

Hands In For Care
Episode Three
FINAL Audio Cut Transcript

COLD OPEN

Runtime: ~ 6:45

MUSIC (ousside)

Erin: Hello and welcome to Hands In For Care, a podcast for school nurses caring for children with complex health needs. I'm your host Erin Sivak.

Today, we jump into the last chapter of Mae's story and find out what path she takes to finally connect with parent Valeria and her daughter Gloria.

Mae sits at her desk, squinting at her computer screen. She clicks open a browser window and types in a search for the *AllCare* Community Health Center – the center that Shane mentioned in their last conversation about Valeria and Gloria. She sees on the center's website that they hold events that cater to children and families. Mae pulls open her filing cabinet and thumbs through her records. She finds that not only Gloria, but *a number* of her students have the *AllCare* Health Center listed as their primary care site.

So, Mae decides to follow through on the advice that Shane gave her, and connect with the health center. She dials the center extension for community events and Regina, the outreach director and a cultural broker for the center, picks up.

MUSIC OUT

Regina tells Mae they have a health fair coming up in two weeks. They invite representatives from local markets, dental offices and childcare centers to connect families to crucial services and hold them in the evening so that working caregivers can attend . Regina tells Mae they would love to have health services staff from the school district come and set up a table.

Mae realizes this is a chance to meet Valeria and Gloria in their community *and* connect with other families and students in her school.

MUSIC (ousside)

With some quick planning Mae, Shane, and another nurse are able to have everything ready for the event and the health center makes sure one of their interpreters is available for their table. Throughout the evening, Mae and her colleagues have great conversations with students and their caregivers.

As the event continues, Regina waves across the room to two people. Mae quickly realizes it's Valeria and Gloria. Valeria approaches Regina with a smile and looks over the school health services table before saying to Regina...

"I have never seen anyone from Gloria's school here before." Regina responds in Spanish telling Valeria that the nurses requested to be part of the health fair. Valeria nods as she hears this, but has to step away for a phone call, and then leaves the event.

As the health fair is coming to an end, Mae thanks Regina for her help and out of curiosity asks how she knows Valeria. Regina shares that she immigrated from the same country and that they go to the same church on Saturday nights. She says that Valeria brings Gloria to the services and that she often asks the community to pray for her. Mae realizes how little she knows about this family and tells Regina how she's been trying to connect with them. Without missing a beat, Regina asks if a cultural broker has ever worked with the school and family.

Mae says no and Regina suggests that she and Mae call Valeria later in the week together. She says: "I have a good relationship with Valeria and maybe with my help we can hear more about her perspective."

MUSIC FADE OUT

A week later, when they are all on the call together, Valeria feels comfortable enough to share her side of the story.

MUSIC (In My Eyes)

Valeria lives with Gloria and her mother, Lucia. Lucia takes care of Gloria and helps around the house while Valeria goes to work. Lucia doesn't fully understand autism. She says that back in their country, kids didn't have these health issues. And in all honesty, Valeria doesn't fully understand Gloria's diagnosis either. But, she has strategies that help Gloria in their daily routines and has learned how to use Gloria's communication device to help calm her when she gets frustrated at home.

Every day, Valeria follows a schedule: She and Gloria wake up, share a quick prayer, and eat breakfast made by Lucia. Then, Valeria drops off Gloria at school, and heads to work at a local car manufacturer. The work is exhausting, and the pay is little, but the hours are good and her manager is understanding of Valeria's situation as a single parent. Lately though, Gloria has been getting dismissed from school more often than usual. Valeria has started to use her 30-minute lunch break to pick her up and drop her off at home with Lucia.

Every time Valeria gets a call, her heart races thinking something is wrong with Gloria, OR that she might have gotten kicked out of school. She also worries about how the

constant calls affect her work; last time, she was stuck in traffic on her way back to work, and got a warning. She often wonders how many more calls she has left before her manager loses their patience. And will she ever have a chance to eat lunch!?

When she gets to the school, she often hears Gloria screaming while the school staff stand by looking perplexed... She thinks, "What's the point of bringing Gloria to school? In my house, she is safe with her grandmother and isn't screaming." School staff are constantly requesting Valeria for paperwork from the doctor but when will she get this done? They don't know about Valeria's tight schedule. She brings Gloria to all the appointments that she can but she worries about taking more time off of work.

