

Hands In For Care

Episode Two
FINAL Transcript

COLD OPEN

Runtime: 4:30

MUSIC IN - “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 check back in with Mae, the new school nurse at Robinson Middle School. When we last left Mae, she was replaying her last interaction with Valeria, the parent who’d run into the clinic, taken her upset daughter Gloria, and rushed out again with a wave of her hand.

Now, Mae takes a few deep breaths and thinks: “I really don’t want that to happen again... we need to make sure that Gloria’s dismissal rate goes down. But how can I make a connection with Valeria, so we’re on the same page?” After thinking it over, Mae decides that she needs to get Valeria and the school team to sit down together and work this out. She reaches out to Gloria’s teacher and finds out, to her surprise, that the team had an IEP meeting with Valeria two weeks ago.

MUSIC OUT

Gloria’s teacher Lee tells Mae that the IEP meeting is typically the only one that Valeria attends throughout the year. And she doesn’t say much, even though the district Spanish interpreter is there, too. Lee says that he would really like to make Gloria’s experience at school and their relationship with Valeria better. And he’d be happy to work with Mae to make that happen. Mae’s glad to hear that, and tells Lee that she’ll call Valeria the next day and ask her to come to a team meeting so they can work together to improve things.

MUSIC - “ousside”

Mae asks the district Spanish interpreter for help — and even though their time is spread thin across multiple schools, they agree. Once the interpreter is on-board, Mae calls Valeria to suggest a meeting. Valeria says that the “school meeting” already happened. Mae tries to explain that this would be a different kind of meeting. That they want to make things better for

Gloria. Mae tells Valeria: “We want to figure out what to do for Gloria’s stomach pain, so she isn’t dismissed from school so much.” Valeria says that all the school does is tell her what to do for her daughter, but she already knows how to take care of Gloria. Then, she says she needs to get back to work, and hangs up.

MUSIC FADE OUT

Mae is at a loss; the interpreter says that at the IEP meetings, Valeria gives short answers, does not ask questions, and just signs the paperwork they put in front of her. “What is going on here?” Mae thinks. She hasn’t found one person at the school who has a good relationship with this family.

Mae needs help.

DRUMS - “ousside”

She calls her mentor Shane, the school nurse at the high school, and explains the situation. It turns out that Shane has faced this kind of scenario before. They say that building a relationship with a family over a language barrier takes time and a lot of effort. But, Shane says, they have a student who lives in the same cultural community as Gloria, and they’ve developed a great relationship with the student’s dad. Once Shane and the dad had a good rapport, they asked dad how interactions with the school *felt*. The dad shared that the school meetings sometimes felt intimidating, like he was being talked down to by the staff.

DRUMS OUT

From talking to the dad, Shane learned that families want to see people in school meetings who look like they do, who understand their community, and who they can trust.

Shane says they had much better luck communicating with families *after* they attended an event at a local health center called *AllCare Community Health Center*.

MUSIC - “ousside”

Shane tells Mae that once the families saw a school nurse talking with healthcare providers they knew and trusted, they were much more open to working with them. “It’s always a good approach to ‘meet families where they are,’” Shane tells Mae, “Once we started communicating, I learned so much more from the parents. They are the experts on their kids, and I don’t know that our school teams always make them feel that way.”

Mae realizes it's time to start thinking outside the box. For now, school is not the place Valeria feels respected, and getting there is hard because of her work schedule and limited transportation options. What can Mae do to meet this family where they are?

MUSIC OUT

INTRO

Runtime: 1:24

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.

In our second episode of Hands In For Care, we continue our conversation about our school nurse, discussing some of the challenges that she *and* her student's family are facing, and how everyone can get on the same page. 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'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.

THEME FADE OUT

ROUNDTABLE

Runtime: ~ 28:53

Erin: I have three guests joining me today to discuss how Mae can move forward, so let's hear a little bit about each of you and how your experience lends itself to our scenario. First, I have Tina Rusak –

Tina: Hi. Thanks, Erin. Yes, my name is Tina Russak. I'm a nurse care coordinator for Gardner Public Schools in North Central Massachusetts, and I've also been a school nurse for eight years. I am really looking forward to talking about how school nurses can improve connections with parents when there is a language barrier and also when there is a cultural barrier.

Erin: Thank you, Tina. Next, we have David Bjorklund.

David: Yeah, thank you for having me, I'm David Bjorklund, and I am a social worker at a school based health center in Western Massachusetts. I'm also excited to talk about, you know, cultural competency and approaching families, um, from where they're at.

Erin: Welcome, David. And bringing our parent perspective today, we have Natalie Korpics.

