**Transcription – Module 3: Spreading the Word**

Speaker 1 0:24

The Autism Society of America is the nation's largest and oldest grassroots autism organization. We've been serving the autism community since 1965. It's our mission to create connections empowering everyone in the autism community with the resources they need to live fully. With close to 70 affiliates across the country. We serve more than half a million people each year through education, advocacy, information and referral support services and community programming. As a national network with Local Roots, we serve communities across the country, which offers us a unique understanding of the diversity within the autism community.

Speaker 2 1:08

The Autism Society of America launched its Vaccine Education Initiative in response to the COVID 19 pandemic, which shed light on a critical area of health equity within the disability community. The Vaccine Education Initiative is a tailored public health model designed to provide vaccine education, inspire vaccine confidence and improve vaccine accessibility within the autism community. We piloted this program and 12 sites within our affiliate network spanning urban, rural and suburban regions, we listen to the needs of the community hearing from children on the spectrum, autistic adults, families and caregivers, and listening to questions and concerns of providers. We've identified best practices for inclusive care which have led to improved vaccine experiences in communities across the country. Together, we've redesigned the vaccine experience reducing anxiety at every stage.

Speaker 1 2:07

To understand the barriers to vaccination within the autism community, we have to first understand the autism experience. And while no two experiences of autism will be the same, one reality that is shared by so many is the lack of accessible healthcare solutions. With one in 36 children receiving an autism diagnosis, co occurring medical and mental health conditions and premature mortality rates. It's critical that we prioritize health equity in the autism and disability community. In addition to known social determinants of health, the autism community faces unique barriers to accessible health care, stemming from social, sensory, cognitive and communication differences. And it's important to remember that these needs can be visible or invisible, but are impactful nonetheless, the sensory challenges experienced by many autistic and neurodivergent people are often unsupported in community settings. In healthcare settings, the environment is filled with lights, sounds and smells, with unpredictable environmental changes. And in most places without accommodations, the social pressures of a health care appointment can be a single point of anxiety for many people with autism. From entry into the building to the interactions that check in the unknowns of who will be checking your weight and height today to the unknown of what questions will be asked during a routine appointment. How much small talk or filler between those important questions will be required? And will you come off as rude if you choose not to engage? The social pressures alone fueled by social stigma are often barriers that are misunderstood, go unnoticed and are unsupported. And parents and caregivers face social stigma as well. worrying about whether a behavior will be judged whether their loved one will be met with compassion, given the patience to support self advocacy and autonomy, and also struggling to both appreciate the providers time, care and expertise. While wanting more support and seeking better outcomes. We know the impact of health literacy. And for those with autism comprehension goes far beyond the ability to read or to decode. For those with autism. There will be patients who are non readers, as well as those whose reading levels far surpassed the majority of their peers. Some might be overwhelmed by too many lines on a text. Others might struggle to interpret directions as written. families and caregivers are excellent resources. Start by asking is there a better way for me to share this information with you or with your loved 120 to 30% of those with autism will remain non speaking throughout their lifetime and additional 20% may lose access to speech in high stress situations, known as situationally nonverbal, some autistic patients will use written communication strategies, while others use AAC devices technology to support speech output, or exchange pictures. Regardless of the method, we encourage providers to engage with their patients using their patient's preferred method of communication whenever possible. These barriers are too often viewed as patient barriers, when in fact, there are environmental barriers, resource barriers, training barriers, systems barriers, and status quo barriers all which contribute to pervasive trust barriers.