Even worse, during the IEP meetings with school staff, Valeria often feels looked down upon. Her Spanish is perfect, but because of her limited English, she sometimes worries that she'll offend the school staff or say the wrong thing. Also, the written materials shared by the school are not always translated or are shared just before the meeting so she doesn't have time to review them and worries she's missing information.

At this last meeting, Valeria tried to share an activity that Gloria enjoys, humming her favorite song, in hopes that the school team might see it as a way to keep Gloria happier in class. But they were dismissive, noting it was a nice activity for home, but it would be hard to teach the whole staff. As the last meeting wrapped up, they asked Valeria if she had any questions and only gave her 30 seconds to respond. As she gathered her thoughts, the meeting adjourned.

MUSIC SHIFT

Mae thinks for a moment before responding, "There is so much work to be done here." She thanks Valeria for sharing and says she will do everything she can to make the relationship with the school and Gloria's care better. Regina responds that she would love to help and says, "Let's schedule a time to meet next week, perhaps your principal and nurse leader can join us."

MUSIC OUT

INTRO

Runtime: ~ 1:27

THEME

Erin: This is Hands In For Care – a podcast from SHIELD, the School Health Institute for Education and Leadership Development at Boston University’s School of Public Health.

THEME

In our third and final episode of Hands In For Care, we wrap up our conversation about our school nurse, and discuss how she can move forward to build lasting trust with the family of her student with special healthcare needs. Because in this scenario — and in so many real, school settings — systems of communication and trust are not at their strongest.

And when kids have complex health needs, parents, educators and other caregivers need to work closely together to make sure that everyone feels heard and taken care of.

Hands In For Care is a podcast where we bring that communication right to you, and lift the voices of everyone on the team. I talk to real nurses, caregivers, and other experts to learn how to overcome these hurdles. We learn about ways to engage and connect with families, keep our students’ health and support networks strong, and create a better experience for kids with special healthcare needs in the school health clinic and beyond.

BEAT / THEME OUT

ROUNDTABLE

Runtime: ~ 24:15

Erin: I have three guests joining me today to discuss our story. First, a close colleague of mine for many years – Betsy Steinberg.

Betsy: Glad to be here! I'm a school nurse in Natick. I've been there for about 20 years

Erin: Next we have Oanh Bui. Hello, Oanh. Welcome.

Oanh: Hello Erin. I'm a parent myself of a young adult, who is on the spectrum and professionally, working at the Department of Public Health.

Erin: Thank you, Oanh. We're so glad to have you. And Felicity Crawford.

Felicity: Hi everyone. I am a clinical associate professor of special education and the director of the education for equity and social justice master's program at Boston University.

Erin: Thank you all so much for coming to talk about the ending of this narrative that we've gone through for two episodes now. I'd like to begin by discussing how this experience might feel familiar to some of you.

So, Oanh, I'd love to start with you. I imagine you heard some causes for alarm while you listened to this story. Tell us how it relates to any personal or professional experiences you might have had.

Oanh: As a single parent of a child with special needs, um, also as an immigrant, I myself have been looked down on from the professionals, from the school as well. I have been being dismissed many times at my child's IEP meeting. And of course, I don't know how many times I got called and pick up my kid.

And in terms of language barriers, nobody explained to me about whether or not I should have access to interpreters, or I should have access to materials that can be translated into my language. And similar to Valeria's in many contexts that I don't understand what autism is, earlier on in the beginning. Nobody explained the impact of that on my child across the board, nobody explained to me in terms of how the team at the school work.

So, similar to Valeria's story that at a good numbers of IEP meetings, I was also asked to sign off the IEP right there and then, telling me that, alright, if you don't sign off Oanh, you're just not going to receive any services.

I'm very new to the country back in the day, I have no idea about the language of special education, as well as my rights as a parent accessing special education. So knowing and hearing Valeria's story, I feel so relatable.

Erin: Thank you for sharing your experiences with us Oanh. I really want to emphasize this scenario that you just described in your child's IEP meeting. For our listeners who may be doubting the reality of that and thinking "no way this would happen in my school," you know, hearing "if you do not sign there will be no services." Such a calloused response from a team that is supposed to be supporting your student *and* you – these things actually happen and that is why we need to be having these conversations.

So, Felicity, you have a deep knowledge of special education. Tell us how this story resonated with you.

Felicity: Valeria's story exposes several equity concerns within the school system. It highlights the importance of cultural competency and collaboration in supporting students with disabilities and their families. What really needs to occur is that there needs to be professional development for educators. That's clear, right? Culturally responsive practices are really important in guiding people in situations like this.

