Approaches for Resolving Ethical Dilemmas in Pediatric Audiology, presented in partnership with Salus University
Recorded Oct 14, 2020

Presenter: Ryan McCreery, PhD
AudiologyOnline.com Course #35858

- [Moderator] It is my pleasure to introduce today's presenter. Dr. Ryan McCreery is the director of research at Boys Town National Research Hospital in Omaha, Nebraska where he leads a multidisciplinary team of scientist who conduct research to improve health and wellbeing of children and adults. With no further ado, I'll turn it over to you, Dr. McCreery.

- [Ryan] Thank you. Good morning or good afternoon everyone depending on where you are. My name is Ryan McCreery and I'm very excited today to be presenting on behalf of AudiologyOnline and Salus University on the topic of pediatric ethical dilemmas in audiology. So without any more introductions, we'll move right into my disclosure. So from a financial disclosure standpoint, I'm employed by Boys Town National Research Hospital, I receive grants from the National Institutes of Health and I received an honorarium for this presentation. My nonfinancial are that I'm a consultant for the British Columbia Early Hearing Program and a member of the Joint Committee on Infant Hearing. I am not gonna talk about any specific product or service and the sponsor of this as we indicated is Salus University and AudiologyOnline and I just wanna thank them for the opportunity to talk with you all today. So these are our learner outcomes. We're gonna identify clinical situations that may present ethical challenges in pediatric audiology. We're gonna think about a patient and family-centered approach to resolving ethical dilemmas collaboratively. And we'll describe evidence-based processes for supporting ethical decision making by children with hearing loss and their families.

So you already heard my introduction, so I'm not going to spend a lot of time there but my current role at Boys Town is director of research and so I oversee the strategic leadership for the research program at Boys Town that includes now 30 labs that study a wide range of research areas in communication disorders, behavioral neurosciences. And I also run my own research lab where we are looking specifically to try to develop new ways to help kids with hearing loss who wear hearing aids. So related to my experience with ethics, I was a pediatric audiologist for 12 years before I went back to get my PhD and moved my career into a more research and administration oriented process. So I spend a lot of time working with families and some of the cases and things that we're gonna talk about today are loosely based on those experiences. I also for eight years was a member of the Nebraska State Licensing Board for Audiology and Speech-Language Pathology and some of the issues that we encountered as a board are also sort of informative for these case studies as well.

So I just wanna kinda give a brief overview of the ethical considerations in pediatric audiology. So I think the first point is that awareness is one of the most critical issues. And the number of times that myself or colleagues of mine ended up in a situation where there was an ethical dilemma where just simply being aware of the potential ahead of time would have averted a problem is worth considering. So there's nothing that any of us could do to try to predict the future or anticipate what might happen in a given clinical situation but I think if we think about the times and you then can reflect back on the clinical experiences that you've had that have resulted in an ethical dilemma, there's always situations and flags ahead of time that can help to try to resolve those things.

And what I'm hoping that we'll land on today is not sort of a flow chart or something really basic but more of a framework to think about how to approach ethical dilemmas in a way that will resolve them because unfortunately, there's no cheat codes or easy button when it comes to resolving these ethical dilemmas that we encounter as practitioners and so it's more about having a way to think through these problems and rather than trying to say, well, this is how you should deal with ethical issues. So the main ethical concepts that we're gonna talk about that are gonna be the sort of building blocks for our framework for ethical decision making are listed here. So the first is autonomy and that is the idea that patients should have the ability to make informed decisions about their care. There's beneficence which means not only do no harm but we have to sort of weigh the relative benefits and that the patient and family benefit is the key consideration when we're making ethical decisions because there can be benefits to others in the situation or equation and we have to sort of weigh those benefits and be transparent about them. And then the third ethical consideration is awareness of vulnerability and avoidance of coercion and that falls under that umbrella of justice. So when we think about justice, sometimes we think about the law or court proceedings but when we're talking about ethics in clinical decision making, justice refers to the fact that we are thinking ahead about possible vulnerabilities and potential situations where coercion may exist so that we don't put families in situations where they're in an ethical dilemma that we didn't anticipate. So those concepts seem very simple and straightforward and many of you are thinking, well, that's easy enough, can we get off this presentation now and go about our day now that you've given us those three concepts, and unfortunately, it's not as straightforward as that.

