The Atlantic tells story of adult autism through research at UNC

Joseph Piven, MD, and his team are trying to fill the gaps in our understanding of what it has meant and will mean to live with autism as older adults.

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The Atlantic has published an incredible story on adults with autism, the difficult work of caring for this population, and the research of Joseph Piven, MD, Distinguished Professor of Psychiatry in the UNC School of Medicine.

Jessica Wright, PhD, initially published the story in the Simons Foundation’s weekly newsletter Autism Spectrums with the title “The Missing Generation.” https://spectrumnews.org/features/deep-dive/the-missing-generation/” The subtitle gives a sense of the great need for Piven’s work: “Left to languish in psychiatric institutions or drugged for disorders they never had, many older adults with autism were neglected or forgotten for decades. Efforts to help them are finally underway.”

The help has not come easy, largely due to difficulties in finding adults with autism. One effort is underway at UNC, where Piven leads the Carolina Institute for Developmental Disabilities.

This brief excerpt from the article explains some of the work Piven’s group has done to bring these men and women out of the shadows:

“... Piven has faced similar challenges in trying to locate “missing” adults with autism. In 2010, he helped organize a working group in North Carolina https://www.ncbi.nlm.nih.gov/pubmed/22091837 to explore aging with autism. The group’s first step was to look for adults aged 50 or older with autism. At first, the search seemed easy. By scouring medical records, Piven found 20 adults with autism diagnoses.

“Strikingly, many were in their 80s and 90s. On further digging, Piven found that all of them had a diagnosis of fronto-temporal dementia that had preceded their autism diagnosis. This particular type of dementia can lead to social deficits that look like autism. It was clear, Piven says, that none of the individuals ever had autism at all. Relying on medical records was a bust.
“The team next sent out more than 14,000 emails through an autism society in North Carolina asking for people over age 50 to give them a call. “We didn’t get a single call,” Piven says, and few email responses. It wasn’t until the researchers began recruiting people from group homes and the University of North Carolina’s autism programs [and other programs around the state] that they were finally able to identify 19 men older than 50. Scott Hartman, whose mother drove him to Piven’s clinic on her own initiative, was one of them . . .”

“Piven’s clinic” is a joint effort between UNC’s TEACCH Autism Program and the Carolina Institute for Developmental Disabilities.