Speaker 2 5:47

That Vaccine Education Initiative improves access to vaccination for neurodivergent people. Through the Vaccine Education Initiative, or V AI. We're working to break down barriers at every step of the process to ensure equitable and accessible vaccine experiences. By centering the needs of those with autism with some of the most complex needs. We've identified best practices to support inclusive care, which improves access to those with and without disabilities. And we like to share some of those strategies. There are a number of barriers to accessibility that occur before anyone steps into a vaccine clinic. The standard vaccine announcement signup and preparation can be modified to increase accessibility, reduce stress and improve outcomes. We start by using multiple methods to announce and promote vaccine clinics. Some of our affiliates have used social media or posted invitation videos on their website, sharing information about the vaccine clinics and how to sign up visually. This type of support while required for some is beneficial to many more. The registration process is an excellent way to gather information needed to support a successful experience. Beyond the standard registration questions, we asked about past vaccine experiences and information about any support that the person receiving the vaccine may find helpful, offering visual samples of tools and strategies that they may choose to use at the clinic. We also asked about social communication preferences, recognizing that some benefit from social conversation as a distractor and for others, any social demand is anxiety producing instead of the standard. So you're in eighth grade. How's that going? We can equip providers with the patient's favorite subject or passion reducing what's awkward for some and anxiety producing for others. We encourage patients to bring items or objects that help themselves or their loved ones feel safe. And we offer a range of sensory tools. But for some, they're very specific and personalized things that come from home that can carry a deeper sense of safety. If your clinic is unable to supply things, like fidgets noise cancelling headphones work communication supports, reminds family members to bring the supports that help their child in other settings. The information provided by families helps us ensure that we are best prepared on the day of the clinic.

Speaker 1 8:31

We also provide supports to ensure that vaccine recipients are best prepared using evidence based practices to support those with autism, which includes social stories, visual schedules, and visual supports given before the appointment. social stories and visual schedules create access to information about the vaccine appointment and reduce anxiety by foreshadowing the process of the vaccine. While social stories are an evidence based practice for supporting those with autism. They can support a much wider range of vaccine recipients.

Speaker 3 9:09

myself and a colleague of mine created a series of social stories to address what is COVID-19 which back seeing you could choose from what are in each of the vaccines and the side effects you may experience. We also made a nother social story that addresses the vaccine hesitancy parts. We go deeper into explaining historical events like the Tuskegee experiments or past experimentations of people of color that did not involve consent whatsoever. And we also covered possible religious views as well. And finally, we pretty much use the second guy to reiterate that the vaccine is for the most part, say, what's in the vaccine, where to go for your vaccination, what to look for, if you experience side effects, and also giving people examples and testimonies of those who took the backseat already, especially in the disability. Also story on getting the COVID-19 vaccine in communities of color by Chicagoland disabled people of color coalition, and Institute on Disability and human development COVID-19, all the Coronavirus. It's like getting the flu, but it's worse than the flu. Some of the signs of having covered it include coughing, shortness of breath, loss of smell, or taste, pain, fever, or chills. The response to those social stories was amazing. And, in fact, we also began to consult with other organizations on how to create they're all sorts of stories based on their local areas about coding related topics. I feel it's important to not only focus on numbers and data, but also personal stories where you could feel the pain, you could feel what people are saying you could actually see with your own eyes, what's going on, I think the combination of story stories, they the information will go a long way.

Speaker 1 11:55

visual schedules are a familiar tool to many used in homes, classrooms, and universally in many areas of public health. visual schedules break down a task or a procedure into clear steps, creating predictability and structure to an otherwise stressful and chaotic experience. visual schedules can also be used to demonstrate the passage of time, reinforcing what's been done and what is next, which can reduce anxiety for parents, patients and providers. access to communication is central to closing the health equity gap. The Vaccine Education Initiative uses a range of accessible tools, including communication boards, written prompts, and supporting assistive technology. We also allow for parents and caregivers to provide feedback or recommendations to plan for sensory and environmental support. We identify sensory and physical barriers by mapping out the vaccine experience from arrival to departure. We make it clear that we have tools available, but that preferred items from home are not only welcomed but encouraged.

