Hands In For Care

Episode One
FINAL Audio Cut Transcript

COLD OPEN

Runtime: 4:00

MUSIC - “In My Eyes”

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, I’d like to share a story with you. It’s about a nurse named Mae, who just started a new job at Robinson Middle School. Robinson’s a big school in a large urban district. Mae’s only been working at Robinson Middle for two months, but she has six years of experience working in pediatrics – in hospital *and* primary care settings. So even though school nursing is new to her, Mae is excited and feels well-prepared to support the students who come to her clinic.

One day, Mae is working in her clinic when she gets a call from one of the 6th grade special education teachers. They’re sending a student named Gloria down to Mae’s clinic along with a classroom aide. The teacher thinks that Gloria might be sick. And she asks Mae to assess her.

Mae knows that Gloria is a student with Autism Spectrum Disorder. She’s non-speaking but she can make a range of vocalizations and she uses a communication device. But Mae wants to learn more, so she takes a look at Gloria’s visit records from the last school year.

MUSIC FADE OUT

Scanning the records from the previous school nurse, Mae learns that Gloria was dismissed from school *seventeen* times. These dismissals followed verbal outbursts, crying, pulling and scratching classroom staff, and refusing to eat. All behaviors that – the records say – might be related to gastrointestinal distress.

MUSIC - “In My Eyes”

When Gloria gets to Mae’s clinic, she’s making screeching noises and trying to pull her communication device away from the aide who is carrying it for her while she is in distress. Mae tries to take Gloria’s temperature and check her abdomen, but Gloria can’t sit still, so the assessment is too difficult to complete. Running out of options, Mae asks the aide what the last nurse did to make visits to the clinic easier for Gloria.

Basically, the visits have never been easy at all.

MUSIC OUT

The aide, Jeremy, tells Mae that most of Gloria's visits last year ended with a call to her mother, Valeria, a dismissal from school, and a recommendation to follow up with Gloria's primary care provider. Jeremy tells Mae that Gloria and her family only speak Spanish at home, and because there's no Spanish-speaking interpreter on staff at Robinson Middle, Valeria can only have basic conversations with school staff.

MUSIC - "In My Eyes"

He also says that, in the past, Valeria has seemed upset when she came to pick up Gloria. She also doesn't always follow up with the nurse about whether Gloria was seen by her PCP.

Mae doesn't know what to do. Understandably, she's afraid of missing something important. So, she ends up following the same routine. She calls up Valeria and tells her that Gloria seems to be sick and needs to be dismissed. Valeria says, "Ok," and hangs up quickly.

MUSIC OUT

Jeremy and Gloria wait in the clinic for 45 minutes until Valeria arrives. When she finally walks in, Valeria seems annoyed. She doesn't look at Jeremy, and motions at Gloria to come with her. Mae tries to talk to Valeria, but Valeria waves a hand at Mae and says, "I have to get back to work. This happens too much." Then, Valeria and Gloria walk out of the clinic.

MUSIC - "In My Eyes"

"Well, that was intense." Mae thinks. She sits down in her office chair and closes her eyes. She's not sure how to move forward with Gloria's care at school. She needs to be able to assess her. Would it make sense to try and bridge the language gap between Valeria and the school staff, so everyone is on the same page? "How can we make this better?" She wonders.

MUSIC OUT

INTRO

Runtime: 1:36

MUSIC - THEME

Erin: I'm Erin Sivak, a long-time school nurse turned nurse educator. And 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.

Some of Mae's story was ripped from the pages of *my* school nurse life. It touches on countless stories from other RNs who face similar hurdles when working to support kids with special healthcare needs. And a lot of the time, those hurdles boil down to communication.

When kids have complex health needs, parents, educators and other caregivers need to go the extra mile to build cooperation and trust, so that *everyone* feels 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 caring for children with special healthcare needs.

