



JACKIE CZYZIA:

Thank you, everyone, and welcome to the webinar, the Autism Friendly Initiative at Boston Medical Center, Improving the Healthcare Experience for Patients with Autism. This is part of the AUCD autism Acceptance Month webinar series. My name is Jackie Czyzia. I am senior manager for the team at AUCD. Thank you for joining us today. We would like to cover a few logistical details. You will be muted throughout the webinar. Feel free to submit questions at any point during the presentation using the chat. We will also have time at the end, about 10 minutes, or questions. Feel free to unmute yourself at the time. We will also have captioning available. If you would like to access it, please click this easy button at the bottom to view the subtitles. This webinar is being recorded and will be available after the event, as well as the transcript.

Before I introduce the Autism Friendly Initiative team, I would like to do a quick poll to see he was here today. You can also introduce yourself in the chat. If you can take a minute to let us know who you are.

SPEAKER:

It is really cool.

SPEAKER:

It is really cool. I don't know if we ever used the poll feature, Alex.

ALEXANDER FRIEDMAN:

Is ZoomT ext here.

JACKIE CZYZIA:

We have a few more.

SPEAKER:

And I just think whoever created that poll that allowed me to click more than one answer?

JACKIE CZYZIA:

It is a new feature. I didn't invent it. I know many of you come from more than one program. OK. Great. It looks like you can see my results. We have a lot from LEND. About 46%. DBP. UCEDD, and if you are other, feel free to introduce yourself in the chat. Great. Welcome, everyone, again. I would like to give a warm welcome to Alexander Friedman and Lauren Bartolotti Busa. Alex's program coordinator at the Autism Friendly Initiative at Boston Medical Center

Thank you, Lauren and Alex.

LAUREN BARTOLOTTI BUSA:

We are so excited to be here. Welcome, everybody. I am sure we will see more faces pop on, but we are so excited to get to connect with so many people from across the country. My name is Lauren, as Jackie assured, and I'm here with my colleague Alex to tell you more about our Autism Friendly Initiative at Boston Medical Center and how you can be thinking about improving the experience for healthcare at your prospective practices. Full transparency, Alex is



sharing the slides, so I will give him a note for when to switch slides. Thank you for being patient with us. Go ahead, Alex.

I want to share that we have nothing to disclose, but we do want to share that we recognize there are certain choices in talking about individuals with autism. Some people choose to use identity first language, others choose to use person first language. As a program, we decided to use person first language. For the purposes of this presentation, I just want to sort of put that caveat out there that that is how we are going to be referring to patients with autism throughout this presentation. Go ahead, Alex.

So the Autism Program at Boston Medical Center is a multidimensional family support program embedded within the division of developmental behavioral pediatrics. Historically, our core work has been around supporting patients with ASD when they come to the hospital around getting the evaluation for their diagnosis and follow-up care. Over the past 10 years, we have really started to move into other spaces in the hospital, thinking about how patients with autism can access healthcare in a sort of any department or clinic. Over the past four years, our Autism Friendly Initiative has started to take shape. We are excited to walk you through that journey and tell you where we are today.

So our objectives are to share more about the aspects of medical care and how it their inherent nature may make it more difficult for patients with autism and their families to access optimal healthcare. We want to review strategies, tools, and interventions for optimizing care for patients with ASD, and we want to help you guys to think about how you may take some of that work back to your respective practices and think about the accommodations and changes you might make any care for patients with ASD, wherever you are coming from.

We do want to share that we recognize there is amazing work being done across the country. We have learned so much from collaborating with other institutions, and we always welcome that collaboration. Please be in touch with us after the talk if you want to continue the conversation. Go ahead, Alex. So individuals with autism have higher rates of almost every medical condition with the exception of cancer. They are higher utilizers of the healthcare system, seeing their clinicians four times more often than neuro-typical peers. They are actually more expensive to healthcare institutions. Individuals with autism can cost three to seven times more than typical peers. While this is, as we all understand, a kind of best practice issue and consideration, it is also a financial consideration as well for institutions.

In a national survey of Children with Special Health Care Needs, parents reported difficulty navigating healthcare services, lack of decision-making and care coordination for children, and ultimately adverse family impact. We know adverse impact can lead to longer-term avoidance and aversion of healthcare encounters. We are thinking about how the acute healthcare encounter can impact long-term healthcare outcomes.