So when we talk about autonomy in pediatric audiology, there are some very specific aspects of autonomy that we have to think about. We have to think about whose autonomy are we considering? Is it the parent's autonomy to make decisions for their child? And at what stage does the child's autonomy start to weigh in to the situation and the equation? So in some of the scenarios that we're gonna discuss today, there will be conflict between what the child wants and what the parent wants and we need to think about, as professionals, how do we manage that? And some of that may be determined by legal standards where we practice and where we live, but beyond that, making sure that we meet the legal obligation to the parents and their decision making doesn't necessarily avert the potential for an ethical issue if the child doesn't have any involvement in the decision making process. So we'll work through some examples and talk through some examples with that. We also have to think about what is required for autonomous decision making. It's not just the ability to make a decision, it's knowing the risks and benefits of that decision and having those risks and benefits disclosed so that people are making a decision with a full picture of the implications. And that's not only the things that we know about, but also acknowledging what information is unknown or uncertain because I think as audiologists, sometimes we're really good at weighing the facts of a given situation and the, you know, here are the things that we have evidence, for example, to substantiate but what about the things that we don't know or that we're uncertain about? And so sometimes it's not just about saying, well, here's a pile of research studies that support what we're doing but also acknowledging where the gaps in our knowledge are about a particular intervention or those types of things. I think we wanna avoid what I refer to as autonomy theater, and that is this idea that somehow if someone is convinced that they're making a decision but in reality the decision has already been made or they don't have control over that decision, that's what I refer to as autonomy theater because it's not really a decision making process, they don't really have autonomy but you're just trying to create this appearance that they have the ability to make a decision and that's not true autonomy, that's just going through the motions to try to get them to think that that's what's happening. And then transparency about who is involved in the decision making process and what those considerations might be.

So related to pediatric audiology, we have specific aspects of beneficence that also come into play and that is sort of weighing the risks and benefits to patients and their families. There's the most obvious one that we all think about which is do no harm. We hear that repeatedly but I would say most of the ethical dilemmas that I've been involved in as a pediatric audiologist had nothing to do with actually harming the patient, at least not in a significant way, it has more to do with harms that are more challenging to quantify. So unlike surgery or other areas where sometimes the treatment can actually kill you, one of the benefits of being a pediatric audiologist is the treatments and things that we apply have life altering consequences, but fortunately don't involve the potential in most cases for someone to die, so this is good but it doesn't mean that we're completely absolved from some of these ethical considerations. We have to acknowledge potential personal or professional benefits that might exist from decisions that families make so that they can be aware of what the incentives are for various people who are involved in those decisions. And think outside the box in terms of when we talk about benefits, I think it's very easy for people to think about financial benefits and financial conflicts of interest but thinking about benefits in terms of the loss of opportunity or status or other types of benefits or loss of benefits that might occur from a ethical dilemma. And then the justice aspect of it is really just understanding the vulnerability that our patients and families might have. So that might be limited knowledge which then our goal is to try to give them access to that. It might be that they come from a background where they don't have access to care because of a financial status or where they live, in a rural area, for example, where they don't have access to care. And the point with justice is just being aware of those aspects of vulnerability so that we can avoid processes or situations that exploit that variability or create coercion. And most of the time, this isn't a process where someone is advertently trying to do something, it's more subtle than that and that's where it becomes challenging. So now that I've given you sort of an overview of the ethical framework that we're gonna be discussing, we are for most of the rest of the presentation going to be talking through some ethical scenarios.

So these are examples that are potential clinical situations and you'll have poll questions with each one that I would encourage you to participate in by typing your answer into the poll. And I want you to be thinking as we talk through these cases about how autonomy, beneficence and justice influence these situations and then we'll discuss potential solutions. You should also feel free if you have questions or if you have a comment to enter those into the Q and A box. So I don't want you to feel constrained by the polling, that's to sort of streamline some of the discussion, but I also hope that we can have some questions and some open discussion. And so if you insert a question into the question and answer box, that will come to me and the other moderators directly, it's not gonna pop up for everyone to see and I will try to sort through the questions that I feel like are guiding the discussion. So if I don't get to your question, please don't be offended, it doesn't mean it wasn't a great question, I'm just gonna be trying to sort of shape the discussion that we're having and also keep us within our time constraints. And so I appreciate your flexibility and your willingness to participate because this will not be very useful to any of us if it's just me sharing my opinion about these things. So I have to put in a little disclaimer here that these are based on situations that have occurred to me either clinically and it doesn't mean that it was necessarily my patient, but these are situations that are sort of loosely based on my experience. And some of the identifying details have been removed, obviously, but also I've modified some of the details. So these aren't designed to represent anyone in particular and I just need to say that in the event that you would happen to know someone who I worked with and say, hey, that's my Uncle Terry or something. We don't want that to happen, so if you think it's your Uncle Terry, I promise it's not. Alright, so moving into our first ethical scenario to think about. This is a hospital based cochlear implant program where the surgeons determine which manufacturer of cochlear implant devices the patients receive and the patients are essentially presented with the surgeon's device choice.