So, on each episode of Hands In For Care, we'll hear a story that highlights a challenge school nurses face when caring for children with medical complexity. I'll talk to real nurses, caregivers, and other experts to learn how to overcome these hurdles. We'll 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.

MUSIC - THEME FADE OUT

ROUNDTABLE

Runtime: 27:21

Erin: To discuss Mae, Gloria and Valeria's story today, I'm joined by three guests, each with their own experience caring for children with special health needs.

For the school nurse perspective, we have Barbara Singer, who has worked in schools for more than two decades.

To give us a parent's point of view is Beth Bostic – mother of a child with medical complexity and a family advocate for 15 years.

And for more insights on students with special needs, we turn to Molly McHale – a former special ed teacher who is now a board certified behavior analyst at a public school for children with autism.

Welcome everybody! I'd love to hear a little bit about each of you and why this story might strike a chord for you personally.

Beth, let's start with you. As a parent of a child with special healthcare needs, did Gloria and Valeria's experience resonate with you?

> **Beth:** Oh, most definitely. As I was listening to the scenario, it was striking to me that I had a very, very similar experience with my own son, who I affectionately call King James. As the expert on James in particular and also on his condition, which was a rare medical condition I spent a lot of time putting documents together and information together for the school nurse to make sure that they had everything that they needed.
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> Despite that, I would get phone calls from the nurse because James had a condition called dysautonomia where depending on what would trigger his tone, he could break out into huge bouts of sweat. He was actually okay, and very often this happened when he was trying to do something really, really hard, and he was very tenacious, he didn't give up easily. And so I would get phone calls from the nurse saying that he was in distress and he clearly wasn't in distress, but they had never seen it before. And what they said to me is, I've never seen anything like this before. This is not normal. As though that was a reason to not listen to the information I had provided to her to help her to understand the fact that he really wasn't in medical distress.
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> It was as though everything that I had done very carefully and with them in mind was ignored. And the years of experience I had with him in my home didn't seem to matter. It's an ongoing frustration because I think everybody wants to do the right thing, but people are really at a loss as to where to begin. And time is often working against you.

Erin: Thank you so much, Beth, and I like that sentiment that everybody's working towards the same thing, and we're up against time and other barriers. Barbara, given your experience as a school nurse leader, you've spent a lot of time working to break down those barriers between nurses and parents, right?

> **Barbara:** Definitely, the highest priority is building that trusting relationship because uh, parents of children with special health care needs are their student and child experts, and so their input is invaluable and really kind of the foundation of which we can then build our plan of care.

Erin: Absolutely… Speaking of that plan of care, that involves the whole care team: nurses, parents, and educators working together. So, Molly, let's hear a few words about your experience and expertise working with children with autism, and how common Mae's experience is, in terms of how she's seeing the relationship between Valeria and the school staff play out.

Molly: I think these kind of situations happen all the time in schools. So parents especially with children who are not yet able to advocate for themselves effectively are putting an enormous amount of trust in the staff and in their school. You know, working in a school over the years, the past decade, um, I think what's helped me to develop trust and rapport with families, is just taking that little bit of extra time to show the investment in their children, and it's true that teachers don't have a lot of time during the day, but I always found that it's worth a little extra effort to make this connection, and it's important that the parents and the staff are on the same team.

And it doesn't have to be anything extravagant, um, some small things can help make a huge difference. For example, you know, sending home positive notes about their child's day and not just negative things that occurred, making a phone call just to talk, in person, or every so often, just to let them know the things that are going well and then some of the things that are being worked on.

Barbara: You know, I think a key point, too, here, is not waiting until there's a stressful situation, such as Gloria being brought to Mae's office to try to be assessed, and then Mae's feeling like she doesn't have the information she needs to do it, and she's calling Valeria to come get her, that's a trusting relationship is not going to be built in that scenario then, because there's a lot of frustration.