Nathalie: Hi, thank you. I'm Natalie Korpics. Uh, I'm a parent of a 26 year old now who had complex care needs and a disability. And I've sat in at least 15 IEP meetings, uh, over the last many years. So I'm excited to bring my perspective to what that felt like.

Erin: Excellent. So thank you all for being here, and I am excited to dive into yet another great discussion with some people who have excellent perspectives to bring to what is really turning out to be an incredibly tricky situation for Mae, Valeria, and the student Gloria.

So one of the first things I'd like to do is just maybe talk a little bit about what Mae is doing right so far. Uh, Tina, I'd like to start with you. As a school nurse care coordinator. What do you like about Mae's approach to the student family? What might be lacking and how did Shane help fill the gaps here?

Tina: So I think that Mae is doing a great job so far as a new school nurse. Um she's identified a problem, you know, high dismissal rate, really not feeling comfortable with her assessments of Gloria and the need for connection. She's identified that no one in the school has a good relationship with Valeria. And the fact that Mae has reached out to Shane, her mentor. So She's identified that she needs to get help in this situation. So, um, Shane has filled in some gaps in um gaining Valeria's trust and how does Valeria feel? So approaching, um, the conversation with Valeria, um, wanting to learn more about Gloria and, um, meeting on Valeria's terms those are very important pieces for Mae to consider.. Um, but she's on the right track.

Erin: Thank you so much, Tina. I agree, there are some really good things that are happening with a new school nurse who is just starting to see what kind of dynamics might be at play with this family and taking steps to address them in a really thoughtful way.

So, Natalie, as a parent, are there patterns in this story in the school culture that sound familiar? What are things that you appreciate or *don't* appreciate about Mae's approach in figuring this out?

Nathalie: I, I agree that Mae is doing a great job with trying to reach out and building that empathy on trying to understand where, Valeria is coming from, you know, maybe learning a little bit more about what is it, why is it, It's challenging for her to have that connection with the school and, the fact that the nurse wasn't really included in the IEP meeting, I look back a little bit and I don't think the nurse was ever included in the IEP meetings and I feel like my daughter spent a lot of time with the nurse, so that would have been very helpful, um, in this scenario where, uh, it was, it was brought to our attention that the parent was called many times. And we know that, um, you know, that, that Valeria is working when these calls are coming to the home is also something that I can relate to.

I've always been a working parent, and, and so is my husband. And, um, that gets tiresome, especially, in this case, I felt like, is there really a good medical reason for sending the child home, um, while she's disruptive, she's complaining of having a stomach ache, so therefore she must go home, um, doesn't necessarily make it the right decision for the child and in the best interest of the child.

But I think, trying to figure out a way, like, how am I going to connect, how, I, I think a big part of it might be trust, right? She hasn't really gained Valeria's trust yet and working on that would be a, a, you know, good next step

Erin: Excellent. And I'm glad we're hearing again about the dynamics when there's a working family. We touched on this in our first episode as well. We have to acknowledge and honor the experience of the parents and caregivers. It takes enormous time and effort to coordinate care for a child with medical complexity and this is often being done while holding down a job and caring for other children and family members

So it's really important to put yourself in a space of empathy as the school health professional, listen to the family and understand their priorities and what they're facing every single day.

So David, I'll ask you, in your experience as a social worker in a school based health center, uh, how crucial is it for health professionals to understand their students, and the communities that they're serving, *before* making recommendations for care?

David: Yeah, I think that's, it's such an important part and I appreciate Nathalie bringing up the idea of trust. Something that we often say in our office is that, uh, progress moves at the speed of trust. And so if you don't have that built in or you don't have that foundation, then progress really can't be made. Knowing the cultures, and the communities that our families come from, understanding how that might impact the way that they communicate, and not just as far as translation services, but understanding where they feel comfortable communicating, whether that's in a meeting, whether that's more individualized um is really important.

Also understanding, whether they're working, how often they can be at those meetings, when would they have more time to be more available? And it also impacts problem solving. Uh, different cultures approach team based problem solving in very different ways. The one thing I'm I'm interested in hearing about when we're talking about IEP meetings is Valeria doesn't feel like her voice is necessarily heard in those meetings. I also want to know what Gloria is thinking. Um, one of my main roles when I go to IEP meetings is I'm going to talk with that caregiver and that student separately and together to understand, well, what do you guys want to come out of this meeting? What are your goals in that meeting? Because if they don't feel that they can speak up. I can sort of advocate for their goals and speak to their needs.

