

Autism Prevalence and Outcomes in Older Adults

John Elder Robison 

Recent studies of mortality, illness, and suicide among autistic adults paint an alarming picture. Autistic people appear to die much earlier than the general population, and they seem to be far more vulnerable to a surprising range of medical problems. Suicide and depression seem far more common than in the general population. If correct, that suggests an older autistic population in silent crisis, with few if any supports. If so, older autistic people should be a focus for public health and human service agencies. But is the picture complete? Autism researchers ask for answers, identifying problems and their scope. This article discusses the limitations of our adult autism knowledge, and the challenges we will face studying adults. Researching and ultimately serving older autistic adults presents a unique set of problems that have not yet been addressed by scientists or clinicians. *Autism Res* 2019, 12: 370–374. © 2019 International Society for Autism Research, Wiley Periodicals, Inc.

Lay Summary: Public policy toward autistic people is driven by data. Most autism data to date have been derived from and about children, because autism tends to be identified and supported in the public school system. This has created a public perception of autism as a childhood problem. In fact, autism is a lifelong difference or disability, and recent studies suggest serious overlooked concerns for autistic adults. This commentary discusses how we have evaluated adult autism so far, limitations of our knowledge, and how we might evaluate adult needs going forward. The commentary makes a case for specific new adult prevalence and outcome studies to inform public policy.

Keywords: diagnosis; outcomes; prevalence; treatment

This commentary springs from deliberations of and around the NIH Interagency Autism Coordinating Committee (IACC) [IACC, 2018b], but it is not a work product of the committee. Rather these are personal thoughts informed by the author's committee service and experience as an autistic adult and parent. IACC is the senior Federal autism committee, raising questions that public health agencies seek to answer and reporting on progress in autism research. IACC is made up of representatives of concerned government agencies and public members drawn from the autism community.

One of IACC's principal duties is to ensure government has the necessary data to make informed autism policy. To that end, the committee has realized we need to know much more about autism in adults. Over the past few years IACC has arranged several presentations of adult research, all of which portrayed an adult population with serious unaddressed concerns. That first came into sharp focus following IACC's September 2014 workshop on under-recognized co-occurring conditions in ASD ["IACC Workshop," 2014]. All the available data pointed to worse health outcomes for autistic people, with more, and more severe, medical challenges as compared to the general population.

Public members rightly pointed out that adulthood represents the majority of most people's lives, yet adult autism issues have received an insignificant share of Federal funding to date. In the most recent portfolio analysis (2014–15 funding) [IACC, 2018a], only 2% of ASD research funds went to lifespan issues, while 32% was directed at genetic research. That is an improvement from 2012, when lifespan issues received just 1% of funding, but it remains very low. Members of the autistic community are increasingly calling for better adult services. There is growing support for that idea, but more information is needed. This commentary considers what we know and how we might move forward.

A 2015 study from Lisa Croen of Kaiser Permanente described health issues of autistic people in the Kaiser Permanente system [Croen et al., 2015]. Subsequent mortality studies [Guan & Li, 2017; Hirvikoski et al., 2016] suggest a diminished lifespan for autistic people. Studies from Autistica in the United Kingdom (U.K.) found much higher rates of suicide and debilitating depression ["Personal Tragedies," Cusack et al. 2016].

Unfortunately, there are significant limitations with the existing work. When discussing autism in public policy our first question might be how many adults are actually at

From the College of William & Mary, Landmark College, Springfield, MA (J.E.R.)

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Address for correspondence and reprints: John Elder Robison, College of William & Mary, Landmark College, 347 Page Blvd, Springfield, MA 01104. E-mail: jerobison@wm.edu

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risk? The fact is, we do not know the size of our adult autistic population, and we do not know if the outcome data we have is broadly applicable, or only applies to the subset profiled by the studies. The arguments that it does not apply are just as strong as those that it does.