So it's so important when you know that there's a student with special healthcare needs, who's going to be in your school to really start building that relationship proactively and I see in this situation too, there hasn't been a translator available. And that's so important because Valeria is the expert in Gloria. But if she doesn't have a way to communicate that or doesn't feel like she's being felt, heard or understood, then she's not going to be able to move forward with that relationship either.

So we need to have culturally responsive interpreters and translators available to all of our families. And the other key piece that I want to sort of put out there is that nurses are not provided with curriculum in nursing school about working with students with disabilities.

Erin: Barbara thank you for saying that because you just struck a chord that has been a frustration of mine since I became a nurse. We are not prepared in school to serve this population that is so important. I think many listeners can also relate and may have some very strong feelings about what should be done here. So, I'll ask Barbara, as the school nurse, what course of action do you think May should have prioritized here. What options did she have?

> **Barbara:** Well, again, it goes back to building trust. She needs to build that relationship with Valeria. Does she have anyone out in her community that she might trust that Mae could also collaborate with. Could she send her questions about what does Valeria do at home when Gloria is exhibiting these symptoms? What helps her?
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> Because Gloria may have these symptoms that look distressing at school, but they may be part of a coexisting condition that she may not be sick. So just, she just needs that information about Gloria's life at home and how it translates to school.
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> The other thing that Mae, at the same time, is building a relationship with Gloria. So I see her going into Gloria's classroom when Gloria is not feeling ill or not in a stressful situation and trying to observe her, trying to maybe do something that's really positive with Gloria in the classroom so that Gloria sees her as a trusted adult and not somebody to be worried about or nervous about when she is brought down to the health office.
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> Mae could become familiar with Gloria's assistive technology, her mode of communication, so that maybe she could even have a nurse's page on there, so that it would just help with Gloria being able to advocate more for herself and get to know May in that way.

Erin: Thank you, Barb. Those are all really great suggestions. I'm thinking about Beth and your perspective on this as a parent. You already shared an anecdote that really parallels this story and even what Barbara was just talking about, with being able to share information with the providers at school, which is just so important. One of the family engagement principles that we want to highlight in our show is that building trusting relationships between families and school systems is a shared responsibility. So Beth, what do you wish the nurse and the school staff could have done differently to make you and your son feel comfortable and cared for?

> **Beth:** One of the things that I think nurses can forget is the amount of work it takes to keep these kids going. You know, I think about my own experience of raising James who was non verbal, non ambulatory, G2 fed, hearing impaired. So, managing all of that and his medical team, and his recreation. Oh, and by the way, I had another child who needed attention, and who often reminded me she was here first, right?

Lead with empathy. Really try to think about all of the things that this person is doing every single day, making sure that you are cognizant of the fact that this is hard work that doesn't ever stop, you're never off and you never get a break.

The other is really recognize that I am the expert. I've been the one constant in James's life. So I can tell you everything that's been tried, everything that's been failed, everything that's been successful. I can give you insights on the whys, tell you about the medications, the levels of medications, the environments he does well in, the positioning he needs, how often.

And if I take the time, as I often did, to write things down as clearly as possible, I recognize that people have very full days and reading everything can be very, very difficult. But I put a lot of time and effort into providing information to you so that you would have it to refer to. At the very least, acknowledge that it's there. And then take the time to read it. I do that so that you have it. I'm trying to make it as convenient as possible for you. And I know that there are other parents who do the same thing.

And then thirdly, when it comes, you know, Barbara touched on this with the cultural responsiveness. Many of these parents have been through incredibly challenging circumstances just to get here. Taking the time to really get to know the family and think of it in terms of doing things *with* the families and not *for* the families or *to* the families. We're a team. And the parents, they are the team leaders.

And I wish that I had gotten that kind of respect more often. To be regarded as the expert, the team leader, the person who ultimately is going to have to make final decisions about what's going to happen with my child, and wanting to engage the rest of the team to help me to maximize his learning and his health. And if we could do those things together, life was going to be a whole lot easier for all of us.