Nathalie: Can I say something? What I really appreciated hearing from you is having a conversation about the IEP meeting before the IEP meeting actually happens. I was never given the documentation that I was going to be signing off on before the meeting. So I can only imagine what that would feel like, not understanding the language, you know, not having had a chance to actually process the information, think about it, coming up with questions. So it really doesn't surprise me that Valeria didn't have a lot of questions or wasn't really an active participant. And not because she didn't care or she didn't have anything to say or add, but because they weren't as, as proactive as you are, David, in pulling the family into the conversation before the meeting and saying, well, this is what's going to happen, and, and what would you like to see and what would you like to get out of this meeting?

Erin, to your point in terms of just adding that language barrier on top of that stressful, moment and feeling like you're being judged, you know, your, your child's deficits are being discussed during these meetings and, I think that's definitely a best practice is to try to have some of that conversation before the IEP meeting itself.

Erin: I like how fast we already identified some ways to work around the barriers to communication in our schools... Nathalie, you suggested making sure families are prepared for the IEP meeting *before* it happens, and David you mentioned having a separate meeting with families to make sure they feel heard. So, two options for best practices that we can share and give to our listeners, and I also think I have one of my new favorite quotes, progress happens at the speed of trust.

Tina: Can I add something? Both David and Natalie made me think about getting together with families. As a nurse care coordinator one of my jobs is getting together with the parent and, a lot of times the student as well before the meetings and preparing because I'm reaching out to medical providers to get information. Um, but one thing that Natalie said that I wanted to mention in terms of the nursing standpoint is that students that have IEPs that are seen frequently in the nurse's office often have a pretty good communication, going with the parent. So those nurses really probably have more of a connection with the parent than a lot of the members of the IEP team in some cases.

Erin: I wholeheartedly agree, Tina. We see things in our clinics that no one else in the school may see, and vice versa, so reinforcing how important it is to have everyone who's got a stake in the success of the student and being there to hear the student, which I'm so glad David touched on, it's so important.

Tina, you talked about this a little bit in your role of care coordinator, but I think it would be helpful for listeners to know why it's so crucial for nurses to attend IEP meetings, and be involved in the development of these individualized education plans... And so Tina did you have any alarm bells that went off when you started to hear about the experience that Valeria had?

Tina: So this sounds very familiar to me. I was a new school nurse, at a middle school. And I don't know if it was because I was brand new and I didn't know anything about IEPs – which we don't, we don't learn about IEPs in nursing school. So, uh, when you become a school nurse, you have to learn, um, the process very quickly and all the language that goes along with IEPs and 504s. I did do health assessments. You know, in terms of just looking at records. Do I have any concerns? Did the student pass their annual screenings that we do in the school nurse's office?

So through that process, I identified which students had an IEP and I could then let the team know when I had concerns and then I started getting invited to those meetings. But school nurses have a role that a lot of staff do not understand. And as we

know, as school nurses, we continually have to work at making sure we have a seat at the table when we need to be there. And so when I listened to this story, one of the things that I thought about is what is in place in the school to improve family engagement, because I'm wondering if there's just not enough there, um, to help Valeria feel connected to the school staff.

Erin: I love that you brought up family engagement, because we ground these episodes in family engagement principles. It is our responsibility to make sure our students and families are being engaged, feel valued, and are given the floor to make sure they have a voice and are included.

So, Nathalie, I wanted to get your perspective. You talked a little bit already about some of the challenges for parents just attending the IEP meetings. So, you're already walking in with a sort of negative feeling if that's been your experience and if that was Valeria's, you know, what can be done here? How can families be included?

Nathalie: For me, it was, uh, the, the people who sat at the table were often the biggest advocates for the services that my child needed. So I'm thinking, making sure that parents understand what their rights are. I know the interpreter was there at the meeting. Was the IEP translated? The full document so that that could be read and parents could understand it. When I'm thinking about engagement, thinking about are there resources in the community that the school can help Valeria connect with? Like, is there a Facebook group of parents of children with autism who are Spanish speaking,

The other part that I would be very careful about is, and I think David, you mentioned this a little bit, is, is being very conscientious about, what the cultural expectations are. I'm thinking, you know, in a situation like this, it might be that a parent, that a school, uh, professional might ask, well, what do you do at home when this happens? Whatever happens at home is private and stays at home. I'm not going to tell you how I'm going to raise my child. So that might feel threatening, right? So being careful in, in terms of how to ask those questions and how to relate to, um, the parent to make sure that culturally, you're, you're also being sensitive to their needs.

David: You know, Natalie, you, you made me stop and think, because I, I do, I often ask that question, how does this work at home? What's working at home to make sure we can see if it's working in school? I didn't necessarily always think, like, that might not be something that a family wants to talk about. And so I just thank you for bringing my awareness to that. We all have blind spots and I, I love these conversations because they help us address those.