So when you think about the autism diagnosis, one of the things we often think about is most striking around the diagnosis is there is no sort of set of presentations. Every individual with ASD is going to present differently. So when we are thinking about creating interventions, when we are thinking about adopting care, when we are thinking about changing our practice, we need to think in a way that is flexible. We need to think and a way were not sort of one

presentation of autism is going to be supported and others are not. But there are some core features of the diagnosis that we can sort of frame our thinking around.

There is often difficulties with social communication and interaction. Often heightened preference for routine, difficulties with transition, difficulties when things happen that are unexpected. New experiences, new people. There can be sensitivity to sensory stimulus. It can be oversensitivity or under sensitivity. And difficulties regulating emotions or behaviors. Imagine, think about the typical clinical encounter. We have all been there. We have all had to go to the doctors. It can be overwhelming; it can be stressful. There might be new people, new faces, places, and we can't predict how many people will be any waiting room or elevator. We don't always know that our favorite nurse isn't going to be there to greet us. And during this time of COVID we recognize an added layer of anxiety production. Staff are wearing gowns, masks, facials, and for patients with ASD and all individuals, that can be pretty off-putting and dysregulating. So we recognize inherently that clinical encounters are challenging.

They can make us feel overwhelmed, anxious, and dis-regulated. When you add to that and layer and all the different facets of the diagnosis that are present for so many individuals, that can make clinical encounters that much more challenging. So we wanted to sort of bucket the defining features of a negative patient experience into different buckets. The way we have thought about the negative patient experience is an sort of three areas. There are the unique sensory needs of patients with autism, there are communication barriers, communication challenges, and huge variability in the way individuals communicate. There is a significant gap in knowledge, not just for clinicians, we are not just talking about doctors, but for nursing, front desk staff, security personnel, phlebotomy, sort of in any healthcare encounter who a person may come across may not have the knowledge or training on how to best accommodate their practice.

So I want you to think for a moment, put yourself into, be a child for a moment. Yes, we are a pediatrics program, so we tend to think from the perspective of children, but I will give a caveat that all of our interventions are being scaled up into the adult space as well. Think about your own practice and on exam room. Think about the waiting space where you work. Are there fluorescent lights? Is there a crinkly paper on the table? Is there a sink that may be very exciting? Is there a lot of people going back and forth, in and out? Does the smell have any, does the room have any antiseptic smell? Think about all of the different things that could heighten that sense of this is unfamiliar, this feels uncomfortable.

Now, we all know when we are in a heightened state of anxiety or worry or stress, our ability to cope with those emotions, our ability to regulate our behaviors, our ability to engage in what is being asked of us, is really being tested for all of us. When the doctor comes in and is asking about pain, or stating to look in a child's ears or needing to take a blood draw, we are heightened and overwhelmed. Our ability to engage in that process productively and safely is not necessarily going to be there unless there are some accommodations made to help me feel supported, to help us feel supported.

So patient and family voice is at the core of what we do. Again, because we are a pediatric program, we often rely on the voices of parents. We wanted, when we started out on this journey, we wanted to hear from families what their experiences were like and navigating the

health care system. So we said, "Tell us the good, bad, and ugly." Tell us all your experiences. We want to learn from what you have been through as a family. These are a couple of snippets of things they have shared with us. "I get stressed from the moment I wake up on the day of that appointment." "It's frustrating for me, because I feel like I am not being listened to."

"All I could hear was Mason screaming, and the next thing I knew, I found him and a straitjacket." "I couldn't really process what was being said to me during the appointment because I had to make sure my child was safe." "... Not just me trying to hold her down, but also another staff member trying to hold down whatever I couldn't hold because she's really strong, and then two other people trying to get the blood draw."

These are not unique scenarios. All of us can think about a time where an interaction or an encounter didn't go as positively as we wanted to go. And kind of at the most intense were severe and of the spectrum is when something that is really medically necessary can't happen because of an inability to kind of meet the patient where they are at. We have providers tell us all the time, "We weren't able to get that blood draw," "We weren't able to get that exam done, "There's so terrified to come back and for follow-up that we can see them in person." We want to change that by making the environment, by making the staff more accommodating and more welcoming to our patients and families.

