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EHDI - Florence

The Power of a Metaphor: EHDI System Improvement Through Creative Communication

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[Speaker off mic].

>> All right... I'm going to go ahead and get started. Hello, everyone, thank you for coming. My name is Cara Weston. I'm from the great state of Minnesota. And... I'll get started with a little about me. Is that how it looks up there? Just a second... I'm going to change the... you're going to miss the top half of my slides if it's like that the whole time. Okay... I don't actually know how to fix that. Oh well... I'll just go with it.

I'm the follow‑up data coordinator in long‑term follow‑up at the Minnesota Department of Health. So... as the newborn screening program receives results for babies who are screened for hearing loss and once they're confirmed as hearing loss, they get sent over to ‑‑ from short‑term to long‑term and that's where I work. I do a lot of talking with primary care providers, audiologists, but I also ‑‑ oh, and I'm hearing. I'm also an author and artist, so... I bring that with me to my role at the Department of Health and I try to involve it in the work that I do whenever I can. So... that's like, for example... that's a picture and copy of my book. I'm a science fiction writer. There's Wonder Woman and there's an illustration from a book that I was privileged enough to help create for another unit, or another program in my unit.

It's called "I'm Growing with CAH" for children with congenital adrenal hypoplasia. This experience was informative for me, understanding how Department of Health staff tend to think about story‑telling and use of metaphors. This is for resources we provide for children and families.

Kids are kind of like flowers. Every flower needs water to grow and some flowers need extra water. Kids with CAH need different things to be healthy and that's okay. Your doctor needs to check your blood to make sure everything is working the right way. They might poke you in the arm. Sometimes pokes make people feel stormy, but it's okay to feel that way. Remember how flowers need water to grow some sometimes the water comes from a storm. Storms might feel scary, but the water is still important.

So... I helped ‑‑ I illustrated the book and I also helped write it and... you have no idea how hard I had to fight to get this metaphor included. People on my own team, who thought that it's not facts, so... we shouldn't include it. But... we're ‑‑ I mean, we're talking about communicating with children and it's not just children, adults too, can help reach a deeper understanding through the use of metaphor and it's a really simple one. And got it to be included and the book has been really successful and powerful and helpful. We've gotten a lot of good feedback from families ‑‑ it's been translated into Japanese and getting translated into Hebrew. It's a good resource, solid resource, but... it gave me some insight into how people who might be more databased look at story‑telling.

And story‑telling techniques. So... this is the activity example I'll go through. Some of it I'll breeze through... but it's just an example of one way that an extended metaphor can be used and you can really learn a lot.

So... what I did was asked a series of creativity‑inspiring questions at the Department of Health. Our division is community and family health. It took less than 15 minutes and just in that 15 minutes, we reached an incredible variety of answers and depth and each unit came up with at least one idea that none of the others did, and... we all reached into an understanding of our work as a division ‑‑ as a whole and that's what I'm hoping to get across here, the idea that these simple tools, some of you, I think already know, how useful these can be. Can help you understand your own work, your coworkers, people at other organizations, the experiences of families, the experiences of children ‑‑ the perspectives of other professionals. It can be really powerful and... it's incredible how quickly that depth can be reached.

And it was all based around this series of graphics. Now... who, here, has seen this set of graphics before? Great... yeah... most of you. It's pretty well‑known. I, I put out along the bottom, the resources that we took this one from.

So... initially, we were just going to use this ‑‑ here, I'll read through it, so that everybody ‑‑ in case you can't read through that in time. Three boys of different heights are standing on boxes of the same height to help them look over a wooden fence to watch a ball game. The shortest boy cannot see over the fence. It's assumed that everyone will benefit from the same supports. They're being treated equally.

In the second image, the tallest boy has no box ‑‑ the shortest boy has two boxes to stand on. They're all able to see over the fence at the same height. They're given different supports to make it possible for them to have equal access to the game. They're being treated equitably.