Erin: I think that's an incredibly important place to stop and reflect on too, is when we're asking questions. How is it being received on the other end and taking the time to understand the culture that the student and family are coming from is just an essential component of building that trust.

So David, we talk about how important it is to collaborate between disciplines between professionals when working with students. What might a team with a school nurse and a social worker be able to do to help meet this family's needs?

David: I think when a team is working well together, there's opportunities for doorway moments. My office and our health center office is right next to the school nurse's office. And so, there's kind of like a constant flow of me going over to talk to the nurses, or the nurses coming over to talk to me and to our medical providers in our health center. I think when we have that proximity, we can really increase the amount of time that we can talk to each other because time is constrained in a school setting. You have so much, you know, so many hours in a day, and when there's that free flow of information back and forth, that can be really helpful.

That goes for within the meetings too. I sometimes think that, within those team based meetings, we don't have enough time to get through everything. I'm trying to get in touch with families beforehand, and kind of make a plan for those meetings because they do feel so tight. So, I think good collaboration comes down to good time management, and just, being able to, to talk back and forth.

Erin: Absolutely. And you work in a unique environment at your school based health center. So I would love to hear you tell us a little bit more because I think school based health centers are an example of a resource that can be available in communities to help with connect with families.

David: Yeah, so our school based health center is within the middle school and high school, and there is an office and within that office, there is a medical provider who is there five days a week. There is a behavioral health provider who is there five days a week. And then occasionally, there's dentistry. We have optometry sporadically, and nutrition, too.

So the collaboration with the school starts at an individual level with each student, talking back and forth between school administration, guidance counselors, nursing staff, as well as teachers. And it goes all the way up to a community level where we might do medical or behavioral health trainings for the school community. And then

there's little bits of opportunities to collaborate everywhere in between. School based health centers exist mostly in urban and rural areas where there is lower access to health care. and they're usually sponsored either by a hospital or a federally qualified health center that might be in the community.

Erin: That is excellent information David and important for anyone who is listening to know. Make sure you research your communities and find out if there are School Based Health Centers available to you... So Tina, I would also like to hear some of the more creative ways you connect with families given how busy you are as a school nurse?

Tina: So, when I was a school nurse at the middle school, I was one nurse with just under 600 students. The health offices have students coming in almost every few minutes. There's a lot to juggle as a nurse who is responsible for an entire school building.

My current position as a nurse care coordinator, I am not as student -facing. So I am able to have those conversations with parents and I work very closely with a social worker in the district. We do not have a school based health center in the district, but we do have myself that focuses on the medical needs, especially of complex, students

One thing that I wanted to mention when Natalie was talking about how a parent might not want to talk about what's happening in the home. One thing that I found very helpful is to ask permission. Because that way they can say no. I think that that's a way that really has helped me to gain trust of parents.

So, thinking about this situation, I would like to know how Valeria is supported. Is there, a family member, a neighbor, a friend, and we would only find that out, but by first, you know, being able to communicate with her and see if we can, encourage maybe a family member to come to the meeting. Are there advocates in the community? Is Valeria already connected with, um, a community center or advocate? So finding a support resource for her, I think is going to be very important.

Nathalie: As, as a mom, I really appreciate that. Oftentimes as a parent, you know, you go to the doctor's office and they're like you need to do this exercise 10 times a day and you need to do this and you're doing this wrong and you're giving the wrong food and you're you know, there's a lot of feedback on how to be a, quote, unquote, better parents. So showing that empathy to the mom too, that's another way maybe to build that connection a little bit

Erin: That's great, Nathalie... I think you've given us some amazing insight already, but another question for you – what do you think is going through Valeria's mind during these meetings?

Nathalie: So for Valeria, I'm making assumptions here, but, I think she's probably just going through the motions. Like I have to be here. I'm just going to let them do their talking. I don't know what they're talking about. You know, maybe they're interpreting it a little bit, but I don't know what my rights are. I don't know what the options are. So probably what's going on in her mind is like, I'm just going to have to get through this process and sign off on the piece of paper and get back to work, right? But I think if she was lucky enough to have Tina and David, you know, in her corner and have had that conversation in advance, had had a chance to have some questions for herself.

You know, I mentioned that oftentimes, uh, the emphasis is on, on where the child may be lacking or where their weaknesses are versus focusing on their strengths. And one thing that I learned, I actually have a background in rehabilitation counseling, is for every negative you need to come up with two positives, or opportunities for growth, right? So rather than focusing on this is, you know, where, where the child's weaknesses are also think about, well, she's, she loves it when we play music in the classroom or, you know, she seems to get really engaged. So every negative, come up with at least two positives.