So thinking through some of you may work in a scenario like that, some of you may work in a situation where the approach to determining what implant manufacturer the hospital uses is determined through some other manner, but this is how these decisions are made in this particular hospital. So for our first sort of thinking about autonomy, beneficence and justice, I want you to think through these questions and enter your responses into the poll. So should a patient or family have a role in decisions about a particular device or implant? And what are the potential benefits for the surgeon choosing the device? And then what vulnerabilities exist for a patient or family who does not make a decision about a device? So we're gonna put the poles up and I would love to give you just a minute or so to enter your responses into the poll. And then if you have questions or other thoughts, then enter those into the question and answer box and I will get to those. Alright, so we're sort of wrapping up those responses there and I'm just gonna talk through the responses that we've received so far. So as far as I can tell just scanning through this, everyone unanimously was in agreement that the patient or family should have a role in decisions about the device which is good. It's always good to start with a very non-controversial answer and I think we all agree that family-centered care is important. So when we think about vulnerabilities that exist for families or patients who don't get involved in making the decision, the sort of themes that have emerged here are related to autonomy. So some of you are talking about the fact that the patient may not understand what the implications of the device choice are, that involving the patient in the decision process gives them some kind of involvement or ownership. Again, that relates sort of to autonomy and it may affect their confidence or their ability to engage in that rehabilitation process and that's related to justice and beneficence and autonomy in a way because you want them to have an active role in that process, so that's all very good. And then what are the potential benefits for the surgeon choosing the device? There's a lot of medical and surgical considerations there, but there are some other interesting comments here that basically the surgeon doesn't really need to be involved in the decision and in fact, someone commented that they ideally should not be, so that's sort of a different opinion. But there's a lot of you noting here that there's potential for financial conflict of interest related to financial incentives for certain device companies. So that's, you know, those are very important but the fact remains that surgeons are the ones who are putting it in their head and I think most of us would agree that we want them to be comfortable with the aspects of the device that are related to the surgical procedures.

So we can move on from that and I appreciate all of your questions and answers there. So for our next set of questions for this scenario, how can we balance the surgeon needs and the family needs? Should families be aware of potential benefits to surgeons or hospitals? And what is the best approach in terms of a decision process for minimizing vulnerability? So we'll pop those up here and I'll have you enter your impressions there into those questions. So how can we balance surgeon needs and family needs? Should families be aware of potential benefits to surgeons or hospitals? And what is the best approach for minimizing vulnerabilities? So you guys are entering your responses. So how can we balance the surgeon needs and the family needs, lots of answers around communication, transparency, a team approach. So I think that's a really good point is that having other professionals like audiologists, speech language pathologists, early intervention providers involved in the team can help to sort of make sure that it is really a group decision and identify potential sources of ethical issues that are related to that. So, should families be aware of potential benefits to surgeons or hospitals? Of course, but I guess the question is what extent should we make that knowledge? So for example, our patients at our facility until recently were not aware of the fact that the hospital received certain financial incentives from specific manufacturers for reaching a certain number of devices per year. And those were not transmitted to the team or to the surgeon directly but it is something that we felt that families should be aware of that we had these device quotas, if you will, with specific manufacturer so that they were just aware of the fact that there was a financial benefit to the organization for a specific device and just letting people know about that. And then in terms of the best approach for minimizing vulnerabilities, again, transparency, communication, team approach, these are all great answers.