Speaker 2 13:05

We took note of the high impact tools and resources that made a difference for participants and designed a guide to accessible vaccination and created accessible vaccine kits for both families and health care providers. are accessible guide outlines high level strategies to facilitate access, inclusion and belonging at each stage of the vaccine experience. Along with our guide, communication board, social narrative and visual schedules. Our kits include sensory tools like sunglasses, fidgets and noise cancelling headphones, and for healthcare providers pain suffering injection tools like shot blockers and buzzy bees. This model is helping to rewrite the vaccine experience to reduce traumatic vaccination. All healthcare providers from pharmacists to nurses can ensure that they're prepared to accommodate the needs of autistic individuals, their families, caregivers, and more broadly, people with disabilities when they receive vaccination services. At each clinic. We provide training equipping healthcare providers with knowledge and tools to meet diverse needs. This training is a key aspects of our collaborative model, which has celebrated a 99% successful vaccination rate. In our clinics we offer two type of injection tools, Buzzy these and shot blockers of buzzy V is a small device using a combination of cooling and vibration to block sharp pain and provides distraction when giving injections or other medical procedures. A shot blocker is a flexible piece of plastic that uses a number of blunt contact points to saturate the sensory signals around an injection site, distracting the patient from pain signals of the needle. It is a simple non invasive drug free method And that instantly reduces needle pain and anxiety. These pains offering tools are one of the many high impact strategies that are making a big difference for providers and vaccine participants. We must meet the needs of the disabled individuals, their caregivers, and health care providers where they are. And we understand there are many unique barriers which contribute to low levels of trust. It's possible that you've done everything right in your support of the patient, but due to past experiences, they may remain fearful. Creating a sense of belonging is a critical step towards building trust and improving outcomes, we find it helpful to collect as much information from the participant, parent and caregiver to be able to personalize their experience. First, we engage and ask questions to learn about the individual. For example, tell us about past vaccination experiences, what has worked and what didn't work. This immediately shows an interest and allows their voice to be heard. It shows that the healthcare provider cares and that there's a transfer of power, modeling positive expectations. And when healthcare providers engage patients as proactive and empowered participants, it builds trust and relationships that will lead to better overall health outcomes. Further questions about communication, sensory and environmental barriers can include does a patient like to engage in conversation or is that going to be triggering? If so what's the preferred subject or a high interest area? Does the patient need an area to move around listen to music, or where noise cancelling headphones? What's the best way to communicate? Would it be helpful if a visual schedule was reviewed with the health care provider to prepare you for the next steps, we also find it important to include all types of communication as it makes a big difference talking and a soft tone helps build a calm atmosphere, and reassurance while keeping language simple without jargon and making it easier for people to understand. We also have to remember about nonverbal communication when we use body language. We want to make sure the patient feels safe, respected and heard. And remember, people are often anxious in healthcare settings. So patience and compassion goes a long way.

Speaker 1 17:27

We are increasing vaccine uptake by removing barriers to vaccination, from information barriers, physical barriers to social barriers, to increase access that improves the vaccine experience for all involved. We start by learning about past experiences. Here are just a few examples of previous vaccine experiences, which have been shared by our vaccine clinic participants that have shaped our understanding of patient needs. He doesn't like the medical office setting does not like unfamiliar people to touch him. He will need to be held down to get his shot and he'll cry and resist during hates shots hasn't gotten any any years. We have never been given any other options. So all we've ever done when he received vaccinations is hold him down while he cries. They have never had a positive experience with shots and has always needed to be held down. We will try anything that you think would help has extreme anxiety and fear of vaccines. She will cry and scream and say she's being tortured. Giving her information about what to expect is helpful. They're diagnosed autistic with sensory processing disorder have complex medical history and gets anxious in clinical settings. Previous vaccines have resulted in flailing and needed to be held down while crying has medical trauma and will get physical and very anxious he will not lay down for this reason last time damn had to hold him in his lap. The nurse had to hold his legs has PTSD and odd this should go well, but if she panics, she just needs extra time to calm down with zero pressure. She can then get back to the shot severe anxiety surrounding all aspects of healthcare, especially vaccinations, when someone feels heard, acknowledged and celebrated for their differences, especially in a healthcare setting. It changes the dynamic between provider and patient when we recognize barriers to care, not as resting within the person or the family. But as resting within our environment and our traditional methods. We feel empowered to make changes to provide accommodations that better meet the needs of our patients and their families which improves the experiences for providers as well. We've witnessed that small and meaningful changes have strong and lasting impact at our clinics, we support the environment. And we support each provider to feel confident in the tools that they're using and supported. While a typical vaccine appointment might last 15 minutes, many individuals with autism and their families spend days preparing for those 15 minutes. There are so many strategies that healthcare providers can offer to support that preparation by offering resources such as visual schedules, social stories and communication supports. Providers are showing their patients that they're seen, understood, supported, that their needs are important, and that they belong or artistic and neurodivergent patients and for those who are needle phobic, fearful of medical appointments or those with negative past experiences. Creating a sense of belonging is a critical step towards building trust and improving outcomes at each point of interaction from registration. Check in screening to pre appointment conversation, procedure, education and follow up. Think of the ways that you can provide accommodations, can you foreshadow the steps of a procedure in advance? Can you reduce small talk or limit to high interest conversations that are dictated by patients and their passions? Can you offer environmental accommodations? Provide or welcome personal safety items or sensory tools? Where can you offer choice using this or that method or a visual menu of options, like choice of bandaid choice of which arm can you provide pain, different options like the shot blocker or the buzzy bee, you don't need to use every tool in the toolbox with every patient. But by offering strategies and gathering input from patients and their loved ones, you'll be setting yourself and your patient up for success during each subsequent visit. To show the impact of these simple accommodations, I'd like to share some of the feedback that we've had from caregivers after attending an accessible vaccine clinic hosted by the Autism Society. getting this done in a low stress guilt free environment alleviated my own stress as a parent about being judged for my child's behavior. I appreciate the patience my children were shown. And getting to play afterwards helped to create a more positive memory of the event, which will hopefully help for the next time a vaccine is needed. This clinic was a game changer for my family. Thank you so much for putting it together. This was a great experience. We would love to see this expand to include more vaccinations like the flu shot each year. This was such a wonderful event. We loved that our boys were able to have a positive experience to associate with their vaccination. No tears were shed, the different tools used to distract my son, to make him as comfortable as possible allowed me to feel relaxed, and that nobody held him down. The staff was wonderful, and our boys were completely comfortable and calm through what is typically a stressful situation, helping my daughter have a positive vaccine experience and helping her move past her fears. Seeing her be so well respected by staff and volunteers. There was no anxiety about getting the second shot because of how smooth the first one went. Everyone was absolutely awesome. And you provided a positive experience for both me and my child. Thank you for the best vaccination experience ever. Our family was overjoyed to have been a part of this clinic. One of the biggest surprises to us in this work was our own miscalculation surrounding vaccine hesitancy in the autism community. After all, we've been responding to misinformation surrounding vaccination long before the pandemic, we leaned in and heard again and again from parents who were vaccine hesitant, not because they didn't trust the safety or the efficacy of the vaccine, but because they were unwilling to subject their child to a four point restraint and experienced the long lasting trauma related to the appointment. This is why the Vaccine Education Initiative supports health care professionals, patients and families and caregivers to eliminate these traumatic practices and rewrite the vaccine experience. We continue to educate and empower healthcare providers to communicate, engage in support autistic patients, to listen and to have a conversation that leads to improved outcomes for all.