School staff should really actively listen to Valeria's concern and avoid talking down to her. The school team should collaborate with Valeria to learn about her strategies and routines so the IEP meetings really should involve input and activities that calm Gloria, and that it should be valued.

Erin: Felicity I'm so glad you've identified all of these areas in which the school could do better...

And this is a good place to pause and note how important it is for school professionals to listen to advocates in the disability community as well. You have to be aware of movements within that community and use that knowledge to help guide you on what kinds of professional development to ask for.

I talked about this with our BCBA guest in our first episode – Applied Behavior Analysis or ABA, is widely used in educational settings and viewed as a beneficial therapy for people on the autism spectrum.

However there is a movement within the autism community against ABA that shines a light on some of the harms experienced by people who received it. So, as practitioners we need to stay abreast of changes in best practices and *always* center the voices of our students with that lived experience.

So with that in mind and thinking about best practices let's hear from our school nurse. Betsy, can you address some of the barriers school nurses encounter in the education system and what someone like Mae could do to overcome them?

Betsy: Well, if you strip everything away from what's happening here, it's all about communication, and there's no point person for facilitating communication. And I look at how far she was able to go just by going to a community event. I'd really like to see nurses in this situation make home visits and take a member of the special education team and really dig into how Valeria manages her discomfort, how she manages Gloria's stress, anxiety, because I look at this child and say, this is a child who's stressed and anxious.

It may be in part due to the language barrier that she's learning in English, dealing with English speaking teachers, but it could also be that no one is sort of picking up on what she's telling us all, because even though she's non speaking, there's a lot of subtlety with kids who are, have autism spectrum disorder and how they communicate.

Erin: Thank you Betsy. I am curious to hear Oanh chime in on the idea of home visits. In our last episode one of our guests brought up a great point about how important it is to ask permission and consider how it feels for the caregiver to have someone in their home. So Oanh, tell us about your perspective.

Oanh: Yeah, I love the idea of having nurse come in home and visit. In Valeria's, um, family, the grandmother is the one who take care of Gloria. Because many times parents has to be the breadwinner and parents has to work. And because being in this country as the immigrant, that pressure is a lot.

The grandmother might have more insight, but I don't think that we have any conversation with the grandmother. So I like the idea that Betsy shared, nurses coming to the home to really have that hands-on, first hand experience to really see what had happened at home that could be effective.

Having and connecting with community leaders or connecting with a cultural broker who has been successfully navigating the system, who really help parents understand where things are, how the US system works, what their rights are, what is the nuance between the US and your home countries? Because if we talk about family engagement in the US, it's very different from family engagement in the different countries.

Erin: I love that point Oanh. And I appreciate what you said about how helpful community leaders like cultural brokers can be to families navigating systems that are so different from what they are familiar with. Because in our story it seems clear that Regina's role as a cultural broker has potential to really help our family so I want our listeners to know what a cultural broker really is and where we can find these people.

Oanh: So, there's no profession by trade that's called cultural broker, per se. However, it can be anyone who are bilingual, bicultural, who has been successfully navigate the system well, who already understand the community and who work with the community, who have that trust relationship with the community. So it can be a community health worker as any healthcare centers, parents who already walked a journey before.

So by definition, the cultural broker is a go between who advocates on behalf of another individual or group. Really understanding how the U.S. system works, how their home country system works, but at the same time, they also help the professional to really understand where the parent's perspective is at and what factors can impact them.

We know that in medical healthcare setting, cultural broker has been playing a really critical role, but I don't think that this cultural brokering model has been introduced that much in the special education or in the school setting.

Because if we talk all about immigrants, right, all immigrants are different. They all have their own different narratives. So we need to really kind of work with cultural brokers to really understand not only where families come in from, and then also in the context of the community at large as well, having a child with disability or having a child with some special needs like that, family can be dealing with a lot of social stigmas as well.

Erin: Thank you, Oanh. That's really good information. Helping us understand what a cultural broker can do and why having someone with those skills is so important to have as an ally for the family when they're working with schools and within these larger institutions. And I think Felicity will have more to say on that because we've had many conversations about it.

So, Felicity can you talk more about how *you* see the role of the cultural broker? And how can the school do a better job of addressing some of the cultural differences here?

Felicity: So the role of a cultural broker is to build trust and communication, there's so much research that has been written about this. You know, when I think about Valeria's frustration and feelings of being belittled in school meetings, it is important for both the schools and a cultural broker to understand that we need to employ a trauma -informed practice that really creates an opportunity for a safe and supportive environment for her.