When we started out, we surveyed our clinicians and staff from all across the hospital. We asked him, "What do you need? Where the challenges our what do you need?" More than one staff member told us, "I need more knowledge, I need more training." In fact, someone said, "My lack of knowledge for how to care for patients for ASD is limiting my ability to provide the best services for them." 71% of the individuals we surveyed wanted more training. Taking that information, taking the stories from families, taking the needs of our colleagues from all across the hospital, and when I say all the hospital coming from the front desk, security staff, faculty and the Department of pediatrics, to those down and lobotomy and radiology, we wanted to hear from all of them. With all of that feedback, our Autism Friendly Initiative at Boston Medical Center was born in 2017. Our goal is to improve the overall hospital experience for patients with ASD. Notice we don't say children. Our goal here is any patient seen in any department or space across Boston Medical Center should be able to receive optimal healthcare. Should be having experiences that make them want to come back to our institution.

We aim to provide clinicians and staff of the tools, information, and training to better support patients and families. We aim to develop new and innovative interventions based on valuable input from stakeholders, inclusive of individuals with autism, their families, researchers, clinicians, staff members, of course the literature, and our own research and evaluation on the impact of the things we are doing and trying. We know how important it is to see if the work is making a difference. We are constantly engaging in measuring the impact of what we do.

Our team is made up of myself and Alex, our program director Shari King, Marilyn Augustyn, colleague Sarabeth Broder-Fingert, our amazing staff, Liz Ferriero, Jacqueline McKendry, and Belinda O'Hagan. We are the core group that helps to drive this initiative and think about at the ground level how it is impacting the families we serve. We are also informed by three formal steering boards. We have a steering committee made up of multidisciplinary group of hospital and community stakeholders, and they help think big picture. We have a quality improvement

board that meets six times a year that is really focused on thinking about how we scale up our interventions, how we study interventions, and how we adapt interventions with different populations across the hospital.

We also, which we are very, very excited about, this is a new board that we launched just last year in 2020, we have a group of adolescents that meet with us to talk about their healthcare experiences and how the Autism Friendly Initiative can continue to grow and expand and think at that ground level, how was it impacting patients? Just to reiterate again, patient and family voices at the core of what we do, broad engagement of stakeholders is so important. We always think about how our interventions can be scaled, can be tailored. We want them to be multitiered and really be able to be implemented with lots of different considerations in mind. We believe in real-time monitoring and evaluation. We have a commitment to our value of improving the Healthcare experience for patients and families.

I talked to you a little bit about the needs assessment that we completed. We did a hospitalwide staff survey. We also engaged in a parent focus group, which gave us a lot of really rich information around the good, bad, and ugly of family experiences in the healthcare setting. It is a comprehensive literature review and conducted an ethnographic study where we followed patients with autism across the hospital and throughout the medical encounters to see where the barriers existed, to see what challenges occurred, to see what was unique about that patient experience. We also analyzed our own patient data. This is to give you a little bit of perspective in case you were thinking of doing something like this at your own hospital.

This pairing up all of the different features of our needs assessment hope to give us the most comprehensive view and the best starting place for developing our interventions. We are now at the place where we have implemented several interventions across four different domains, which Alex is going to talk through now, and we are really excited to be at the place where we are now scaling them up, where we are thinking about adopting them into the adult space and our adult clinics, where we are thinking about how we can collaborate with other sites and be measuring impacted other sites. We are just really excited to continue this conversation. I am going to turn it over to Alex, who is going to talk you through our interventions. We are excited to answer any questions you have at the end. Thank you. Go ahead, Alex.

ALEXANDER FRIEDMAN:

Thank you so much, Lauren. I completely echo everything Lauren has said. It is a tremendous privilege to be here speaking about our work. I did say this to Lauren, I will broadcast this to everyone now, my internet has been cooperating all day. We will see if that continues now that it is my turn to speak. The initiative has four domains of work. We want to talk about each one of these domains about what we are doing here at BMC to be thinking about them. Our first domain is related to individualizing care. When we think about individualizing care, we think about this as the concept of just learning as much as there is to learn about who our patient is. What is there to learn about how our patient communicates our does our patient communicated verbally or nonverbally? How might our patient communicate pain? Might our patient be able to tell us verbally that some component of our procedure is causing discomfort, pain, anxiety, or stress? Or is there going to be another mechanism to which our patient is going to communicate or express to us they are in pain or discomfort? Maybe nonverbal signals we wouldn't otherwise be picking up on.

