

OPINION

# Adults with autism face old age without much support

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Fifty years ago, few people had heard of the term ‘autism,’ let alone known anyone with a diagnosis. Not surprisingly, many adults with autism over the age of 50 have never been diagnosed; others received their diagnoses late in life.

In either scenario, these adults enter old age facing a loss of independence that comes with **unique challenges** — ones that society is ill-prepared to address.

An article I wrote last year highlights **how little we know** about aging with autism. Since then, however, there have been a smattering of studies aimed at better identifying and understanding autism and aging, along with a spate of editorials about how sorely such studies are needed<sup>1,2,3</sup>.

In most countries, a diagnosis of autism might help people gain **access to support services** — such as visits from aides, which can make living on their own possible. And knowing that someone has autism could help others understand why certain routines, for example, may be critical for that person’s well-being.

In a rare study looking at older adults with autism, **Hilde Geurts**, a neuropsychologist at the University of Amsterdam, followed up on the observation that many of the men and women she sees in her autism clinic also **have depression**. This suggested to her that older adults with depression warrant a closer look for signs of autism.

Her study, published late last year, revealed that 31 percent of adults between 60 and 90 years of age who have depression also show signs of autism, compared with only 6 percent of older adults without depression<sup>4</sup>.

“Most people still think that if [someone has] autism, it should have been diagnosed early in life, because it can be,” Geurts says. “When there is indeed someone with a long history of depression

and difficulties in life, you still need to think about a diagnosis of autism.”

## Coping skills:

Geurts and her colleagues are following a group of older adults with autism to see whether certain skills track with depression. They’re particularly interested in whether depression might stem from a sense of helplessness in one’s daily life.

“We want to see whether mastery — whether you can make your decisions yourself — has an influence on how strong the relationship between autism and depression is,” she says.

In a study published last week, Geurts and her colleagues documented the prevalence of psychiatric disorders and symptoms in a group of 344 adults, 172 with autism<sup>5</sup>. The study included 48 older adults with autism — individuals between 55 and 79 years of age.

Interestingly, psychiatric symptoms were less prevalent among the older adults with autism than the younger ones. The researchers found the biggest discrepancy with social anxiety, suggesting that adults with autism are developing ways to cope with social situations over time.

The independence that allows adults to develop these coping skills is often hard-won. But independence fades, often dramatically, with age, as physical and mental capacities wane. For people with autism, who often cherish their self-determined routines and even solitude, the decline can be especially traumatic. A number of adults with autism are now voicing these fears.

## Mandatory bingo:

“The isolation that many people on the spectrum experience due to social and communication difficulties is likely to worsen with age,” Susan Dunne, a woman with autism in her early 50s, wrote in a **blog post** for *The Guardian*. “Having a chirpy care worker turn up at unexpected hours to make small talk and suggest joining bingo at the day centre is unlikely to be of benefit, however well meant.” Her perspective echoes the sentiments in many comments made in response to my article and others like it.

Researchers are aware of these problems. But because so few elderly adults have an autism diagnosis, healthcare workers have little experience helping them navigate the pitfalls of old age. And the unusual needs of most elderly adults with autism are likely going **unrecognized and unmet**.

“What happens when you’re in a nursing home and the nursing assistant may change every shift, and put you through a different routine?” asks **Joseph Piven**, professor of psychiatry at the University of North Carolina at Chapel Hill. “How to care for these people is not at all clear.”

Figuring out how best to look after adults with autism is not easy, but researchers are finally taking strides toward solutions. The first step is acknowledging that autism exists in this older generation. The next steps will involve pinning down what autism looks like in these older adults — and applying that knowledge to help them adjust to aging.

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