Erin: That is so important for us to hear, Beth. Thinking about what we just heard from the parent’s perspective, Barbara… you talked about a few steps you could take to make the relationship between the parent and school nurse better, and I'm wondering, you know, how would those steps set up Gloria for success in school? Because that's the ultimate goal, right? We all want the student to have the most positive, engaging, and best school experience possible.

Barbara: Correct. I think if Mae and Valeria could come to an understanding, how can they best communicate with each other? Because I think that home-school connection is so important so that if Gloria woke up that morning and say, had a stomachache or something, if Valeria was able to, uh, relay that to Mae. That's important information because if Mae has baseline information that's important about Gloria, maybe Gloria doesn't have to be sent home right away. It comes back to what does Valeria do at home to help Gloria when she's exhibiting symptoms like that? And it would be great then if Mae had that information so that she could also implement those same interventions. And it's really how to communicate, so that they can really keep dialogue going,

Erin: That’s great Barb. And I keep hearing dialogue and teamwork, and I feel like we're talking about school and where our student is so much, and we can't talk about that without bringing in our person with special education experience. So Molly, I am curious to know more about the special educator's perspective. And someone in Jeremy's role, too, as an aide or the teacher in the classroom, what are you prioritizing in this moment and in this situation?

Molly: It's tricky because, like everybody's saying, if, if nobody's on the same page and we as a team at school, think that, Gloria is sick. at least I'm not expecting her to, you know, do her best work, work to her full potential. And I'm worried about her and I want to see her in school and learning. But I think that if we're sending her home 17 times without a conclusion, then there's obviously some barriers there. Maybe Gloria's not doing this at home, so mom doesn't understand the significance of what 's happening at school.

I'm wondering if the teacher ever had a conversation with her, whether that's with a language line or, you know, at our school right now, we have Spanish speaking paras. I think everybody wants the safety and well being of, of Gloria, but the communication piece is, is definitely missing there.

Beth: Can I just add something else too? What I have found, um, both as a parent and as an advocate is that often school nurses are not able to attend IEP meetings. It means that we're not leveraging all of the expertise that's available to us. I've often had to be the person to initiate the invitation, even to consider having the nurse in the room, even if it's just for part of the time, because that's also just a different setting where you might be able to get some more information, not only from the parent, but from the rest of the team. So to the extent that it's possible, the nurse is a part of the IEP team.

And if they're not present when the rest of the team is discussing this child's needs, which also happen to be medically oriented, then to me, that's a failure of the team.

Erin: Beth, thank you for being a parent who says that. Invite the nurse to the IEP meeting. I'm biased. I'm soapboxing for school nurses right now. And Molly was just talking about, you know, partnerships between the classroom staff and the parents, that partnership needs to extend to the school nurse too. So, Molly, when you're thinking about partnerships with classroom staff, parents, other school health professionals, how do you think communication could have been approached differently here?

> **Molly:** I think that going forward, the relationship has to be repaired. Um, there's a lot of, like rebuilding of the trust and the communication between all the parties. Like everybody's been talking about, the nurse needs to be included in that as well. And I think we need to figure out like, what are the, what are the barriers? Is there a reason that Valeria is picking her up every time, but is she taking her to the PCP or does she know that this is a thing that's not that serious?
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> **Barbara:** The other thing I want to piggyback just about is Valeria bringing Gloria to her PCP. Does she have insurance? Because that can be a barrier. And where is the medical provider? Is there an issue with getting them there? Those are things that need to be figured out so that if that is a barrier, we can help Valeria overcome that and get access to the care.
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> I would want to know what are Valeria's cultural beliefs just around autism and the illness, because this again, like you touched on Molly, it may not be a big deal to her, but we just don't have that information.

Erin: I think it's important that this conversation has veered towards, mutually acknowledging the effort that teachers, parents, the students, the school health professional, the nurse are putting in. And when communication falls through the cracks, this is when we start to have these relationship strains, or they can't even get started.