What are our patient's specific sensory needs or triggers? Do we have a patient highly avoidant of bright lights or loud noises? Certain smells, certain tastes, or feelings against our skin? What are the safety concerns we should be aware of? Do we have a patient with a history of kicking, biting, eloping from an exam room, taking your tools and grabbing them? Aggressing towards a caregiver or towards staff? What can we learn about the safety needs of our patients we can be prepared in advance and not learn them in real time? And really just what does our patient want us to know about them to make their experience more comfortable? It can be as easy as saying, We recognize that coming to the hospital, coming and seeing a clinicians, coming and getting your blood drawn, coming and getting a shot can be really stressful, really frustrating, really, really overwhelming for many of our patients. What can we do to make this more comfortable for you? Listening to what the patient says and making sure we logged that.

LAUREN BARTOLOTTI BUSA:

I just wanted to interject, Alex, I will kind of monitor that chat so we can answer some questions. The ACS right now is being administered by trained staff. They are being reviewed by members of our core team before being put into the electronic medical records. Those are all things we do internally. The ACS can be made available. You can connect to us off-line and we can make that available to you. The only thing we ask is you keep our logo on it, but it is certainly something that can be used across other institutions. We also give it to families and say, "Fill this out and have it available wherever you are saying." If you go to a new dentist, doctor, or specialist, bring this with you. We really try to empower families to use it and have it as well. Go ahead, Alex. Sorry to interject.

ALEXANDER FRIEDMAN:

No, I really appreciate it. There is a lot we can talk about about our ACS. On this site you will see the cover of our Autism Support Checklist form. This is one of several pages that collects a brief battery of information on all topics we discussed. There's about 12 questions total. Here is an example of what it looks like logged and our medical record. At Boston Medical Center we use EPIC. We log it as a care coordination note, a snapshot encounter. You can see it right when you log into a patient record. For example, you might learn by glancing at this patient's ACS that they might understand the procedure best if you demonstrate on another person. Perhaps a member of your clinical team or your patient's caregiver. We also log it as a telephone encounter as well to establish some permanency into the record.

We think about individualizing care most prominently at our hospital by way of our Autism Support Checklist, but there are a number of ways we can think about individualizing care beyond one specific tool. Our second domain of work is related to visit preparation. Lauren spoke about this earlier. Challenges with transitioning, challenges with new experiences can be inherent in a diagnosis of autism for many of our patients. As such, coming and seeing your medical specialists can represent huge deviations from your routine schedule. It can represent a major sense of unknown or of transitioning from what a normal Monday or Tuesday might look like to a Monday or Tuesday where you are coming and seeing your primary care, or you are coming and seeing a specialist. We think about visit preparation as being a really important component of our work.

We think about visit preparation a number of different ways. We think about social stories. I am

going to show you in a moment our healthcare oriented social stories website, which has about two dozen social stories on and covering many, many different medical encounters. We are going to check one out for ourselves. We always think about integrating or implementing social stories if it might be helpful for a patient as they acclimate to the idea of a new procedure or a new medical visit. We are so fortunate on our team to have autism resource specialists who can assist with levels of care coordination, opportunities for desensitization, real-time visit support, collaborating with care teams and providers to ensure that patient wishes and needs and expectations are carrying forward to a visit and then can also feedback from clinicians to patients and families to make sure everyone is feeling prepared and knowledgeable for the components of a visit.

We are going to talk a little bit about one of our experiences with our incredible autism resource specialist team. Before we go there, I want to share a bit more about our healthcare social stories website. I am going to really throw my internet for a loop now by changing the screens around. Let me know if – let me stop my screen share. I am going to share again. Can folks see this website now? Great. This is our autism friendly healthcare social stories website. It is currently available in English and Korean. We are continuing to grow our language library so this can be available to all patients regardless of what language they might prefer to view these in.