In the third image, the fence has been changed to a see‑through fence. All three can see the game without any supports or accommodations. Because... the cause of the inequity was addressed. The systemic barrier has been removed.

So... this graphic is attempting to convey ideas about equality, equity, and then ‑‑ I've seen the third one called justice and seen it called liberation and... what we were going to do, initially, was look at the graphic, so... I think, just sort of say, hmm... okay... and move on.

But... instead... we started asking ‑‑ each of the programs what do these things represent if the game is a routine well‑child check‑up for the children that your program serves. So... the kids were different subgroups, children of teen mothers, children like, of course, for our program, EHDI program, children with hearing loss, or at risk of hearing loss, in a certain sense, we are ‑‑ children are everyone, because every child should get screened ‑‑ and asking questions about, like... what affects the kids heights. And... the first place our minds go to are race, possibly developmental ability, other physical abilities, but... then, what are the boxes made of and who built the boxes?

Things, the boxes might be things like public insurance programs or help with transportation to the baseball game, the well‑child check‑up and the boxes might be built by whole systems of organizations working together. And... the legislation and... advocacy, that's done to create that legislation.

And then, what about the fences? So... in this scenario, we could imagine that the fence materials might be the cost of medical care. Who built those fences? Who created that cost? How is it being maintained? How is it being addressed? Can we build new fences? We started reaching a lot of creative ideas really quickly. Some people imagined the baseball players are the medical providers and clinic staff and what about all the people sitting in the stadium audiences? Are those kids with good insurance? Who gets to go inside the stadium and who gets kept out? Who's deciding? This is just a brief summary of all the different answers we reached and... I wanted to show this just because... it seems so simple... but... we got so many different answers. I think it can really be helpful to dig a little deeper and ask people to think more creatively. Things that stand out are like... incarceration ‑‑ I never would have thought of incarceration as something that might be offense, but for some children it is.

The hours of the clinic, lack of employ lead time, provider miscommunication about what's needed. Negative previous experiences, it might be because of racism or classicism, personal trauma, negative previous experiences with the Health Care system. And let's see... some of the creative answers for what the boxes are? Interpreters or boxes that people stand upon to see over the fence. Accommodations, friends, family, strong community... longer hours at clinics, public health research that supports and builds up the justification for new programs. Safe affordable housing. Integrated systems. Technology and then... the bigger picture ‑‑ what affected how tall the children are? Because... that's, you know... of course, not choice with the child, they don't choose how tall they are.

So... in the metaphor, we can use that to try to describe something that we want others to understand in our system, not the choice of a child.

Income, the level of education of the parents and the level of the education of the children that they reached. Knowledge of healthy development and developmental milestones. Race, historical trauma, chemical use, and other socioeconomic factors.

And these are some of the key responses that I received that I thought were really impactful, the idea that as boxes show up, the fence just gets taller in America and then, sustainability over time. What if a box only exists for half a game and then the funding is pulled away from it?

What about a baseball season? What about seeing more than one game? That can be really important and is the idea ‑‑ the idea that is the fence bad? Is it bad to pay our medical providers? Of course it's not bad ‑‑ but an important question to ask. And then, who even knows the game is happening? And who wants to watch another game instead? And just a little insight into the Department of Health perspective, where does MDH come to play in the scenario? Should we be tearing down fences? Building boxes? Should we be doing both? MDH is mostly the first picture, but over time, we're working towards the second and third picture.

It's still ‑‑ there's still a lot of work to be done. We create new boxes and help others construct boxes and sometimes, we just make material kits and hand them to people to put together themselves. Like an IKEA bookshelf.

And... I think I'm going to ‑‑ this is too much to read through... but you can have this PowerPoint if you want it, I'll send it to you.