We have to think about connecting Valeria with parent groups, for families of kids with autism that can provide her a sense of belonging. If I were in an administrative position and had the funds to do it, finding a way to provide Valeria individual counseling also matters. Some might say it's outside of the scope of what the school can do, but if it, if it redounds to the child, I'd say, let's try it. And even providing opportunities for training around autism would help empower her as well.

So when I think about what should happen for Gloria, her story really highlights the struggles for equity.

The lack of a Spanish speaking staff and lack of translated materials really does not feel welcoming. All of this violates Gloria's right to a free and appropriate education as identified on the special education law, the IDEA Act. Parents wouldn't know about it, especially if they're immigrants. They have no idea about these rights and we should really make an effort to ensure that if we're going to put equity front and center. That they should understand and a cultural broker can do that for them.

Erin: Thank you Felicity for telling us about how schools can do a better job. And even though listeners cannot see it, I think Oanh was appreciative of that answer as I saw her nodding her head quite a few times. I also want to make sure we share some practical examples with our listeners -- actions they can take when working within an institution that might not be set up to successfully provide that culturally responsive care.

And in my time with Betsy, I learned a lot from her. And I do have an example of how she showed me how to meet families where they are.

We had a group of METCO students and they were coming from a different city into the district...

So, for listeners who might not know, METCO stands for Metropolitan Council for Educational Opportunity. And it's a program designed to increase diversity and expand educational equity to students in the Boston area from under-performing school districts. So these students are often commuting very far from their home neighborhoods to go to schools in completely different communities.

So Betsy, I'd love you to tell us about working with this group of students and what you did to meet these families where they were.

Betsy: So, I got to know our METCO director and said, you know, I wish that I could meet some of these families because I keep having to call them when, things aren't good, but they don't know me, and I don't know the kids very well, and I'm asking them to come an hour sometimes commute out to pick up their child when really, maybe we should have some parameters for when I should call you, or maybe I need to know more about their health.

And so, our METCO director invited me to go to the open house to meet these families and then she got into the habit of bringing them by the office when they would come to our school. And it's been so helpful because we've actually been able to make some really good connections with families. We have them in our school for four years.

It's been really valuable. We've had kids with more health concerns recently. Some parents had been concerned about sending their kids with health concerns so far away from home, but they know when they come to us that they're safe there. We know them. We know their families. There's not any intimidation about calling us and asking us for help, and that's really, really, really helpful for the kids. And, it's good to, to know that I'm trusted.

Erin: I think hearing I'm trusted and knowing that and having that reassurance from the families is again, one of the biggest wins you can walk away with when you're trying to work within these systems. Felicity, you run a whole master's program that prepares educators to prioritize equity and social justice. Can you talk about why there's a need for this, and what about our story demonstrates why your program is so important.

Felicity: So I think what, what we really need to pay attention to programs like the one we've developed, the Education for Equity and Social Justice at BU, really focuses on addressing the deficiencies and, or disparities in systems.

And when we think about the experiences for children with disabilities, we have a system that is shaky, and for many, is falling apart. And we get to think about what are the policies and procedures that we utilize in our everyday practices that can be tweaked in order to more honestly provide children access to resources and to opportunities that would allow them to thrive.

Children of color who've been marginalized for a number of reasons, and children with disabilities who also constitute the largest minority group anywhere in the world, when we think about their experiences and the lack of opportunities, it is obvious that a program that focuses on equity matters.

And when I talk about equity, I mean access to resources and to opportunities so that children can reasonably expect to flourish.

It's important to recognize that there are systemic inequities that persist in our systems. And that's why it's important to think about how this affects children with disabilities in general and other children of color who are continually marginalized by their experiences.

Erin: I like where we just left off on systems and looking at them with an equity lens and what needs to happen within schools. So, we left our narrative on a bit of a cliffhanger. It seemed like a connection was made. We finally heard from Valeria and Regina had some thoughts.

So if we put ourselves at the end of the story where we just see the little bit of the door opening, I'd like to hear from everyone. Betsy, as an experienced school nurse, thinking about where our story ends and the systemic change that's needed in the school district, what can Mae do?

