the Durham Center for Senior Life. On a recent afternoon, Meek sat near the eight-foot windows at one end of a sunlit game room. Elderly men and women encircled a half dozen round tables, playing cards or checkers, doing puzzles, knitting, or flirting. Next to Meek was Goyette, who

sees himself as “a combination of Alfred and Robin to Sloan’s Batman.”

They call the duo Meek Noise. In other contexts, their repertoire can be pretty noisy. Some Duke engineering students outfitted Meek’s wheelchair with clamps to hold a guitar or keyboard. Goyette puts a guitar in open tuning, a traditional technique that allows a chord to be played with just the strumming hand. Meek lacks the dexterity to play melodies or form chords in standard tuning, but he can strum. Anderson has likewise reprogrammed the pitches of the keys on a keyboard so that there are no dissonant notes. “It often ends up being quite beautiful,” says Goyette.

Sometimes Goyette, who is most comfortable as a drummer, places a small drum kit on the sidewalk, and Meek bangs along on the guitar. “He could just make all this crazy musical racket,” Goyette says. “It probably looks like guerrilla disabilities rock.” In that setting, with people walking by but no one really paying much attention, Meek’s voice might drone along to an experimental rhythm or a loud rock song. “He can really belt, and I so want to take advantage of it,” Goyette says. But Meek is a bit shy about doing this in front of an actual audience.

And so Meek Noise treats the senior center’s captive audience instead to gentler Americana and Motown hits. Goyette sings and plays guitar, relying on his laptop for lyrics and chords; Meek cries out when it feels right. After the first set on this particular afternoon, Ernest Collins—a man built like a defensive end—approached the baby grand piano 20 feet from where the guys were sitting. “Do you know any standards?” he asked.

After a few misses, he and Goyette settled on Louis Armstrong’s “What a Wonderful World.” Collins played a bass line with his left hand and arpeggios with his right while crooning the melody, like he’d been performing the song for 50 years—which he has. One of the women got up and joined the singing. At the song’s end, Collins launched right into “Fly Me to the Moon.” Goyette struggled through these songs he had not practiced, strumming along as best he could.

“Everyone’s always really supportive,” he says. “We really are just sharing our friendship. We’re sharing the joy of music. The seniors clearly love having Sloan there and knowing he’s going to be there.”

After Collins left the piano, Meek used his head to control a joystick connected to his laptop, scrolling through a list of songs he and Goyette had prepared. When he reached his choice, he pressed what looks like the Staples big red “Easy” button

with his hand.

“Milkman of Human Kindness,” spoke the robotic voice, indicating a Billy Bragg song. “This is a song about being helpful and loving,” the computer announced. “I hope you like it.” Meek was worn out by then, but he contributed some “ba-ba-bahs” to the last chorus.

Next Meek chose the song “The Rotting Strip,” by Crooked Fingers, a local band. Goyette felt a little sheepish. “It’s a song about a drunk and a prostitute,” he said quietly. But it also gave him a chance to point out that he plays the two songs with his capo—a device that changes a guitar’s pitch—in the same position. Meek was giving him an easy segue. “I feel like he really added it up,” said Goyette. “It shows his knowledge of music.”

When the set concluded, Goyette packed up and then pushed Meek’s wheelchair toward the elevator. They couldn’t get past Marjorie Young, who wore a pink flower in her long gray hair as she knitted a blanket for a friend’s great grandchild. “Let me call you sweetheart,” Young sang to Meek, “I’m in love . . . with . . . you!”

“He’s my sweetheart,” she told Goyette.

Back at Durham Presbyterian, after Meek and Anderson sing “I Am for You,” the service moves into a time of prayer. The congregation names individual requests, then they recite the Lord’s Prayer. Meek starts his recorded version a bit late. “Deliver us from evil,” says the lone virtual voice, after a hundred other voices have finished the prayer. “For thine is the kingdom, and the power, and the glory, forever and ever. Amen.”