In the stadium seats, who decided some people get to sit down? Thinking about who those people are that are putting effort into keeping people out of the stadium, making sure they need boxes. Who's that profitable for? And the idea that as a Department of Health, one of our roles is to help people in the stadium and maybe even the baseball players on the field, realize the importance of bringing all children inside. So we can work towards a world where they don't need boxes. At all... because everyone has a seat. And I just want to note that I saw an incredible presentation yesterday that did what I'm advocating for. The Seat at the Table yesterday that used a metaphor, asked everybody to consider their place in it, reflected on what we thought. That's exactly the kind of thing that I'm hoping we can think towards, for systems improvement. Like big‑picture, how everybody is connected. One of the thoughts that came up that I think is really important is that part of our role at MDH is to simply take the photograph, take these photographs. Do surveillance, collect the data, put out the data so people know the state of the situation.

So... in this context ‑‑ it'd be the state of children who are deaf and hard of hearing and their families too. What is their current situation? What has it been in the past? 10, 20 years ago and what are we hoping to move towards in the future? Because we are constantly building new fences and building new boxes.

Some of the people at the Department of Health are also players in the baseball game. There's also the issue of boxes being built by other organizations, like the Department of Education, Department of Health and Human Services and a lot we don't know about. What we don't know about can reduce our effectiveness.

And what about the question of trying to make everyone the same height? What exact role do we play here? The fence was made by people, it's not immovable or unchangeable.

This is the second part of the activity. I won't read through that. Where does the metaphor break down? When do these pictures not work for the situation? Because... no one metaphor will work for all situations. We can't just have a general fence, it's different in every community. We have to talk about what people will see the fences as. Because people within a given community disagree too.

Questions came up like... how can everyone even agree on what the fence looks like, let alone what needs to be done about the fence or about the boxes. Some people can't even get to the game. They can't even get to the, to the systems that we've built, already. To be outside the fence.

And... we need to always ask ourselves, what might bias the way we see the fences or the boxes? And can we recognize it? And... just to finish out the activity example ‑‑ how might this help us in the work we do? It's motivating to help us collect more precise data. So we make sure no child gets missed. It's a way to think about more complicated issues in simpler terms. Explain the need for data sharing between organizations or within an organization, we can use this to share with our stakeholders to generate discussion. Use it in the initial stages of a project to talk about planning. And come back to later to help with evaluation. All of these things are the kind of things that, that, seem very outside the box. For a lot of data people. To use graphic images as a metaphor to help explain data. And then evaluate that data and make plans for the future. It can be powerful and convey a lot of meaning. This is big picture ‑‑ this game ‑‑ if it's a well‑child check... thinking about what is screened, what questions are asked and what data is documented in a screening? Stepping back from that, even further, to think about the sport, itself of baseball. Primary care in our country. How we, as a society, routinely care for children. We can target those levels to think about where we might have a vision for changing the scenario to make children's lives better.

So... then, these are just some of the examples of elements that we might think about for improving EHDI systems. This is not everything, but... I didn't want to just overwhelm the sheet with giant dots everywhere.

So... deaf kids, hearing kids, hearing technology, interpreters, culture and language, race and ethnicity, legislation, other special health needs, parents and care‑givers, audiologists, teachers, all of those people might be involved.

So... what if we change what the baseball game is? What if we think about a deaf or hard of hearing child who wants to join a robotics club? At their school. Or... stepping back from that, all the children in Minnesota who might want to join the robotics club or all the children in the United States who might want to join a robotics club. That's the game ‑‑ we can use this as a tool to try to understand what might be going on. Can we understand better, the role of parents and caregivers? Are they part of the fence? Or they not wanting their child to get to the ‑‑ to get to the game for some reason? Are they the boxes building up the children? Are they helping build boxes with teachers? Are they... is there ‑‑ is there tension somewhere in here? So... we can ask, what's affecting the height?

