

Are we ready for a test that could 'pre-diagnose' autism in babies?

July 31 2015, by Karen Rommelfanger, Jennifer Sarrett

For children with autism, early intervention is critical. Therapies and education – especially in the first two years of life – can facilitate a child's social development, reduce familial stress and ultimately improve quality of life.

But while we can reliably diagnose [autism spectrum disorder](#) (ASD) at 24 months, most children are diagnosed [much later](#). This is largely due to a lack of resources, poor adherence to screening guidelines and the fact that [primary care physicians](#) are often uncomfortable [talking about](#) autism risk to parents.

But what if we could use a simple, routine test to screen every baby for autism? It's not as far-fetched as it sounds. Larger-scale clinical trials for an eye-tracking device that could be used to predict autism are [slated to begin](#) this year.

This presents a new and unique set of ethical concerns. Technologies that predict the possibility of a neurological disorder have the weight of affecting conceptions of not just "what" these children have but "who" these children will become.

As a neuroethicist and autism researcher, we believe it is time to have a conversation about these technologies, and what it will mean for parents and children or for people with autism.

Why use eye-tracking to predict autism?

Many researchers have [found](#) that autistic children prefer to [look at](#) different things than typically developing children. This is called gaze preference. In fact, gaze preference changes can be detected prior to the onset of autism. Researchers have been using eye-tracking devices to record where babies gaze when viewing videos of social scenes. And they have been using this device not to diagnose autism, but to predict autism.

A 2013 study using an eye-tracking device found that differences in gaze preference can be detected in infants as young as two months. When viewing videos, the infants who look at mouths more than eyes and objects more than people are more likely to later be diagnosed with autism. These infants experienced a [decline in attention](#) to [other people's eyes](#).

The researchers from this study are working to replicate these findings in larger studies and are heading up the development of the [eye-tracking device](#) slated for clinical trials this year, and should the trials be successful, researchers will seek FDA approval for the device.

The device is noninvasive, relatively easy to use and portable. And it could provide a standardized, objective measure for predicting autism. In other words, it would be a pre-diagnostic tool. This means that, by identifying the possibility of autism early, eye-tracking devices could increase the chances that children will be officially diagnosed earlier. This would especially help children who tend to be diagnosed at later ages because of disparities related to [race](#) or [geography](#).

In fact, researchers have suggested it could be used as part of a routine [well baby checkup](#) for 18- to 24-month-olds. And if the technology proves to be useful in predicting autism in infants, why wouldn't the

device one day be utilized even earlier for two- or six-months-olds? A pre-diagnostic assessment for autism could be easily built into regular checkups, instead of waiting for parents to report symptoms and get an appointment with a specialist. This could be a major leap forward for getting kids diagnosed early with ASD and started on therapy, or providing interventions even prior to the development of autistic traits.

What does 'risk' of autism mean?

Imagine your baby is assessed for pre-diagnostic autism with an eye-tracking device, and you learn that he or she is likely to be later diagnosed with autism.

What does that mean? How should we talk to parents about this? And bear in mind that autism is highly variable and has a very wide range of both symptom profile and age of onset, which complicates how accurate such an assessment can be.

A positive assessment would indicate a higher likelihood of the child being diagnosed with autism. A negative one would indicate a lower likelihood. That is not the same thing as getting a diagnosis for autism in infancy. This is pre-diagnostic. A positive assessment could be used to justify an early therapeutic regimen even prior to an [autism diagnosis](#). Early intervention can provide long-lasting improvements in the quality of life of the children, families and caregivers of children with autism. For pre-diagnosed children, the hope would be that intervening before the development of significant autistic traits would be even more beneficial.

The promise of having an opportunity to provide earlier intervention – perhaps earlier than ever before – and to implement this technology in routine community pediatric care requires that we consider the development of this technology very carefully.

For example, what exactly will parents be told upon receiving such an assessment? The word "risk" may fail to communicate the vast range of possible outcomes and instead place too much focus on negative outcomes related to an autism spectrum diagnosis (ASD). Not every child who receives a positive assessment after all will actually be diagnosed with autism (to be sure, even with a tool with as much promise as eye-tracking, there will be false positives).

We should be mindful of the effect a positive assessment (false positive or not) could have on a child and their family. In many cultures, for instance, a condition like autism would stigmatize an entire family.

In the absence of care and resources, especially for children so young, a positive assessment (even if the assessment is found to be wrong or a false positive) could be seen as more of a sentence rather an opportunity for intervention, a sentiment that could occur even within research trials.

How do you treat a child "pre-diagnosed" with autism?

While several research groups have raised the possibility of an objective test for toddlers using the eye-tracking device, eye-tracking has also been used in a preliminary study to predict autism in two- to six-month-olds. What if, in the future, babies are regularly assessed at younger ages, for which we do not yet have interventions? What could (and what should) a parent do in that situation?

There are currently no evidence-based interventions available for babies under 12 months. The next phase of studies following upcoming trials will involve testing the development of a [novel early intervention](#) for [12-month-olds](#). Other researchers are attempting to develop interventions for [six-month-old infants](#).

A positive assessment might motivate parents to invest unnecessarily in expensive interventions, surveillance and treatments. It could also lead to changes in the life trajectories of the child, caregivers and entire families such as changes in their financial plans and reallocation of time and material resources to a child's early intervention or care.

Even after a false positive (an assessment for high risk that is determined to be wrong) is identified and the likelihood of getting a diagnosis of autism is determined to be quite low, caregivers may be unable to stop looking for signs of autism as a child ages.

There are no autism-specific medications (because we still do not know the causes of autism), though drugs are frequently used to treat children for a variety of autism-related symptoms.

In fact, psychotropic drugs have been prescribed to children less than two years of age, and risks of these medications on early development have yet to be determined.

And adherents of a growing [neurodiversity](#) movement – an advocacy position that rejects notions that autism is unwanted and should be cured and, instead, acknowledges [autism](#) as a natural variant of human neurological development – would resist the use of "risk" in relation to ASD.

Not a diagnosis, but a pre-existing condition

Policymakers must consider the impact of the possible integration of these tools into regular pediatric practice and infant care as a new, community-wide pre-diagnostic assessment tool.

Predictive detection technologies such as these will present a new set of policy considerations. Will insurers pay for the test? If they do, will they

pay for treatment and intervention afterwards? Because of the potential for long-term health-care savings, would there be penalties from insurers for not undergoing such an assessment? Right now, we just don't know.

Keep in mind that insurers were not prohibited from denying people coverage for preexisting coverage until the Affordable Care Act (ACA) was passed. But with this test, we aren't talking about a preexisting condition. We are talking about a predictive technology, a "pre" whose results essentially create a new category of health or illness, well before the condition even becomes a preexisting one. Think of it as a pre-preexisting condition. This situation is not addressed by the ACA.

The insurance implications can spread beyond childhood. How a predictive assessment will affect life insurance policies and long-term care insurance is unknown.

Because information about one's brain health often feels especially identity-forming, privacy policies will need to be created to determine how pre-diagnostic information be kept and who will have access to the results of these assessments. Will schools, future employers or insurance agencies have access to this information?

As eye-tracking devices head toward clinical trials, it is critical to think about and address these concerns in a public forum and alongside the development of these technologies.

Without such a discussion, these tools, despite their enormous potential, risk losing resources and public support to be fully developed and advanced or risk being underused or not used properly at all.

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Source: The Conversation

Citation: Are we ready for a test that could 'pre-diagnose' autism in babies? (2015, July 31)
retrieved 26 April 2024 from

<https://medicalxpress.com/news/2015-07-ready-pre-diagnose-autism-babies.html>

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