So let's go to one of the social stories. Let's go to getting a blood draw. So you will see there are ways to navigate through this social story. If I were to click on this button we would have it available as a downloadable or printable PDF. But we can also just click through a social story about getting a blood draw.

LAUREN BARTOLOTTI BUSA:

This is mobile friendly. So if you pull it up on your cell phone, it does look nice. It is not wonky like a lot of websites are. We are proud of that as well.

ALEXANDER FRIEDMAN:

Yes. This was developed by one of our student teams that has a huge, huge, huge amount of intellect and all things technology. So not a product of me personally. And that the and you can see we have built in reinforcements and rewards to celebrate the completion of the social story. These social stories are all developed in tandem with stakeholders around campus who know these procedures best. For example, for our getting an MRI social story we work closely with our nursing team and radiology. Similarly for our getting an x-ray social story. Getting a COVID test. We looped and folks on campus most closely providing those frontline COVID tests. These were all developed with expertise in mind and have been really successful so far in assisting patients with navigating many different aspects of healthcare.

Alright. We will return to our presentation. No need to start all the way back at the beginning. Great. I mentioned earlier that we have on our team an incredible group of autism resource specialists that provide real-time support, care coordination, and collaboration with clinicians and patients. I want to share a really remarkable case example of how visit preparation can really go right with the proper thinking and supports. This case example is about one of our 14-year-old patients who needed an EEG for seizure activity. When coming to Boston Medical Center previously, staff had observed a history of significantly challenging and potentially

dangerous behaviors. Often necessitating involvement by our public safety team.

Our family, our patient and their family had reached out to one of our autism research specialists as this particular family had an ongoing relationship with our program for years around just assistance for preparing and executing this EEG. One of our autism resource specialists, a phenomenal member of our team, Jacqueline, a trained PC BA, really assisted with this level of a visit preparation for this particular family. So what Jaclyn did, she reviewed the patient record to understand what might've been attempted in the past, what is going well, what hasn't gone well, develop some visuals that were procedure specific. So around getting an EEG. I then collaborated with medical providers as well as our family to figure out a strategy for what would work best. I want to share a couple of aspects of that strategizing that really came through well on the day of the EEG.

So the preparation really started with reviewing the social story, asking our patient for input on what they feel and think about getting this procedure, thinking about what items might be most helpful or most crucial for ensuring that this procedure could be as comfortable as possible. For example, headphones and sunglasses, favorite stuffed animals from home, and on the day of the EEG our ARS Jacqueline met our patient at the car with a social story, a visual schedule, and with a wheelchair. Because in the past, our patient had indicated a preference to being wheeled into visits. We made sure to provide many choices throughout the visit to help our patient to feel more in control. Waiting that extra few moments for an empty elevator to decrease those sensory overstimulation that can come from crowding onto a full medical elevator, we avoided the waiting room. So based on collaboration with the care team, we were able to secure an empty space for a patient to come right into rather than waiting in a waiting room.

We utilized visuals for every step of this visit and previewed what our patient would earn at different intervals during a successful visit. For this patient was a trip to Target and Snickers bars, which I think we can all at this time of day benefit from a Snickers bar. Frequent verbal praise throughout the visit as well. Asking our patient to become as familiar with the equipment as she needed to be. So touching and feeling the equipment becomes involved during an EEG, touching the parts of the body that the equipment would be attached to, just becoming familiar with that sensation. Working with the team to make sure that we were OK or an agreement with the degree to which physical movement would be allowable during the encounter. Working with our patient and developing some workarounds.

So moving our patient's hands to our autism resource specialists body rather than hitting or putting her hands on her own body in a way that would disturb the EEG. Everyone celebrated and cheered when the visit was complete. We made good on that Snickers bar and trip to Target. Making sure that everyone felt good wrapping up and that our patient left the experience smiling, really comfortable. Our staff similarly remarked on how incredible and phenomenal this experience had gone.

So moving now to our domain on sensory accommodations, we think about the sensory space quite a bit as part of our autism friendly work. We think about sensory accommodations by the use of things. We can also think about making accommodations for sensory needs without needing things at all. Today we want to talk a little bit about some of those things we utilize. We

have two primary interventions for our sensory accommodations. Our sensory toolboxes, you can see this on one of our bottom images. Our sensory toolboxes or plastic Tupperware bins that contain a dozen to two dozens that can calm, distract, and redirect patients who may be feeling overwhelmed or overstimulated by aspects of a medical encounter.