So we started out with kind of an easy one where we're getting a lot of consistent answers, which I think that's always the way to start, so thank you for that and we'll move on to the next scenario. So a big issue in pediatric audiology that we discuss is this issue of parent autonomy versus child autonomy, and in most places that I'm aware of where audiologists practice, parents have legal rights to make medical decisions for their kids. And so what we're thinking about with this is not necessarily that there's some place in Wyoming, for example, where children are allowed to make their own medical decisions against their parents, it's more about this issue of at what point ethically do we need to start considering the perspective of the child in clinical decisions and how do we manage conflicts related to those things? And when it comes to age, we're not talking about chronological age considerations but also developmental age. So it's not just that you can make a rule that when children are five years old, they can automatically start participating in discussions about their care, you have to make sure, because part of autonomy is informed decision making, that kids understand the implications of that role in the decision making process. So in scenario two, we have an infant with mild to moderate bilateral hearing loss and the parents use spoken language at home and are normal hearing and the parents want to enroll the child in a sign language only early intervention program. So when we think about that scenario, what challenges exists related to the parent's autonomy in this decision process and what are the potential risks and benefits to the child of that decision? So we'll pop up those questions. So go ahead and enter your answers. I'll give you another minute or so to enter your answers. So regarding the first question, and you can keep entering your answers as I'm talking as I'm just kinda parsing some of this stuff.

So I think many of you hit on an important point here which is that what is the rationale behind the parents' decision and what's involved with parent's knowledge of language development and their ability as hearing parents who use spoken language to provide a language model for their child with hearing loss. And so that's an important thing that we wanna think about and some of you have identified that there could potentially be negative impacts to the child in terms of their language development if the families don't understand the ethical implications. Someone also talked about the fact that you have a parent and a child who will, you know, even if we can provide a good language environment for the child, we have a parent and a child who will be using different communication systems, and so, again, that's not to say that all children with mild to moderate hearing loss need to learn spoken language but we wanna make sure that parents understand that if they are gonna be using a communication system that's different from their child, that they're fully aware of that and that they understand what's necessary to foster language development. Because in our institution, we do provide a full spectrum of communication choices for children and their families but that doesn't necessarily mean that every language option is equal for all families and we wanna make sure that they understand the potential implications of that and talking about ways that we could foster bilingual development with sign language and spoken language if that's something the family cares a lot about. Maybe there's a family history of deafness that we're not aware of at the point where we're having this conversation where they have other family members who are deaf that they want them to be able to communicate with. So great answers here and this is a very challenging situation that

I've actually encountered. So we can move on to the next. Great, great answers there. The other aspect of this is recognizing what are our own biases and how can we acknowledge or manage those? So I'll give you a minute or so to respond to the questions regarding sort of our own biases and how that might influence things. And I'm not sure if the poll is, there it goes, okay. So what are our own biases that influence how we might manage this recommendation and how can we manage or acknowledge those biases? So many of us who are audiologists assumably on this are acknowledging the fact that as audiologists, we might have a bias towards spoken language and that's just important to be aware of and to also look at what the communication opportunities are for the child in the local community.

So where I live in Omaha and where I work, we have access to deaf mentors and deaf individuals who can work with families if that's something that they're interested in, but where I grew up in a rural area, that was not an option. There were no people who used sign language in that area and so if you have a family that lives in that area, that may be very challenging for them, and it doesn't mean that it's not an option, it means that it just may require more communication about that. And then how can we manage or acknowledge those biases? Reaching out to the deaf community. Being transparent about your experiences. Being open with families and talking with them. So very, very good answers there. And this is a situation as well where parent to parent support can be really valuable because it may be helpful for them to talk to a family that has used sign language versus a family that has not, and giving them access to the parent to parent support can sometimes be really helpful in sort of minimizing these sorts of issues. Great answers there. Alright, so I think we're ready to move on. So a good segue from that discussion about communication choice is the fact that one of the ethical considerations that we have to manage as professionals is this acceptance of ambiguity and it relates to this question about whether or not we have clinical or scientific evidence that supports a parent decision. And research on a lot of these topics that we're gonna be discussing in this session is constantly evolving and changing which is really good, but we have to think about how does the evidence that we have apply to the current situation that we're in, and then how do we apply research evidence to real situations, this also can be ambiguous. So I'll give you an example where we did a longitudinal study where we looked at the benefits of hearing aids for kids with mild to severe hearing loss. And so that seems pretty straightforward in terms of promoting consistent hearing aid use and promoting access to speech through hearing aids, but when you go and you look at our research what you realize is that all of the children in our study came from homes where monolingual English was the primary spoken language, we didn't include children with additional disabilities, and we didn't include children who received cochlear implants.