So... for groups of children who want to join a robotics club, why can some join the club and some can't? And then... I think, I think, as we think through this, we could ‑‑ little by little, think of ways that each of these can be represented in the graphic and we can realize that maybe ‑‑ well... our singular perspective is not the only perspective. That's for sure. You could talk to children, like what, what motivates you to join the club. What might deaf kids bring to the table for the robotics club that no one else does? What insights might they have that no one else can bring to the table? Or what could they learn from the robotics club that they're not getting from other areas of their education or the social aspect? And then... thinking ‑‑ stepping back, is there legislation that protects these children's rights? You know the the Americans with Disabilities Act, to join a club and what about the teachers leading the club. Are they supported? Is there a way this can be used to help them understand the, the importance that this might play in a child's life. So... eventually, I think we can get to the point where they can understand that ‑‑ understand all of these things through a metaphor. And it's a, a way for everyone to get on the same page.

And one thing to consider, it's important to consider that you can look at this through different levels. The individual level, like... where am I in this? What role do I play? There's the team or program level, how is our team working together? How is our organization working in the EHDI system? How are our partnerships between organizations and then a web or a network of more than three or more stakeholders or groups. It might be parents, teachers, audiologists. Is that the level that we're talking about? Because... sometimes when disagreements come up or I've seen conflict ‑‑ it can be because one person's viewing it as an individual ‑‑ viewing the metaphor through the individual level, while everyone else is looking at it as an organization. And then, finally, policies, legislation and recommendations. We can totally interpret the metaphor differently, depending on which of these levels we're looking at. So... some reflections after doing this activity and thinking about it through the lens of EHDI.

Metaphors can help us understand each other's work, prioritize our next steps, explain why we do certain things in a certain way and then understand why something isn't working. No one metaphor is perfect for all programs and then, sometimes, it's easy to get lost in disagreeing about different elements or the scale or the scope and it won't work for everyone. Multiple approaches are needed.

It's important to value multilingual people who can provide insight into how a metaphor might be more effective in one language than another. Or... might just not work. And then... it's important, also, to recognize that languages evolve continuously, so... it's ‑‑ you have to go with it. Kind of have to go with it, sometimes. And... go in assuming you have biases and being able to think through those biases.

I'm running out of time. So... as metaphorical complexity increases... we need to consider cross‑cultural issues. Things like race, ethnicity, country of origin. There are different metaphors that work better in different cultures and... we cannot, of course, learn all cultures metaphors perfectly. But... it's important not to rely on stereotypes to try to make connections across cultures.

And... also, in some cases, it's better to not try to extend the metaphor, the way that I did in this activity. It doesn't always work, sometimes it can be lost in translation. But... sometimes, also, metaphors can help people to create distance to discuss topics so that, perhaps, they're talking about children in a baseball game and not talking about their own life experiences, necessarily. When we're talking about systems improvement and it's also important to think about change that occurs across time. So... we can imagine the graphic as time progressing and we can also imagine the children's heights as time progressing, because age is one thing that we can imagine affecting a child's height. That one's pretty straightforward, age does affect a child's height, but also within, working within systems like, how children engage with language. Definitely changes across time and I think I'm out of time.

Okay... I don't have time to talk about that ‑‑ so... just to wrap up... I encourage you to think about where in the metaphor of the EHDI system with a given baseball game, where do you participate? This can give you an opportunity to think where ‑‑ is there a certain aspect I'd like to contribute more towards? And then think about how your roles and identities might intersect. Not just your professional role or your parent role ‑‑ but other things that you're good at. Other things that you know about, expertise that you bring to the table and how you can more‑effectively participate and contribute. And is there a metaphor that you connect with? That you think you could use to explain your life ‑‑ your situation, your goals and... one that you might use in the future to help communicate your ideas?

And finally, if you're interested in doing a similar activity or want my PowerPoint, feel free to e‑mail me. I love talking about this stuff. I'm sorry I only had 25 minutes. There's so much to story‑telling and use of metaphors. Any questions? No? Okay... thank you.  
[applause]

[Presentation concluded at 1:17 p.m. ET].

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