And we also cannot have this conversation without acknowledging social determinants of health and barriers to equitable care that so many families face.

So I would actually really want to hear from each of you. What are the barriers that you've encountered? And then what can we do as school professionals? I think a lot of school nurses know we're responsible for care coordination. We're responsible for helping families access what they need, which sounds simple, but it is not always clear cut.

So Molly, tell us a couple of things you thought of, challenges that Valeria might face outside of school and what are those hurdles?

> **Molly** : So one thing that comes to mind Is that you know with this recent intensity of behaviors in school? Is Valeria having a hard time bringing her to the doctors by herself?

My brother is also on the autism spectrum and I know in the past, my mom has had a lot of trouble getting him to walk into the doctor's office. He would, you know, not go in, flop on the floor and stay in the car and it wasn't until the doctor came out to the car to do the appointment at the car because she found a guy who was willing to do that, that it actually, you know, something got resolved. And she was embarrassed about it like she didn't, she she's like I can't even get my kid into the doctor's office.

Maybe something like that's happening and she doesn't know what to do about it. Or, she's already taken a lot of time out of work to pick her up all these times for, you know, getting dismissed at school. It could go in various directions, I feel.

Beth: You know one of the things that I think about with my own experience, before I had James, I had the dream job. I was working as a project manager in a training and development organization, and one of the things I've learned is that over 60 percent of moms in particular end up either changing or stopping work altogether because of the needs of these families.

So when you think about that and then layer in different culture, different language, the trauma that many families have experienced, either from the journey that I'm getting here to the United States, or just the ongoing intergenerational medical trauma that many families of colors experience.

When I think about the story I told you earlier, right, um, the nurse that I was looking at was what you typically see today. She was an older white woman, and she wasn't listening to me.

Now, this was a situation that, sadly, I was all too familiar with, and I had put in so much effort to, to counteract the fact that I am a woman of color. It's very visible when you see me. And so I'm trying to do everything I can to eliminate the stereotypes or the preconceptions that can happen so automatically. So, how do I get past that when, when I'm trying to make sure that my child can do what everybody else gets to do, is just go to school. So really keeping all of those kinds of things in mind. When you think about family engagement, people think of it as an added thing, but family engagement is the way we should be doing business.

If you can meet that person where they're at, what you may think is most important may not be top of mind for them in that moment. Exploring things like food insecurity, shelter, appropriate equipment, insurance, as Barbara mentioned before, right? Um, respite. The mom just may need a break, right? And if you can address the thing that's top of mind for them, it builds the relationship, it removes a barrier, and then you may be able to get to this other thing that you need to talk about. But respecting the fact

> that just because you think this is most important, they may not, and that's not necessarily wrong.
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> So really meeting them halfway and really being more, um, inquiry focused, you know, really focusing on how can I assist you? Because those little victories make all the difference in the world

Erin: I love that – the little victories, and how important it is to pull yourself back. And as school nurses, we're in our realm when we're in the school. If you're in your clinic, it's very hard to take yourself out of that mindset of I am going to work with this family and I'm going to solve *this* issue because this is what is hindering my student from being healthy and successful at school. But taking the step back to listen is really so pivotal in these moments, as you just said, Beth.

And Barb, I'm curious what can we do as school health professionals, because I think that's the other place that we get stuck. How do we move from being an advocate who is action oriented and focused on health interventions to ALSO making space to really hear the families and make their priority your priority.

> **Barbara:** Well, I think, again, it comes down to meeting and building a relationship proactively instead of reactively. You're not going to solve everything, um, all at once, but can there be a mutual goal between the nurse and the school team and the parent, kind of prioritizing what would they like to see first and then kind of build upon that.
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> You know, some of these kids are in the hospital a lot and it's very traumatizing and so the thought of coming down to a health office, even though nurses are so welcoming and warm, it could be really scary for them. I remember I had a student with autism who, was nonverbal and his parent could not get him to his pediatrician for a physical. He would just run and wanted no part of it. We worked with him for a few weeks and actually did a step by step story about some of the things that might happen during a physical about looking in your ear and looking and just really trying to, pre -teach, I guess, and really a lot of reinforcement and he had a successful appointment. So I think it's just starting small and then just building on that.

