

VIEWPOINT

To screen or not to screen: That is not the question

BY MAYADA ELSABBAGH

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On the heels of an intense election in Canada and on the brink of another in the U.S., we're becoming all too familiar with political polemics. Voters are forced to take sides, and even the most complex problems become reduced to two-sided arguments.

I can't help but see a parallel situation in the recent debate about autism screening.

In August, the **U.S. Preventive Services Task Force** announced that there is **insufficient evidence that the benefits of screening** children with no obvious autism symptoms outweigh the risks. The statement is technically accurate and consistent with the conclusions of public health experts in the U.K. and the Netherlands. But it has been polarizing.

Public health experts, on the one hand, believe the goal of screening is to facilitate a diagnosis and expedite care. But they say there's no strong evidence that screening every child for autism in a doctor's office is accomplishing this goal.

For their part, autism experts acknowledge that such screening is fraught with implementation challenges. But they fear it's the only way to gather the evidence public health experts need. They also worry that recommendations against universal screening will make it harder for families to access care.

In situations such as this, I wonder if science and advocacy are uncomfortable bedfellows. If we want our research to affect policy and practice, we make recommendations that generate or reform policy. But policy is rarely based on evidence alone. All too often, it succumbs to special interests and political pressures. This makes it tricky territory for scientists.

Proof versus policy:

New Zealand's chief science advisor, **Peter Gluckman**, who has written extensively about the interface of science and policy, believes that science should not dictate policy. Rather, it should provide "an important base for a rational assessment of options weighed up against those other criteria that politicians and their supporting policy advisors should consider," Gluckman wrote in a **2011 report for the Prime Minister's Science Advisory Committee**. I find his perspective comforting because it values the skills of scientists over their personal values and beliefs, which are no better than anyone else's.

Identifying children with autism is a complex scientific and societal challenge, and we should ask ourselves two questions: Are we considering all relevant evidence? No. And is screening every child too simplistic a solution? Yes.

There is an urgent need for thoughtful deliberation among autism experts as to whether screening is the only or best approach in any context. Too often, instead of addressing this larger question, discussions about screening are reduced to a comparison of screening tools.

This overemphasis on autism-specific tools distracts from what we can learn from other fields, such as child development. It is against this older and larger evidence base that we can continually define what we know and don't know about when and how autism emerges early in life.

I also think researchers have been overly cautious about integrating evidence from genetics and neurobiology into discussions about screening, either because these topics are too complicated for an audience of policymakers or because of societal fears surrounding prenatal testing. It's a shame that biology, which can arguably reveal the most universal 'truths' about us as people, gets low priority among scientists when considering an important health and social challenge.

Perhaps the way forward, as Gluckman suggests, is for scientists to synthesize all the available evidence about genes, the brain and behavior in the context of autism and how it emerges early in life. This exercise could provide a rational basis for a range of options for identifying children at risk and developing effective pathways to care.

One size fits some:

Even if we have better screening tools, we don't know that screening every child at the doctor's office would identify more children with autism than would other surveillance methods that can pick up these children in different community settings. These settings could include maternal and child health programs, social programs and daycare centers.

The best options are likely to vary by community. For instance, where I live in Quebec, there are no screening programs for autism yet, and the wait time for diagnostic and intervention services is a serious concern. If we implemented universal screening in family medicine practices, even greater numbers of concerned parents would end up on waitlists for the services they need, and

socioeconomic disparities in access to care would increase. However, the province does have strong community-based child health programs where identification and support strategies may find a better home.

So instead of recommending universal screening as a one-size-fits-all solution, we should thoughtfully consider how best to identify at-risk children in different communities, piggybacking on strong, existing programs. This approach is also consistent with the United Nations' **Millennium Development Goals**. Although the goals address challenges that are broader than autism — they include poverty and education gaps — the United Nations calls for strategies that focus on process rather than targets and in which success would come from building on community strengths.

I don't think there will ever be agreement on universal screening. But now is not the time to take sides. It's the time to ask better questions.

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