This is a toolbox that has been distributed to dozens of clinics across campus. It is meant to be shared between staff under one clinic and moved from patient room to patient room. Of course being sanitized in between. But with our COVID-19 pandemic, last year we really had to do thinking about sensory interventions are required last sanitizing, less movement from patient to patient. We developed our sensory toolbox. Our sensory tool packs are COVID informed single patient bags that can be discarded or sent home with your patient at the beginning of a visit. They contain less amount of items but still covering those aspects of being suitable for those that might be sensory seeking, those that might be sensory adverse. You can see our sensory tool pack on the top image of the slide and an incredibly photogenic photo of myself distributing these tool packs last summer across our campus.

This is our pediatric emergency department receiving one of their routine supplies of toolbox. Here is somewhat more qualitative feedback we have received on our toolbox. I am not going to read all of these to you. One of our radiology technicians last year reported they got one of our little packs and will tell us everything was so perfect, they asked mom if everything was appropriate because they mentioned our patient was so sensitive to stimuli and she thought they were all great. Her patient especially loved our smiley stress ball and it too. She commented it was like the pack was meant just for him.

Our final domain that we think about on our initiative is really education and training. Lauren talked a lot about this later. That gap that exists in our country as it relates to comfort, familiarity, knowledge, and caring for patients with autism. Only 40% of US physicians feel very confident in their ability to provide the same quality of care to patients with disabilities as to those without. Only 56% of US physicians strongly agreed that they welcomed patients with disabilities into their practice. So it is really, really important all across the US beyond Boston Medical Center, of course corroborated by our hospitalwide survey, that we be providing and supplementing our clinicians and staff with knowledge and familiarity of caring for patients with autism.

On our team, we think about this a lot. We are so fortunate to be able to routinely train many different cohorts at Boston University and the Boston Medical Center. We are part of the mandatory curriculum for pre-doctoral dental students, public safety officers, medical students in their third year at Boston University, medical and dental residents, genetic counseling students, interpreter services team, and we go all across the hospital wherever needed for a 15 minute huddle on the first Friday of the month or for a full day training for new hires. Whatever our colleagues across campus need, we are prepared to talk about. We provide training on caring for individual patients with autism, thinking more systematically about building an autism friendly healthcare practice, and then the resource landscape. How we work to connect our patients with the many different resources and government entitlements books are entitled to once a diagnosis is formalized.

We provide medical simulation events for medical students at Boston University and with our Boston Public School students with autism for an event we call Art Doctors Day. He also worked

with human resources to integrate prerecorded five-minute video bites we use at the emcee. And through all of this we really think about how we scale up and continue to enhance and strengthen this work. We try to maintain a presence across the country and national presentations and conferences. As Lauren mentioned, we are working to make sure our interventions are monitored and evaluated utilizing best practice and our research expertise, including, of course, engaging with stakeholders in forming partnerships nationwide and even globally. And working on a variety of research studies that seek to enhance and further our knowledge.

Some of those research studies included Delphi study. So working together on formalized consensus about what even means to consider yourself an autism friendly healthcare practice. We are engaging in many other studies as well. The impact of our autism resource specialists across campus, utilizing our TEACH cohort to think about the lessons we can glean from patients most impacted by this work, and then assessing impact across the board with all of our different interventions, trainings, tool packs, our work in the emergency department, etc. Here is a good snapshot of partnerships we have made along the way. We have worked with folks in Australia, across the Middle East, Europe, Canada, at least 20 states in the US, and beyond. We love to connect and help others think about how they might help build and expand upon work at their practices to optimize care for patients with autism.

We have a great handout that covers these specific tips. Concrete takeaways that any clinician or healthcare professional can carry with them to start directly improving and impacting their work with our patients.

Relatedly, we are always thinking about ways we can further disseminate and expand our work across the country, expanding the patience of whom we serve and the practice settings, and partnering across others in this community. The final quick plug, although I will let Jackie say more about this, we are in the midst of a partnership with IT AC around a training that will delve more deeply, allow for a more immersive discussion on these interventions, think about how folks might get there, depending on whether they come from a large academic institution, some other practice setting, we are in the midst of finalizing that now. Folks can email Jackie if they are interested in connecting on that.