And so when you start thinking about our research study and how that applies to actual clinical decision making, it can become more complicated in a hurry. The other element of this is that we have to accept the fact that there's not gonna be a research study that will help us to define every decision that we make and that's why these ethical considerations often are based on clinical judgment and clinical experience because we can't possibly have a research study that encompasses the complexities of an individual situation for every parent or child. And so it's not trying to create this perception that as much as I would love as a scientist for science to answer all of our clinical questions in ethical dilemmas, by their very nature, that's not possible and rather than trying to pretend somehow that if only we had the science, we would have the answer, to acknowledge that ambiguity and convey that to families, I think is very important. Because that decision about communication choice is an area where there's not a lot of research that's been well done to show that a hearing family who chooses to use sign language can provide a good language environment for their child with hearing loss if they're gonna use sign language. So that's, you know, we have no evidence of that and so we can't make claims on one side or the other, but we do have clinical experience and clinical judgment that we can use to help sort of sort that out. So thinking about evidence based practice not only about the research in the peer reviewed journals, which is very important, but also thinking about clinical data and experience and then combining that with our ethical decision making framework to try to help parse some of those things out. So the third scenario is an infant with bilateral profound hearing loss by ABR, and as in the previous scenario, the parents are hearing and use spoken language and the parents want to defer the decision about a cochlear implant until the child can decide whether or not to receive a cochlear implant. So I think many of us have experienced a scenario like this or something similar and so how does this scenario challenge the concept of autonomy? So thinking about it both from the parent perspective and the child perspective. There's two separate entries here, one autonomy regarding the parent and one autonomy regarding the child. Thinking about what is required for autonomous decision making. So you're really giving some great answers here.

So we're talking about the fact that making a decision to defer a decision is actually making a decision and the child won't have any actual autonomy, so that's important. The other issue is that autonomy, again, requires that the person who's making the decision has good information and that doesn't necessarily mean that if you tell a parent that by delaying implantation, their child will be in a position to make the decision because they won't have the language ability to sort of understand the implications by the time they're old enough to make the decision. But it's also the case that we have evidence from our clinical experience and from research that suggests that deferring this decision means that there could be significant negative implications for the child's development. And so we have to think about the beneficence and making sure that we're not doing any harm and so those are great, great answers there. So we can move on to the next one. So what are the risks to beneficence for the child and for the adult in this situation? So there's discussion about critical periods for language development. The evidence of poor outcomes for later implantation. So there's a lot of potential loss of opportunity. So again, when we're talking about benefits, it's not just about tangible benefits, it's also about loss of opportunity and that's a situation where we have to think about not just do no harm but also what are the opportunities that we're missing out on here. So there are some good risks to the parents as well. It's good to see some of these responses that you're thinking about parental guilt, the child's identity regarding the family, how that affects the child's perception of their parents, that may have a negative impact on the child's relationship with their parents. So yeah, there's a lot of considerations here that we have to think about as professionals. These are all great, great responses so thank you for participating and for providing such great responses. Negative impact on relationships. Very good. Alright, so we can move on to the next question. So how can we in this situation help to increase autonomy and maximize beneficence for everybody? So you might think back on clinical experiences that you've had and how you managed this situation when you answer this question.

So giving parents more information. Parent to parent support, that's a great answer. Giving resources to support them. So one of the things that I've noted when we as audiologists talk about these types of situations is that as audiologists, we are very confident and feeling sort of at our best when we're providing clinical expertise and when we're providing informational counseling. But one element that I see here but I less often, because I see a lot of answers here that are really great and related to informational counseling but I think one of the things that we miss here that would be helpful and that sometimes our colleagues in social work or in counseling can provide is that sometimes these decisions have nothing to do with the fact that the family doesn't understand the potential situation, it has to do with some emotional or psychological concern and giving them more and more information may actually make it more difficult for them to make decisions. And so it's just important to balance the informational counseling with support counseling as well and that may be something that you're comfortable providing, it may be something that the family can access through parent to parent support or it may be the case that we actually have to them talk with a family counselor or with a social worker to try to help them to work through some of those decisions. Because even if you give them lots and lots of great information, if they're not emotionally ready to move forward, then you may still end up with these issues that come up down the road. And so we just have to make sure that we're taken care of both sides of that equation, and I was glad to see the answers here included both of those elements because we can't, unfortunately again, as a scientist, I wish it was just as much the case that we could present people with evidence and that they would make decisions that we think are in line with that evidence but if it were that straightforward then they wouldn't really need us as professionals to do this work because it's such a careful process and taking into account family needs. So thank you for that.