Speaker 2 24:39

Through our work, we learned that vaccine confidence is not solely a question of trust in the vaccines efficacy and safety. There are many access and trust barriers including health literacy. Health information can be confusing even for those with advanced literacy skills. While collecting Social History, this can be a good opportunity to also screen For health literacy, for example, how happy or confident are you? In your reading level? What is your highest level of education you received? Would you like some assistance completing the medical forms today, our resources, educational materials and presentations are adjusted to the educational and health literacy level of the intended audience. We ensure that our messages are clear and simple and available in various formats, including visuals, audio and closed captioning, and are also offered in different languages at our clinics, we create a shame free environment and a helpful supportive environment. We offer help as needed to fill out forms and explain information in simple terms. We use a variety of communication techniques, using visuals, audio, visual and handouts for all participants. Our health care providers avoid using medical jargon and complicated terms. And we try to ask open ended questions to assess the patient's understanding of the vaccines that they are receiving medication that they are taking, and any other important information that they may need to know.

Speaker 1 26:13

Effective communication gives us the opportunity to learn about a person and that equips us to properly tailor their care and support to their needs. There are a number of ways that providers can improve interactions allow caregivers to attend but don't solely speak to caregivers when patients are present. This is particularly important for adult individuals, but for all non speaking does not mean not understanding. And often non speaking patients are left out of health care conversations, rather than speaking about a patient in front of them. Speak to them even if you aren't expecting a verbal response from them. Ask questions to learn more about the patient and their experiences. This will build trust and can alleviate anxiety, be concrete. Use simple terms and easy to understand language. Confirm understanding before continuing. Offer visual aids to improve accessibility. Show comfort, empathy, acceptance, be sensitive, compassionate, and demonstrate respect.