Here is our contact information. We will have time for questions and to dive more deeply and any topic folks may be wondering about.

JACKIE CZYZIA:

Thank you, that was terrific. We do have some questions into the chat. If others want to add questions in the chat, I will be reading them out loud. Also feel free to join on camera and raise our hand. Feel free to start a discussion. The first question was was it difficult to get buy-in from clinic staff using strategies recommend that would take extra time, extra physical space, etc.? How does it fit with the tightly compressed managed-care expectations for short and efficient appointments? Someone else followed with a similar question. Was it difficult to get buy-in from the leadership at the medical center?

LAUREN BARTOLOTTI BUSA:

This really great questions and definitely something we can spend a lot of time talking about and

will at the next training we will do, which we hope you will be part of. To start out in the space, we had a goal. We were sort of operating under this is the right thing to do and we know this is going to be best for our patients. But unfortunately, what is going to be best for patients doesn't really fund the work. We had to think about how can we make this a win-win for everyone involved? We wanted to think about how we could partner with different practitioners and staff from all across the hospital. From where you said, from your perspective, how can we make the clinical encounters you have with patients go more smoothly? How can we support that patient getting through the 20 minute appointment? You have XYZ thing that you need to check off your list. How can we make that happen in a way that is also going to be comfortable for the patient and have them coming back?

Clinicians would often tell us I'm spending half my day with patients with autism and the rest of my day is falling behind. More than anything else, to get buy-in from across the hospital, we have engaged in collaboration. We have engaged in flexible thinking. When we come up with an introduction we don't say here, pediatric neurology, here is how you helped implement this. We say here is this thing we have. Let's talk about how it can work for you. That is really where we have gotten so much of that buy-in. People willing to engage in a conversation of how can you adapt this to make it work for my practice?

The other way we got by and is really showing the impact. When we have a family who comes into the ED with a child incredibly dis-regulated, I keep saying child, but I should really be saying individual who is really dis-regulated, and there met with an empathetic and supportive security officer who is usually thereto dis-regulate but in this case is there and a source of comfort and support and help to both the staff and the family, that going to leadership, that going to patient advocacy, that being shared is what is getting folks to say OK, this is why we do these trainings. This is why we make sure people are equipped, staff is equipped.

So that feedback is so important. Anytime we implement a new intervention we get feedback. We want to hear from beginning to end how this is working for you, what impact is making on families. Family voice is so important. We often solicit feedback from patients and families because we want to know is this just working because it is the best thing to do or is this actually making a difference in the care they are receiving?

ALEXANDER FRIEDMAN:

I would point to our needs assessment as well. In getting this off the ground at BMC, Lauren had pointed out the many different brands of the needs assessment we undertook. I would point specifically to our hospitalwide survey and care and focus groups, which allowed us to point and say these are Boston Medical Center families, this is what they have to say about the care they have received at our institution. Similarly, hospitalwide staff survey. We can point and see that 60% or what have you of Boston Medical Center respondents report wanting more resources allocated to this.

And then exactly as Lauren said, those stories are so powerful. You have a patient who has not been able to successfully complete a dental visit in five years, all it took was a loving your patient to take a quick walk around the hall every 10 minutes to provide an opportunity to take a breath and calm down. You had a successful visit. It took twice as long, but you have a patient now who may come back time and time again.

LAUREN BARTOLOTTI BUSA:

I did want to say also adding a point to what Alex said, that patient we highlighted, the one we supported in getting the EEG, that was a patient not able to be seen and any physical space inside the hospital. Clinicians would have to meet her at the lawn outside because she would not step foot inside Boston Medical Center because of the negative experiences she had of how disregulated she had become. We went from that to getting her through an EEG. A week later she got an MRI and loves coming to BMC now. What we know is one positive experience is going to be the impetus for more positive experiences. Just like one negative experience can really break all the work that has been done to help a patient feel comfortable. So we recognize that these little success stories are not so little.