For the past few decades, until quite recently, popular media depicted autism as a childhood problem, and sometimes a childhood epidemic. This has no doubt led many lawmakers to think of autism as a transitory concern; something children grow out of. That is very troubling to disabled autistic adults and their families who encounter few if any services after they age out of public school. The first step in addressing this problem is quantification.

Amazingly, there is only one large-scale study measuring adult prevalence. In 2011, Terry Brugha of the University of Leicester evaluated autism prevalence in a British community [Brugha et al., 2011]. That project was based on a survey of 7461 adults and looked at rates of autism and social attainment. Perhaps the most significant finding was that the rate of autism was not age-dependent, but the rate of existing diagnosis was. Brugha et al. [2011] found a fairly constant prevalence independent of year of birth. The older the study participant, the less likely they were to have been previously diagnosed with autism.

The finding that most older adults were not originally diagnosed with autism is consistent with anecdotal accounts of older autistic people that have appeared in the past decade ["Michael Forbes Wilcox," 2018; "Cos Michael," 2018; "Jon Adams," 2018]. Many came to their autism diagnoses late in life, often with no prior knowledge of the condition. If those and the Brugha et al. [2011] data are a guide, there are many older autistic adults who are unaware they would be on the autism spectrum if evaluated today. Brugha et al. [2011] found very high rates of autism among older adults previously diagnosed with learning disabilities, and they found a large number of autistic people living in group or institutional settings. Neither of those findings are surprising.

According to Brugha et al. [2011], with our current best estimates of prevalence, roughly one in 50 men, or one in 75 people of all ages are on the autism spectrum. This is consistent with contemporaneous prevalence estimates for children, such as the 1 in 56 reported by the CDC's ADDM (Autism and Developmental Disabilities Monitoring Network) in April 2018 [Centers for Disease Control and Prevention (CDC) 2018; Centers for Disease Control and Prevention (CDC), Autism and Developmental Disabilities Monitoring (ADDM) Network 2018]. The difference is, the children in ADDM are "on record," and can be followed and studied. The adults identified by Brugha et al. [2011] have, for the most part, no record of autism in their medical history and hence could not be identified by any public health database survey.

What Brugha et al. [2011] suggest is that there is a significant adult autistic population, hiding in plain sight.

They are not diagnosed, and in many cases not aware they are on the autism spectrum. Yet there are diagnosed autistic people in public health databases, in both the UK and America. In the Croen et al. [2015] study, researchers looked at data for Kaiser Permanente Northern California. That system serves over 3 million people, of which 1.6 million were adults at the time of study. 1,507 individuals were identified with ICD-9 ASD diagnoses; or approximately 0.1% of the sampled adult population.

If Brugha et al. [2011] and child prevalence data suggest the actual size of the adult autistic population, Croen et al. [2015] only identified 3–10% of those individuals. Using Brugha et al. [2011] and child prevalence as a guide, Croen's [Croen et al., 2015] study group should contain 20–30,000 autistic adults, but they did not even find 1/10th that number. We might surmise that the individuals the Croen et al. [2015] group found were those whose autism was most disabling; enough that they sought medical treatments for it.

There is a striking difference between the health of Croen et al.'s [2015] autistic adult study group and the general population, but the relevance of that and other similar findings to most autistic people remains unclear. Common sense tells us that the most impaired members of any population will have worse health outcomes as compared to the average. Those are the individuals identified by Croen et al. [2015] and other researchers in their database studies.

It is tempting to say those small and "most disabled" samples do not represent the general autistic population, as that raises the possibility of better health outcomes for the majority of autistic adults. But we must not jump to conclusions—there may be traits associated with any degree of autism that negatively impact health. There is another intriguing possibility. There is no dispute that autism is a lifelong neurological difference. It is clear that autism can be quite disabling, particularly in children and youth. Evidence of that may be seen in any public school. Some autistic adults are also visibly disabled, but their numbers are far fewer than those of kids in school. The relatively small number of diagnosed adults may suggest many autistics "grow out" of disability even as science tells us autistic people remain autistic all their lives. This may suggest that the lifetime trajectory for some children diagnosed with autism is more like that for children diagnosed with dyslexia or ADHD. In those cases we recognize that neurological foundations remain, but for most, disability recedes in adulthood.

