

Transcript Details

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What is the Economic Impact of Autism Spectrum Disorder?

As prevalence rates for autism spectrum disorder increase, so do economic costs. On average, medical expenditures for individuals with an ASD were 4 to 6 times greater than those without a diagnosis of autism spectrum disorder. This has a significant impact on the US medical system.

You're listening to ReachMD. I'm your host, Paul Rokuskie. And with me today is Dr. David Mandell, Associate Director of the Center for Autism Research at the Children's Hospital of Philadelphia. Welcome, Dr. Mandell.

Mr. Rokuskie:

So, Dr. Mandell, I want to talk about economic cost. I know you've spent a lot of time looking at this and modeling this and seeing how the prevalence rates are having an impact on economic costs of ASD in the healthcare system. Can you talk about that a little bit as we've seen these numbers increasing over the past number of prevalence rates updates?

Dr. Mandell:

Yes. First, I should say that when we try and calculate what the cost of autism is, we're calculating the cost of treating autism, treating people with autism and providing appropriate supports and services to those folks who need it. We're also calculating the cost of not treating autism. We know that there are interventions that can dramatically alter the course of autism for the better, and we know that with proper services and supports, a larger proportion of adults with autism can live happily and successfully in their communities than are doing so now, so we're trying to capture both sets of costs, and to do that, part of what you can model is at the individual level. We can look at all of the direct costs associated with services and supports and the indirect costs associated with lost opportunity, both for the caregiver and the person with autism, and then we're going to multiply it by the number of people with autism to estimate the total societal cost. So, of course, those total societal costs are going to be highly dependent on the number of people that you estimate have autism and also are going to be highly dependent on the extent of the impairment associated with autism. And one way we do that is we look separately for people with autism who also have intellectual disability, for example, and those who don't. So as those numbers change, and we use them to estimate the cost of autism, the cost is going to go up substantially as the prevalence goes up, and it's going to go down, though, as a function of what proportion of people with autism we think have intellectual disability. So the short answer is that as the prevalence goes up, the total cost to society on the surface of it goes up.

We can think of prevalence as something that is some kind of ground truth in the community; that is, there's a number of people with autism, and our goal in these studies is to try and as accurately identify as many of them as possible. But if you think that the cost of having autism doesn't change based on whether somebody has given you that diagnosis, then the total cost to society is going to remain about the same if the prevalence, the true prevalence, stays the same.

Mr. Rokuskie:

So, since we have, like, well over a decade's worth of data to go back and look at prevalence rates and economic costs, if we were to chart that out, would the charts, the line charts, be parallel—that was prevalence rates are increasing, the costs are increasing at the same level, or are costs increasing disproportionately to prevalence rates, or vice versa, that they're not going on a parallel but they're slightly off?

Dr. Mandell:

Right, if all things remain equal, then as prevalence increase, those lines would increase proportionately. There are some things that are happening that if we were to estimate costs using the same strategies we've been using would make the cost line not rise as high or as quickly as the prevalence is. The first is that a huge chunk of the increase in observed prevalence from the CDC studies has to do with identifying individuals who don't have intellectual disability, and our assumptions are that the total lifetime costs associated with

those individuals will be less than the total cost for individuals with intellectual disability. The second is we've gotten better and better at identifying these kids younger and younger and getting them into early intervention, and some promising data we have suggests that if you provide intensive, early intervention, you reduce the need for services later. So it may be that if we get more kids into early intervention, we reduce some of the long-term costs associated with supports that are needed in adulthood.

Mr. Rokuskie:

Well, as a follow-up for that, one of the statistics I saw in the study was that even though there's a lot more diagnostic criteria and a lot more tools for physicians to help with the diagnosis of autism in their practices, that you really didn't see a differentiation from the last prevalence study to this one where the average age was at 4 with the hope that we've seen 18 months to 2 years of age where diagnosis can occur accurately, but in the 2 years since the last study, we didn't see a decrease in when that happens. Do we have an understanding as to why that number didn't change?

Dr. Mandell:

So, I think there are 2 possibilities. One is we're not getting any better as a society in identifying these kids earlier, right? And that is significant cause for alarm. And however good we're doing, we could be doing better. But I think there's something else that's going on as well. I think we are probably getting a lot better at identifying children who we think of as kind of classically autistic, with often accompanying intellectual disability, with sometimes relatively severe impairments. Those kids we're good at identifying early. The other kids whose impairment is not necessarily recognized or difference is not necessarily recognized until they get to an older age where some of the challenges they face are more demanding, those may be kids that we're identifying later. So you could think of even as the average age of diagnosis remains the same, that the distribution sort of has 2 peaks. We're identifying some kids earlier, but other kids who don't have intellectual disability, who may be experiencing some of the social differences we observe with kids with autism that are on grade level academically and are acquiring language at the same rate as typically developing kids, those are kids that we may—who may never have been identified before and now are identified but may be identified later than that first group of children.