Betsy: So if I were Mae, I would be speaking to my nurse leader to see if I could get some approval, to go to Gloria and Valeria's house and have a home visit. I'd be talking to Gloria's case manager in special education. There's another piece of this that I'd like to see happen. I'd like to see Gloria have an EL evaluation, to see if her materials are appropriate for her to see if her communication device is appropriate. And I would like to then have a conversation with Valeria about setting up time to chat either on the phone at her convenience to set up an appointment.

I'd like to be able to go through a full head to toe assessment with Valeria about how Gloria's body works, how she communicates about her physical well being. And I'd like to be able to write a plan for Valeria. And for me and for Gloria's team about how are we going to make her feel good at school from a physical standpoint. Because I think some of the behavioral emotional pieces will fall into place if she can be physically taken care of appropriately in school. Um, we want her classroom to be a safe place for her. I look at some of the classrooms where kids with ASD are housed, and I think, you know, we're talking about fluorescent light bulbs. We're talking about tile floors. You know, they're not comfortable spaces. And some kids are super sensitive to that. Is there something we can do to the physical environment for her so that she feels okay?

But I really want Valeria to be a partner with me in that. I want her to feel like she is pointing me in the direction I need to go.

Erin: I love all of these suggestions. And I think all our listeners who are school nurses who are in situations just like this, um, will have some very good action steps to walk away with.

But I also need to hear from Oanh. What do you think needs to happen next?

Oanh: The first thing I feel that it'll start for change is to see Mae visiting the community events. And I think that is also very important for Mae to continue to work with Regina to really kind of figure it out where Valeria's story is, what is the most critical barriers that might prevent Valeria from fully, meaningfully participate into the school team.

And also provide the training to Valeria's and also her grandmother, so that we are consistent in the approach in supporting Gloria, instead of like Gloria's at home dealing with these issues at one way, but then at the school we deal with, in a different way. It's very confusing for her.

The other areas I think that could be also very important for Mae to not only collaborate with the cultural broker, but also we want Gloria to be part of the community. Maybe potentially some YMCA or Boys and Girls Clubs in the area, so having her be in with peers doing some entertainment or doing some recreational activity after that can also be really helpful for Valeria's.

We all work for the common goal of really kind of ensuring that our child is successful. Right?

Erin: I like that you said we all have the same goal. We do, we all want Gloria safe and happy in school, ready to learn. And I think that is a perfect place to turn things over to Felicity, because you also mentioned how Mae should reach further out into the community and really place herself there as a sort of a face of public health.

She has the skills and the knowledge to be able to help educate and connect with the community. And Felicity is doing a lot of this work with us at SHIELD right now in helping nurses recognize themselves as leaders in equity. So, Felicity, what should Mae do next? And how can this new school nurse reach that point where she's ready to be a leader in school and in the community?

Felicity: First, advocacy and collaboration. The IEP document holds the promise for a child's improvement. It holds the promise for their ability to access and participate and make progress in the school curriculum, right?

So school nurses can contribute their expertise on health considerations. And we know that there are some here that might impact learning. I really like that Oanh's pointed out the need for interdisciplinary collaboration. I really like that you asked me about how might nurses help in this endeavor.

Here's another theme – direct support and management. This matters. Health monitoring and management is important for children with Autism Spectrum Disorder and school nurses might be able to, um, have an understanding and communicate that the kids underlying health conditions or if they require medication during school hours.

Teaching kids relaxation techniques, offering a safe space to express emotions, and they can also collaborate with counselors or social workers for that matter for support.

When we think about professional development, school nurses can offer professional development for teachers. They can offer training and support on peer education. And in order for children to be more accepting of their peers with ASD.

At the base of this, fundamental to this work, is on is ensuring that there's a culture of understanding and respect that redounds to everyone, most particularly to the parents and to the child. So cultural competency matters. Individualized approach matters.

Be flexible in communicating, create options, know families don't always have to come to you. You get to figure out how you support them through email, by phone calls, by video conferences, by written notes in a different language if needed. How you accommodate different preferences. These things matter.

Offer up the expertise of school nurses along with educators to advocate for children's needs and to make available resources that they would need to do their job. This support system has to be interdisciplinary and we have to think about how we come to each other with a great deal of respect and a sense that each participant brings a level of expertise that complements the other.

OUTRO

Erin: A big thank you to our guests for this episode – Betsy Steinberg, Oanh Bui, and Felicity Crawford.

Thanks so much for listening! If you enjoyed our show, please subscribe and leave us a review and check out our listener survey in the show notes. If you want to learn more about SHIELD, head to SHIELD.BU.EDU.

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