It may be that some autistic adults remain disabled, but they seek treatment for co-occurring conditions such as depression, anxiety, GI disorders, or epilepsy, and autism itself is not mentioned or in some cases not even recognized.

Scientists already speak of a Broad Autism Phenotype (BAP), which includes people with traits of autism, but not enough disability to merit a formal diagnosis. It is

possible that some children who are disabled transition from autistic/disabled to the less impaired BAP as they age, and that may account for “growing out of autism” and “optimal outcome” as described in popular media [The Kids Who Beat Autism, NY Times, 2014] and journal articles [Fein, 2013; Anderson et al., 2014]. Hopeful as that sounds, it certainly does not represent all autistic people. Brugha et al. [2011] found a significant number of disabled autistic adults living in institutions, and we have similar populations in the U.S.; many with lifelong cognitive disability. Some members of the community argue for a separate diagnostic label for that group, as their needs are so different from the rest of the BAP. Without knowledge of the whole autistic adult population we cannot compare them in any meaningful way, and unresolved arguments rage over which group is bigger and what services each may need. With some autistic adults described as tech geniuses while others require 24/7 support for basic living, parents rightly wonder what the future holds for their autistic children. We owe it to them to find some answers.

Adult outcomes range from institutionalization to invisibly blending into the community, yielding a colossal range of implications for supports and services. If we are to have an informed autism policy, we need accurate data characterizing autistic adults. What studies like Croen et al. [2015] show is that the diagnosed (and therefore identifiable) older adult autistic population has an alarming set of problems, but Brugha and other findings suggest they are only a small percentage of the actual adult population. We do not know anything of the health of the rest. To accurately survey the medical issues of all autistic adults, we must identify a broad enough swath to describe the population. That probably means conducting a larger scale study like Brugha et al. [2011] in the U.S.

In Brugha et al. [2011], individuals were evaluated through a multi-step screening process. There was no reliance on prior medical records, and autistic individuals were identified on the spot using current screening tools. Individuals who were identified as being on the autism spectrum were asked if they had prior psychiatric diagnoses, but the survey’s results were not dependent on prior diagnoses or records. In contrast, studies like Croen et al. [2015] relied on surveying existing client databases of large public health systems. For them, identification of autistic people depends entirely on their having sought treatment for autism within the particular health network. Since many if not most adult autism diagnoses are rendered outside the insured healthcare network, and few adults receive insurance-paid autism services, it makes sense that few autistic adults would be recorded in those databases.

In conversation with autistic people, I have often been told that adults deliberately keep their autism diagnosis out of the medical record, to avoid “having it used against them.” Perceived threats include higher life

insurance premiums, higher health insurance premiums, and possible denial of professional licenses or even jobs. Those are all valid concerns and suggest there may be a good number of autistic adults who are aware of their condition but choose to fly under the radar.

Brugha et al. [2011] identified many older autistic people without pre-existing autism diagnoses. The same is likely true elsewhere; there are many industries where popular perception is, “the companies are full of undiagnosed autistics.” While that may be an exaggeration there is certainly some truth to the idea that there are undiagnosed and unaware autistics in many workplaces.

Meanwhile, autism retains a stigma in the mind of the general public. Many suspect an autism diagnosis is a basis for discrimination, with good reason. One example is the U.S. military’s policy of excluding diagnosed autistics from enlisting [Department of Defense, 2018]. At the same time, there are few services for autistic adults who are not intellectually impaired or seriously disabled, so there is no benefit-related reason and indeed a disincentive for many adults to seek diagnosis.