Erin: Thank you Nathalie, that's a really great piece of wisdom. And it's a piece of advice that we also heard from our special educator guest in our last episode. You have to make sure that parents are getting positive information about their child, too.

So, I'd like to hear from Tina — when these meetings happen, how do they shake out? What should nurses expect going into these meetings and how can they prepare?

Tina: Well, first of all, we hope that they know about them. You don't always know which of your students have IEPs. But making sure at staff meetings you have a voice, letting other staff know that. You know, you'd like to know when there's an IEP meeting so that you can take a look to see if you should attend. Sometimes I've been able to gain access to the schedule of the IEP meetings

Um, I wanted to just go back to something that Nathalie said because it's so important for the parent to have a voice. And when I'm listening to this story, I think about the interpretation services and how they're so limited for the district. It's so difficult to reach out and communicate with a parent if you don't have access to interpretation services. Or, thinking outside of the box, I know people use apps now, where it translates the

information for the parent. And I love the thought of making sure that the IEP is translated.

So in terms of, um, the IEP meetings themselves, it's the service providers, PT, OT, speech, sometimes a behaviorist, special education, other teachers, sometimes an administrator, hopefully the nurse, the parent, and then sometimes a parent will bring along another family member.

There's been a few times where I've sat in on an IEP meeting and it's usually a student that has a rare medical condition or something that's not common and the staff will ask me to really explain why, you know, their disease is affecting their academic outcomes. And on a few occasions I've been caught off guard so school nurses definitely have to be prepared to kind of break it down and you know, let the team members know, like, what's going on and why the medical piece is affecting the academic piece. They need to share their unique perspective on the student at the meetings. And that kind of solidifies your role, making sure that you're providing input in the meetings. Um, the, the school nurse is the medical expert in the building.

Erin: I love hearing Tina talk about school nursing. She truly gives us perspective on how much school nurses do and what they can really bring to the school interdisciplinary team . I want to just pull us back to the guiding principles that we're using from our family engagement framework. They say recognize the parent or caregiver, honor their wishes, and encourage engagement between the school and family. And for anyone who's interested in learning more about that framework, we have links in our show notes.

So I think a nice way to sort of close out our conversation is to hear thoughts from each of you on what are ways that we can do this? I'll ask you, David, to open for us because you work in a unique setting that is designed to address barriers to access. So what do you think of when you hear these three things that we're trying to do?

David: Yeah I think it starts from the first kind of meeting with that family and understanding not just their child, but also their family, their role in the community, their job, understanding their stressors as well as their students stressors, and recognizing their strength, despite all of those difficulties that they might be having and really shining a light on the bright points,

As far as engagement goes, I think the most important thing that I have found is to Allow for more opportunities. to not say, Hey, I've got this time available to meet with you next week. But to say instead, what does your schedule look like next week? And when would be a good time for you? And that goes back to also recognizing that they

have a lot going on. And creating that space for them is important and going to help them be more engaged.

Erin: Thank you. Nathalie, what would you like to share?

Nathalie: I can think of one question that I think would capture a lot of that, and it's to ask the parent, what would be helpful for you? And it may be, I don't have transportation. I don't have time. I would prefer having a conversation before the decision is made that we're going to dismiss the student home, right? That you need to come pick her up. Giving the parents the opportunity to, to partner with making some of those decisions. And I think that that also helps with honoring their wishes. But I think that's a that's a powerful question that could open the door and maybe help with building some of that trust.

Erin: Wonderful, Natalie. Tina, what are your thoughts on recognizing the parents and caregivers, honoring their wishes, and keeping the engagement going?

Tina: I love listening to Natalie and the insight that I'm learning, um, from her and, and David as well. I love that she talked about, asking the parent what is helpful for you because I think, that makes the parent feel like they are, they have a little bit more control, I think that, we need to, , as a school, encourage engagement, between the school and the family, thinking about where the supports are and, you know, what we have in place in the school community to help connect Valeria with the school and with potential other supports you know, events, where we bring in families, where she may feel, comfortable because there's other, Spanish speaking parents there potentially and I love that David talked about understanding the family's strengths. I think that 's so important because that's how, You build those relationships is by focusing first on, the strengths and then create the partnership to identify together, how we can improve, Gloria's care at school.

OUTRO

Erin: A big thank you to our guests – Tina Rusak, David Bjorklund, and Nathalie Korpics. In our next episode, we'll get a better picture of Valeria's perspective, and hear how she and Mae figure out how to connect and make a plan for the future of Gloria's care . 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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