Speaker 2 27:21

We had success using our I got vaccinated because campaign showcasing pictures of autistic advocates, caregivers and family members explaining why they decided to get vaccinated. These trusted messengers, personal narratives and peer communication have been the most effective at changing perceptions about vaccines. We featured images at vaccine clinics in urban, rural and suburban settings across different races and ethnicities and across diverse groups. We developed campaigns focused on educating and serving as that trusted source for accurate information. We make sure to answer questions builds trust and provide clarity by providing timely, transparent, and science based information. We also use plain language and visuals to get information out to accommodate for different literacy and communication preferences. Fostering transparency is also important. For example, all of our information about vaccines communicate side effects, such as you may feel sore, be tired or have a headache the next day. To build trust transparency is central vaccine messaging strategies are critical for the autism and disability community. Since this is a population with high distrust, and may be receptive to different formats, framing and styles of communication messaging. Listening is key. It's important for folks to share their story to feel validated and affirms in their experiences. For some peer to peer conversations are most impactful, while others want to hear from the subject matter experts or trusted messengers within their community. We continue to meet the community where they are by attending health fairs, community engagement events, and providing community education with those trusted messengers through support groups and other social networks. By building relationships with trusted community based organizations and leaders, our voices become an authentic, trusted voice. We'd like to show you our PSA of one of our vaccine clinics so you can see some of our strategies in action.

Speaker 4 29:43

The ongoing impact of COVID-19 is felt by us all people with autism are more likely to experience severe symptoms and complex barriers to health care. individuals with intellectual disabilities are also six times more likely to die from this disease. We see you, we understand the unique challenges the autism community faces. The Autism Society is committed to vaccine education, confidence and access through our vaccine education initiative. Together, we are reimagining the vaccine experience. We prepare, educate, move, respond in support, I doubt like succeeding today. visual schedules and social stories prepare vaccine recipients.

Speaker 5 30:33

Today at the vaccine clinic. It was my first experience using social stories, communication boards and visual supports to help ease children's anxiety and help prepare them to receive the vaccines that they needed.

Speaker 4 30:49

Healthcare providers receive training to facilitate a supported experience. Because of this, our vaccine clinics have a 99% success rate.

Speaker 6 30:58

This was a successful vaccine experience because of that health care providers here that play therapists, that accessory support us for the injection sites. Being in their own environment. It made it very welcoming and comforting.

Speaker 7 31:17

Another great thing we've been able to do with the clinics is offer parents the option to do a drive in so they don't even have to come out of their car we can just pull in, they call us. Our public health workers have been amazing and just gone out. We've talked to the parents done everything gotten the shot, and they're done in a minute.

Speaker 4 31:35

Because of the strength of our affiliate network. We have hosted over 50 educational events and 30 vaccine clinics across the country. Because of you, we continue to advocate for a more inclusive supported health care system.

Speaker 8 31:49

I could not ask for a better experience. It's for all it's for all people all kids could benefit from this,

Speaker 9 31:56

the toys to the stickers so the snack bags to even the shot blocker made a huge difference in in making the experience of getting a vaccine so much more calm and a positive experience.

Speaker 10 32:09

It made me feel a lot more like I was at a friend's house rather than getting a shot. I wish I could get all my vaccines moving forward like I did today.

Speaker 2 32:19

The Autism Society of America is charting a path to improve health equity to ensure that the autism community and their families have both the access and the opportunity to obtain full health potential.

Speaker 4 32:31

Together. We can be the connection, the Autism Society, the connection is you get connected at autism society.org.

Speaker 1 32:43

Remember removing traumatic experiences and creating more positive healthcare solutions will lead to continued vaccinations across a lifetime. The Autism Society of America envisions a world where everyone is connected to the resources they need when they need it. Our goal is to empower patients, families, caregivers and providers to create accessible care across the community. We hope that healthcare professionals, pharmacists, nurse practitioners and public health workers will continue to invest in training to improve health care delivery, and services for the autism and disability community. The Autism Society of America is dedicated to creating accessible and equitable health care for all. Thank you for taking the time to learn from our model today. We hope that you'll take advantage of some of these tools, resources and the strategies that you learned today and bring them into your communities. There are a number of resources available for healthcare professionals who seek to be more inclusive. As you prepare for your next steps as a provider. Know this, you can be the strategy. Stay curious, seek out opportunities to make the small changes that lead to big changes. Ask questions, identify barriers and seek solutions. Stay connected, visit our website at autism society.org. You can contact our national helpline to speak with a trained information and referral specialist at one 803 autism or at info at autism society.org If you'd like further information or have any questions about what was presented today, please reach out to us at V ei at autism dash society.org The connection is you