A few years ago, researchers believed most autistic people were intellectually disabled. That belief was founded on a limited understanding—they only recognized a small part of the autism spectrum as we know it today. Now that our sample is larger, we understand that the average IQ of the autistic population is much closer to that of the general population.

It is possible that the health and lifespan outcomes of unrecognized autistic adults are also similar to the general population, or they may be closer to the worrisome outcomes for the diagnosed autistic group. Given the size of this population and current knowledge, this is one of the most important questions facing the autism community today.

It is vital that we answer these lifespan questions, but it will be very difficult to accurately ascertain adult prevalence in the U.S. It is likely that many undiagnosed adults would not welcome a researcher’s suggestion that they are, in fact, on the autism spectrum. When this study is designed it will be critical to address both privacy and disclosure concerns. If the study is to be credible, researchers will need to use a recognized screening tool such as the Autism Diagnostic Observation Schedule (ADOS) for final ascertainment of ASD in a subject. There will be significant cost and time associated with that, and a study of this sort will represent a major commitment—possibly greater than for the current CDC ADDM research.

Completion of a proper prevalence and outcome study will provide a counter to the nonscientific pronouncements policymakers now hear about autistic adults. For example, advocacy group Autism Speaks claims, *the vast majority of adults with autism are either unemployed or underemployed, with estimates ranging to as high as 90%*, on their website. Such statements are common, but if we do not know who 90% of the autistic adults are, we cannot possibly make an informed statement about their employment status.

Ideally, an adult prevalence study will result in identification of a cohort of autistic adults who consent to long term follow up and participate in future studies. Such a group would be extremely valuable. In this writer's opinion, it would also be prudent to seek participation from children in the ADDM network as they move into adulthood. At this point most drop out of sight when they turn 18. In many cases, services delivered to children are paid for by school districts and leave no trace in medical records.

Autistic adults are rightly concerned about emergent mortality data [Guan, 2017; Hirkovsky, 2016]. Researchers do not know what to say in response. When we look at existing mortality data for autistic people we are primarily looking at an older population who was diagnosed under the DSM-IV definition of autism. Today we would call them the most impacted members of the autism spectrum, and we do not know if their health outcomes reflect those of the broader spectrum.

A present-day prevalence and health survey will not yield mortality data. For that, we need a two-step process; identification of autistic adults today followed by mortality tracking. Until then, the autistic people and the health profession will have to make their own best judgments as to whether current autistic data or general population data is more applicable to themselves and others, with significant consequences.

In conclusion, this commentary identifies a need for three major studies, to be conducted in order:

1. An adult prevalence study that identifies currently unrecognized adults and counts their numbers.
2. A health outcomes study for the group identified in (1) which would facilitate comparison with the general population and the existing study of previously diagnosed autistics.
3. A mortality study based on the group identified in (1) or an expanded adult group that actually represents the majority of autistic people.

Difficult as it will be, I suggest that we need to know much more about adult prevalence and outcomes. If we wish to better help autistic adults, we need valid data on which to base our plans. Adult outcome data will also inform child services, as we look at the long-term results of current child therapies and their influence on maturation of autistic people.

There is one final point, as regards funding. Prevalence and outcome studies do not directly serve autistic people. Rather, they inform and guide us in the development of treatments and policies that will be effective. This commentary compares a proposed adult study to the CDC ADDM study; I believe both should be supported. Surveillance of autism in children remains important; adults are an additional group to be monitored, not a replacement.

When considering this proposal, with all due respect, I suggest this is an important additional priority, and not a

substitute for ongoing research. While it may be true that some people do grow up to have minimal support needs, as the evidence may suggest, there still remains a significant population with great and mostly unmet support needs today. I do not wish readers to think I advocate turning away from them, because I do not.

The identification of a subgroup of the autistic population who sheds disability in adulthood would be wonderful indeed but will not take away from the needs of the many known autistics who do not have such good fortune. Those of us who advocate for autistic people must always remember that our duty is to the community, not just one subset or another.

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