I do see the question about funding. So the Autism Program and the Autism Friendly Initiative, we are completely grant and philanthropy funded. We are not on the hospital's budget, we are a nonprofit hospital, and we don't bill for services. Everything we do is grant funded. The autism friendly initiative in the beginning was sort of a byline of our budget. We wanted to dedicate some funds to that, but we have since been able to get private donor and foundational support to support the work. We don't bill for any of our services. Although we are definitely trying to think creatively about that, especially as the expertise of our staff emerge, we recently hired a board certified behavior analyst to answer so much to our team and what we can provide to families. So definitely thinking about ways that we might be able to bill for what we do.

ALEXANDER FRIEDMAN:

And I will tack on to what Lauren said about our grant and philanthropy funding, we are fortunate at BMC to have a remarkable development office and have folks within that office that we have developed relationships with, that we collaborate on seeking potential additional funding. We will talk about that a bit during our summer training as well.

JACKIE CZYZIA:

There's a few more questions. How much effort is funded to do this work? I think you touched on this a bit. Is your BCBA full time on this project or across multiple other projects?

LAUREN BARTOLOTTI BUSA:

That is a good question. The Autism Friendly Initiative is under the umbrella of the program. Alex is full-time on this program, which is exciting.

ALEXANDER FRIEDMAN:

I agree. It is a tremendous privilege to do the work.

LAUREN BARTOLOTTI BUSA:

And thinking about sustainable funding is something we are always thinking about. We have found innovation to be on our side. We are always thinking some of our best ideas come from patient voices and family voices. And actually the voices of our intern staff as well. We sort of pull from a lot of different places. We love collaboration and thinking with other programs and institutions, how can we get the grant funding and think creatively to sustain both of our programs? We are always thinking about that. It is definitely a huge endeavor. We are happy for anyone to plug any of our programs.

JACKIE CZYZIA:

Yes, absolutely. I see that Brian has his hands up. You want to ask your question?

SPEAKER:

Brian Be, University of Colorado. I was going to also welcome folks to plug their other things in the chat. Ms. a Janet about a program to train adult providers. Also, she can come on camera to say hello and talk about that as well. There she is. I will acquiesce. Please go ahead.

SPEAKER:

My name is Janet with the Vanderbilt Kennedy Center in Nashville. I am study coordinator for a Department of Defense project ECHO, that is aimed at training adult healthcare providers. We are looking for physicians, advanced practice nurses, physician assistants in primary care to join us starting in November for a six-month cohort twice a month for an hour. We do case presentations and didactics. We have a team of folks from across the country, including a couple of neurologist, psychiatrist, a family navigator, two adults on the spectrum, and a (unknown term) provider. We finished our first cohort last Thursday. We look at it and surveys and define the project. He started on the first Thursday in November. I will put my email into the chat. If anyone wants to reach out to me, I will put you on the list. Or you can trim information. We would love to have a boatload of primary care providers. Thank you. Great work. Can I just say I am jealous of what you all are doing? I am almost at the point of tears. I am a parent of a 25-year-old with autism. I would love to know your secrets for an EEG. My son has never been able to get one. My hat is off to you. I thank you. I am so jealous.

ALEXANDER FRIEDMAN:

Janet, thank you so much for sharing with us about your work and also for your kind words about our work. We would be so happy to connect with you off-line and talk about ways we can work together. This is a great partnership in the making.

JACKIE CZYZIA:

Thank you, Jenna. It also looks like you have a question and the chat that maybe you can address. Brian, did you have another question or comment?

SPEAKER:

Same thing. Thank you and congratulations. Briefly, I am cochair for the AUCD Special Interest Group focused around autism, put in the chat where you can register to come to an open house. There are a couple webinars for Autism Acceptance Month.

JACKIE CZYZIA:

We are nearing the end of our time today. Thank you so much. I think everyone enjoyed the presentation. We learned a lot. Thank you for your time. If you have any other questions for Lauren or Alex, we will put their email in the chat. I believe Maureen already added it earlier, but we will repeat it. We also have an evaluation survey that if you can take one or two minutes to fill out, we really appreciate it. If you have any other questions about ITAC and our role or future training for programs with Autism Family Initiative, you can email me at jczyzia@aucd.org. Thank you, everyone. We appreciate it.



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ALEXANDER FRIEDMAN:

Thank you so much, everyone.

LAUREN BARTOLOTTI BUSA:

Thank you, guys. Have a good rest of your day.