Erin: I like the idea of starting small. I think we all operate under these very real time constraints in a school environment in a parent or caregiver role. So I just want to bring it back to Molly for a second. What Barb just described as something that could be helpful at school and at home... Is this something you do in classrooms or do you have a suggestion on how to start this collaboration, you know for a nurse who might be listening going "oh my gosh, how do I make this happen for my student?”

Molly: So we actually build it into our, um, curriculum, to work on these like, kind of, life skill type events. So we have you know, the blood pressure cuff and the stethoscopes and things like that, that we actually will practice with the kids so that when it's a real time situation, they're less afraid. They're more, you know, able to participate in those things.

But, like Beth was saying, our nurse comes to all our meetings at our school, like she's invited to every single one, even if she only stays for 15 minutes, you know, just ask the parent, anything we need from me, like, can I help you with anything?

Beth: I just wanted to add a kind of build on something that Molly said. School nurses have a unique opportunity to contribute to the overall education of a student. And when I think about my son going to school, as far as I'm concerned, everybody who's in that building is responsible in some way of contributing to equipping him to be able to pursue his own self determined life later on.

School nurses can really be an invaluable tool for things like helping a child understand what their medical condition is, what they're allergic to, how to articulate that, how to advocate for themselves, all of those things. That's part of educating a child, it's not just the math, the reading, the social studies. We're talking about a whole child.

Erin: That is such an important point Beth. So to sort of bring it all back can I ask for some closing thoughts from each of you? Knowing that we have to improve the family relationship and the care for the student, what are the most important ideas that our listeners should take away from Mae’s story?

Beth: I think really trying to figure out how to have a conversation with mom that's apart from a crisis. Do a little bit of investigation ahead of time to see if you can understand, what that mom's culture is, what might be getting in the way of the two of you talking with each other having those, uh, interpreters services readily available, if at all possible with a bilingual, bicultural person so that the way that you're communicating can be translated properly to the other person.

Also be aware. in the back of your head of the fact that these are very often our families of color, our families who have experienced a lot of trauma and as a result, distrust is kind of the way it happens. many of them have had. Horrible experiences with the government. Horrible experiences with white people. And while that may have nothing to do with you, it is a reality of the lens that they walk through.

Lead with humanity. Lead with empathy. And when you do that, you will chip away, not only at your relationship with them, but also in helping them to be able to chip away at those, those experiences so that they can actually move forward, not only with you, but with other members of the team and other future teams and as they continue on with their journey with their child.

Erin: Thank you so much, Beth. Molly, what do you think?

Molly: The most important thing I think is to build that trust and to build that relationship between. the school team and the parent so that moving forward we can do what's best for Gloria.

Erin: All right, Barbara, a takeaway for our school nurse, from our school nurse.

Barbara: I think, trying to think outside the box on how can we build the trust, meet Gloria's needs and meet Valeria's needs. Could Mae go to one of the specialist appointments, just so that Valeria sees Mae is really truly part of a team. School nursing is a great specialty. And what's really great is often we have these students for a few years. So you have runway to really build on that.

MUSIC - THEME

And that is just key to the student's success.

OUTRO

Erin: A big thank you to our guests – Barbara Singer, Beth Bostic, and Molly McHale. In our next episode, we'll find out how Mae reaches out to Valeria and Gloria's community to get a better picture of the family's circumstances. We'll also hear from three more caregivers and experts who work closely with children with special healthcare needs.

Thanks so much for listening! If you enjoyed our show, please subscribe, 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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