

VIEWPOINT

Communication lapses hinder autism research

BY CHRIS GUNTER

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The term ‘deficit model’ has traditionally meant treating people with autism by focusing on their limitations rather than their strengths. But I would like to introduce – and ultimately abolish – the deficit model in a different context: science communication.

Communication is critical in helping the public to understand advances in autism research. If we can’t explain the importance of our research, we won’t secure funding or public support. In fact, some granting agencies and tenure committees now require public outreach activities.

Thanks to social media, engaging the public is easier than ever. But most of us are using a deficit model to structure these interactions. We believe that if people are skeptical about a certain finding, they must lack information. Correcting this information deficit will help them understand and act accordingly.

Scientific evidence suggests this approach is unrealistic.

Anyone who has had to address the issue of autism and vaccines can vouch for the fact that simply relaying information is not enough to change someone’s behavior. The field of autism is not unique in this sense. A 2011 study found that informing people about the dangers of climate change actually lowered their perception of the risk¹. Similarly, providing a scientific explanation of synthetic biology doubled the proportion of people **who perceived more risks than benefits**, a 2009 study found.

We have to accept that public opinion is not based on information alone. Rather, it incorporates a person’s trust for the information source and their pre-existing beliefs. This is important because it

affects the types of research projects that get funded, as well as the types of treatment programs and research studies that families are willing to participate in.

John Elder Robison provided an important example in his eloquent address at the **2014 International Meeting for Autism Research**. “There’s the continuing reality that lay people in the community believe that scientists want to do genetic research to eradicate autistic people,” said Robison, who has **Asperger syndrome**. “That may be the farthest thing from a researcher’s mind, but the fact that the public believes it is a disaster for researchers.”

It is a powerful reminder, now that I am establishing an autism genetics research program at the Marcus Autism Center in Atlanta, Georgia. We must collaborate with our study participants and design studies together. For example, current genetics studies differ widely in their plans to return results to participants. When we think about fostering trust, this is an obvious starting point.

How we communicate is also important when we try to engage caregivers in treatment plans — particularly ones that take a long time to pay off. A **new study** by my colleague Nathan Call and his team found that parents might place less value on these ‘delayed outcomes’ than researchers do². In other words, simply informing them of the benefits of a behavioral intervention is not enough to keep them in the treatment program long-term.

Studies like Call’s can help us develop best practices for communicating our findings. As a field, we can develop tools to assess a caregiver’s engagement in a treatment program upfront, and emphasize smaller successes along the way during a longer intervention.

By changing the way we engage the community in our work, we can advance our understanding of autism together. It’s time to reduce the communication deficit.

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References:

1. **Kahan D.** *et al. Nature. Clim. Change* **2**, 732-735 (2012) **Abstract**
2. Call N.A. *et al. J. Autism Dev. Disord.* Epub ahead of print (2014) **PubMed**