

Innovating Accessible Healthcare: The Autism Society of America's Vaccine Education Initiative

By: Danielle Hall¹

¹Autism Society of America

Keywords: autism, accessible healthcare, vaccine education, intellectual developmental disabilities, community-based education, trust

Abstract

The COVID-19 pandemic exposed critical inequities in healthcare, particularly affecting individuals with intellectual and developmental disabilities (IDD), Autism, and complex health conditions. People with Autism often face substantial barriers in accessing life-saving vaccines, driven by systemic workforce shortages, inadequate training, and fragmented healthcare systems.

To address these disparities, the Autism Society launched its Vaccine Education Initiative (VEI) in 2021, a pioneering model promoting equitable access to COVID-19 vaccines through community-based education, healthcare provider training, and universal design principles tailored to the unique needs of the Autism community.

VEI focuses on dismantling barriers to healthcare by incorporating trauma-informed and person-centered approaches to vaccination. By addressing sensory, communication, and emotional needs, the initiative creates accessible, individualized experiences that reduce vaccine hesitancy and foster trust within the Autism community.

The initiative's success demonstrates the value of integrated healthcare that considers the whole person, extending beyond vaccines to other medical services. VEI's emphasis on trauma-informed care, communication support, and policy advocacy is designed to build a healthcare system that is inclusive, accessible, and equitable for Autistic individuals and other marginalized populations. By advocating for systemic changes, including the designation of people with disabilities as a medically underserved population (MUP) and the reauthorization of the Autism CARES Act, the Autism Society aims to ensure sustainable, long-term improvements in healthcare delivery for these communities.

Introduction

The COVID-19 pandemic revealed severe inequities in healthcare access and outcomes, particularly for individuals with intellectual and developmental disabilities (IDD), Autism, and complex health conditions. Despite often being at higher risk of severe illness, many people with disabilities faced significant barriers to accessing life-saving vaccines during the COVID-19 vaccine rollout, highlighting systemic gaps, including workforce shortages, inadequate training, and fragmented systems that fail to meet the needs of disabled populations.

To address these barriers, the Autism Society began its Vaccine Education Initiative in 2021 as a pilot project aimed at increasing access to COVID-19 vaccines for the Autism community. As an integrated, community-based model that promotes vaccine education, accessibility, and healthcare provider training, the Vaccine Education Initiative works to advance health equity by breaking down barriers to vaccination faced by the Autism community.

Barriers to Vaccine Access

Historically, people with Autism and other developmental disabilities have lower immunization rates than their peers without Autism, leaving them vulnerable to vaccine-preventable diseases. Vaccine hesitancy is a long-standing and possibly misunderstood issue within the Autism community.

Although vaccine hesitancy in the Autism community is often attributed to safety concerns, the Autism Society's project identified another important factor: many Autistic individuals and their families expressed hesitancy due to negative past experiences with vaccinations. These experiences often led to stress, fear, anxiety, and, in some cases, trauma. Typical vaccine appointments frequently overlook the unique sensory, communication, and information-processing needs of Autistic people. Even a single difficult vaccine experience can create lasting distrust and barriers to future healthcare, making improving the vaccination experience a critical step towards achieving more equitable healthcare for people with Autism and other disabilities.

The Vaccine Education Initiative (VEI)

At the heart of the Vaccine Education Initiative is the promotion of integrated healthcare, designed to dismantle the barriers that prevent individuals with Autism from receiving equitable care. The initiative incorporates universal design principles to meet sensory, social, cognitive, and physical needs while addressing both the medical and non-medical aspects of healthcare delivery, ensuring care is equitable and person-centered.

By collaborating with more than 12 million individuals and over 7,000 healthcare providers, the Autism Society has spearheaded a national campaign that facilitated over 125,000 vaccinations across 800 clinics in 26 states in just one year. These clinics have been designed to be sensory-friendly, individualized, and accessible, ensuring that Autistic individuals receive care in an environment conducive to their needs.

The strategies, resources, and tools used in this program are informed by the Autism community and by science, applying evidence-based practices for Autism instruction and intervention to the vaccine experience. By focusing on supporting information processing differences, sensory needs, and access to communication, the VEI has worked successfully to transform the vaccine experience.