Mr. Rokuskie:

Dr. Mandell, in the past I've heard statistics thrown around from previous prevalence studies that it's 4.1 to 6.2 times greater costs for an individual over their lifetime that has a diagnosis of autism versus those that do not carry that diagnosis and that there's a much greater, almost 10 times greater cost to families and healthcare systems. Has that number—those kind of numbers stayed the same as prevalent rates have increased? And what kind of cost implications have you seen specifically related to autism?

Dr. Mandell:

So I like to think about it in terms of incremental costs rather than a multiplier. So an individual with autism and intellectual disability accrues lifetime costs in the neighborhood of \$2.4 million in excess of what a typically developing individual would, and if they don't have intellectual disability, it's about \$1.4 million. And those costs are concentrated in 2 areas. One is in early childhood, both a direct cost of intensive special education, and the other is an indirect cost, because we see parents, especially mothers, dropping out of the workforce at much higher rates to be the care manager for their child. These costs are smaller though than some of the costs associated with adulthood in autism where the biggest driver of cost is residential care.

I think as a society we're getting better at providing the supports and services to families early on and also providing enough supports and services that adults with autism are more likely to live in their communities. So when you look at, for instance, one of the first most important studies that was done in this area by Michael Ganz, he estimated lifetime costs to be at \$3.2 million. Now, when we redid the study, we found lifetime costs to be substantially lower. Total cost to society is higher because there are now more people with autism identified than there were when Michael Ganz did that original study.

Mr. Rokuskie:

So, what conclusions are we seeing based off this prevalence data that well over a decade we've seen a pretty dramatic increase, almost tripling, of the prevalence rate from what it was when this analysis was done 10 years ago and that the economic costs are pretty significant? What conclusions should we as a society take a look at this prevalence rate and glean from it?

Dr. Mandell:

I would want to address that in 2 parts. The first is, what we have seen a tripling of is in the number that we get from the CDC surveillance study. Now, remember, that study has never received the amount of funding it should if you really wanted to do a rigorous epidemiologic prevalence study, and therefore, the methods that the investigators in that study came up with are very clever and are the best they could do with regards to reviewing healthcare data and education data and making decisions about which children have autism even if a clinician never assigned that diagnosis to the child in the community but they are still trying to do that without ever having seen the child in person. And there are lots of reasons as autism awareness increases and as services become more available specifically to individuals with autism that a clinician might consider those symptoms and consider the diagnosis and put enough red flags in the

clinical description of the child that the CDC clinician would say this child has autism even though the community clinician ultimately decided they didn't have autism. And I think one of the best pieces of evidence for that comes from the discussion you and Dr. Shapira had about site differences. I'm pretty sure that autism doesn't respect geopolitical boundaries. I'm pretty sure that if you went door to door and looked at kids born in Alabama, you would find a prevalence rate remarkably similar to kids born in New Jersey, but because there's a lot more advantage to having an autism diagnosis in New Jersey than there is in Alabama because of the availability of services, you're going to see differences in the identified prevalence of the disorder in the 2 states. So I think we just have to be really clear about what these CDC numbers mean and how we can interpret them, and they have done great things to bring attention to issues related to autism, and they have been used for some really important studies of disparities in diagnosis and in geographic differences, but we want to be careful about the extent to which we think these numbers really represent the true prevalence in each site.

I think that one of the biggest challenges in talking about this as if it were the true prevalence of the disorder is that because the numbers have been increasing so dramatically in terms of what the CDC finds, that it creates a tremendous sense of alarm about that increased prevalence. That may be due solely to the methods that are being used rather than a true increase in the real prevalence of the disorder.

Mr. Rokuskie:

So, Dr. Mandell, can you talk about the specific financial impact that autism spectrum disorder has on individuals and their families?

Dr. Mandell:

So, what it costs to treat people with autism and to provide appropriate interventions and support is what it costs, and we can use it as a benchmark to try and make treatment more efficient, and we could use some of the costs of not treating and caring for people with autism as a benchmark of what society has to gain economically from providing more efficient and more effective treatments and supports early on, but I think that's a dangerous—that's a dangerous set of equations and a dangerous thought experiment in which to engage, because ultimately, we should be making decisions about how we support people with autism and their families based on our values as a society rather than what it costs. There's a purely utilitarian perspective in thinking about how to treat autism that's going to leave some people out and some people worse off than they were before. So I think we can use these economic numbers as benchmarks to call attention to the problem, to point out that the research dollars for autism based on what autism costs society are nowhere near what they should be compared to the costs associated with other health conditions that the NIH and other federal agencies fund research on, but when we start to think about what the system of care should look like and what services and supports should be available, I hope we would do it with the idea of what maximizes happiness and quality of life for people with autism and their families rather than purely on economic grounds.

Mr. Rokuskie:

My thanks again to my guest, Dr. David Mandell, Associate Director of the Center for Autism Research at the Children's Hospital of Philadelphia.

Dr. Mandell:

I really appreciate the opportunity. Thanks for bringing attention to this really important issue.

Mr. Rokuskie:

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I've been your host, Paul Rokuskie. Thank you for listening.