

research snapshot

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How Reliable Is the Information on Advocacy Websites?

What is this research about?

Parents of children with neurodevelopmental disorders face many challenges, such as making complex treatment decisions. Many will use the internet to seek information and advice on possible treatments. They also use the internet to enhance their knowledge and understanding of their child's condition so that it can be explained to the child and others. The internet can be a useful tool for parents, but it is largely unregulated. Much online health information does not match official treatment recommendations. The researchers aim to find out how much treatment information provided on the websites of popular advocacy organizations for neurodevelopmental disorders is reliable.

What did the researchers do?

Both a quantitative and qualitative analysis was done on advocacy websites. The researchers focused on sites relating to: Autism Spectrum Disorder (ASD), Cerebral Palsy (CP), and Fetal Alcohol Spectrum Disorder (FASD). The top 3 most popular websites were chosen based on the amount of user traffic, and were analyzed for information regarding the number and types of treatments featured on their webpages, as

What you need to know:

Many advocacy websites for CP, ASD and FASD provide a variety of resources. But their information is often unsupported or unverified. The internet should be a place to supplement medical advice for parents, rather than replace it. Physicians and parents would benefit from more reliable and transparent online health information.

well as their conventionality and accessibility (for example, over-the-counter or under medical supervision). The types of evidence provided in support of claims about their safety and efficacy, such as citations to peer-review publications versus personal anecdotes or unsubstantiated claims, were also examined.

What did the researchers find?

146 treatment products and services were identified across 9 websites. Products where scientific evidence for safety or effectiveness was judged to be unnecessary (for example, clothing, toys, and wheelchairs) were excluded from analysis, leaving a final total of 98 treatments. Diet and supplemental treatments were the most common treatments featured. 39 out of 98 treatments and services were considered

conventional, and 81 out of the 98 were readily available over the counter. Peer reviewed publications were cited to back up claims about the safety and efficacy of treatments only 13% of the time. When peer-reviewed publications were cited, 20% were incorrect or irrelevant. Non-peer reviewed work was cited in support of 11% of treatments and 6% had incomplete citations. Overall, websites made frequent unsubstantiated claims about the safety or success of a treatment or service and about the etiology of the disorder.

The majority of treatment claims on advocacy websites were not supported by peer reviewed evidence.

How can you use this research?

Parents may find this research useful while consulting the internet about their child's treatment. Attention should be paid to the site credentials and the types of evidence used to back up treatment claims.

Healthcare practitioners should understand that parents may not be getting reliable information from the internet about their child's condition. They should encourage them to ask their health care team any questions.

About the Researchers

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Cerebral palsy, Autism spectrum disorder, Fetal alcohol spectrum disorder, Advocacy websites, Online information, Internet advocacy, Treatments, Neuroethics

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