Communication boards, visual schedules, and social stories have proven to be helpful in supporting the information processing and communication needs of Autistic individuals and reducing anxiety at each stage of the vaccination process. These tools and strategies have been effective for Autistic individuals with IDD and for healthcare providers, families, caregivers, and other patients who may have needle phobia, anxiety, and other neurodiverse differences.

Accommodating sensory needs by creating sensory-friendly environments and offering sensory accommodations and support also made a significant difference in the vaccine experience. Sensory overwhelm can be a huge factor influencing a person's ability to communicate, manage stress, and stay regulated. By creating a calm and supportive sensory environment, healthcare providers can set the stage for success for patients with Autism and other disabilities.

The VEI has empowered communities with confidence, resources, and accessibility, reinforcing the importance of vaccination for broader public health. This model can easily be adapted and applied to other healthcare modalities, like mental health care, emergency rooms, dental care, and primary care, ensuring that a wide range of medical settings become more inclusive and accessible for Autistic individuals and others with disabilities.

Trauma-Informed Model

The Vaccine Education Initiative incorporates trauma-informed care to support individuals who have experienced negative or distressing healthcare encounters. Autistic individuals are disproportionately subjected to traumatic experiences due to a gap in understanding Autistic needs and experiences. Because of this knowledge gap and to save time, providers often restrain Autistic patients during vaccinations, unaware of the long-term trauma this causes. Those who are held down for vaccines often experience medical trauma, leading to extreme anxiety and/or panic during future vaccine or medical appointments. Replacing restraint with alternative

strategies has been key to cultivating a positive vaccine experience and building a trusting relationship.

Based on the idea that every healthcare interaction is an opportunity to build trust, reduce anxiety, and increase access to healthcare, the Autism Society offers online training to help healthcare providers better understand Autistic experiences and the unique healthcare needs of Autistic patients. This online course, entitled *Accessible Vaccination: A First Step Toward Health Equity*, "covers effective communication strategies, the importance of sensory accommodations, and methods for fostering trust. Visit the [Autism Society's Training & Resource Center](#) to learn more about course offerings.

From Innovation to Policy Change

The Autism Society's Vaccine Education Initiative has addressed systemic healthcare challenges by advocating for policy changes that promote accessibility and equity in healthcare.

Recognizing the gaps in meeting the unique needs of the Autistic population, the Autism Society emphasizes the importance of high-quality, affordable, and individualized care, including access to private insurance, Medicaid, Medicare, and long-term care services. The pandemic has further exposed life-threatening disparities and healthcare coverage gaps, making expanded access and nondiscrimination in care a priority. A key finding from the initiative is that few healthcare professionals receive adequate training on serving individuals with intellectual and developmental disabilities (IDD), which underscores the need for a knowledgeable, culturally competent, and respectful workforce to reduce disparities and improve the quality of life for these populations.

In response, the Autism Society has sharpened its focus on advocating for critical policy changes, including the designation of individuals with disabilities as a medically underserved population (MUP). This designation would unlock federal funding for workforce training, ensuring that healthcare professionals are equipped to address the specific needs of Autistic individuals and those with IDD. Additionally, the Autism Society is leading efforts to reauthorize the Autism CARES Act, a pivotal law that supports the interdisciplinary training of healthcare providers in screening, diagnosing, and treating individuals with Autism. The bill to reauthorize the law includes efforts to enhance this training and develop the network of developmental pediatricians. By enhancing early intervention, diagnosis, and long-term care management, this reauthorization is crucial for improving healthcare outcomes and ensuring the system can meet the growing needs of the Autism community.

Summary

Through continued collaboration with healthcare systems, government agencies, and policymakers, the VEI seeks to create sustainable change that not only improves vaccine access but also establishes a foundation for addressing other healthcare needs within the Autism and disability communities.

The Autism Society of America's Vaccine Education Initiative is a groundbreaking model for how integrated healthcare, public health, and trauma-informed care can come together to address the healthcare disparities faced by Autistic individuals and other special populations. By empowering individuals with resources, educating providers, and advocating for policy changes, the initiative offers a blueprint for inclusive healthcare that benefits the Autism community and society. Through continued innovation and collaboration, the Autism Society will continue to pave the way toward a more equitable, accessible, and compassionate healthcare system for all.

*Thank you to USAging for supporting the Autism Society of America's Vaccine Education Initiative.