All right. So a lot of this breaks down to the age at which we can demonstrate autonomy. So is it a matter of chronological age, is it a matter of a developmental perspective? And it might actually depend on what we're talking about, so one example from pediatric audiology is that some of my colleagues have developed a program for management of amplification for children that essentially allows kids to take on age appropriate tasks that allow them to sort of develop autonomy around managing their hearing aids. And so that's helpful because it's based on a developmental perspective of like, what is something that a typical five-year-old with hearing loss can do to participate in the management of their amplification? So maybe it starting out teaching them how to put their own hearing aids in when they're younger, and then as they get older, adding in skills like changing the battery and developing and sort of building on that so that by the time they are ready to move out and move on to the next phase of their life, they're able to manage all these aspects of their amplification in that and it really has to do with developing that self-advocacy, but the challenge here is that it's so variable across kids.

So I just think about my own children who are all very different from each other and how each of them probably has different levels of autonomy at different ages just based on who they are and sort of what their personalities and comfort level are like. So it's not easy to answer this question about autonomy because there's no sort of ethical standard for how we can demonstrate when a person can demonstrate that autonomy. So scenario four is an infant diagnosed with moderate to severe hearing loss and the parents are hearing and use spoken language and the parents fail to attend appointments consistently. Amplification is often not worn or brought to appointments and the early intervention provider that is working with the family reports that there's not a lot of participation in early intervention. So sometimes the early interventionists will show up and the family is not at home at the time of the appointment and when they do have appointments, the family does not seem engaged in the process. These are very challenging situations. So we have a number of questions here. So what are the risks to beneficence? How do we balance beneficence and autonomy? Is this considered neglect? And in your area where you practice, would you be required to report this as neglect under mandatory reporting requirements for your license?

So thinking through, we're gonna do these two at a time. So what are the risks to beneficence and how are we gonna balance beneficence and autonomy in this case? So many of you identifying the potential language and learning consequences, lost opportunities, language deprivation, social deprivation, isolation. So these are significant concerns. Another one related to beneficence is the fact that sometimes we are in these situations and a child may have other medical concerns, and in my experience, families that have a hard time managing our appointments with audiology also have a problem managing appointments with other providers. So what are the other health risks to the child that may result from this sort of approach? On the other hand, we have to respect people's autonomy to a point and that's where this case really is challenging because if we are trying to balance the family's ability to make decisions about what care they receive and how they participate in that care but we know that that has risks to the child's and the family's beneficence, that creates an ethical dilemma. So lots of good answers there. Getting help from social work, psychology, counseling, more information. This is all very good. Parent to parent support. Very good. Alright, onto the next questions. So would you consider this to be neglect or is it just a situation where the family has the right not to participate in their child's early intervention? Where do we draw the line between the parent's autonomy and the child's beneficence? So lots of great nuanced answers here and not agreement and that's okay because if there's one thing that I hope you take away from today and our discussion today is that the reason that I chose these scenarios to talk about is that they're not straightforward and they're difficult and that's why we're discussing them. So some of you have indicated that you'd be required to report this. Some of you have indicated that you would not be required to report this. So again, it's showing that it depends on where you work and what the laws are and what's required for considering neglect. And we have a lot of disagreement on whether or not it's considered to be neglect in our answers so and again, that's okay. This is not designed to be straightforward.

So as a general point, when it comes to a situation like this where we have consulted with our ethics board and others that are involved and where things have come down, and I'm not trying to suggest that this is the right answer in this situation, but where we've come down is parents have the right to choose the intervention that is provided to their child in these types of early intervention situations but they don't necessarily have the right to not participate. And again, this is something that could be just locally where I am but so families can say, "We don't wanna have spoken language but we will access sign language," but they can't make a decision not to do anything. Now whether or not that constitutes neglect and more importantly, how we help a family through that decision making process is more up in the air but that's at least where I'm coming from in terms of mandatory reporting and neglect, and it's not a straightforward situation so I appreciate the varied perspectives on this and there's no right or wrong answer here. Alright, so we can move on to the next one. So as I mentioned, do the parents have the autonomy to do nothing and how can we support a family who does not want to be supported? So as in the previous answer, some of you feel that the parents have the autonomy to do nothing and some of you clearly feel that they don't. And again, there's no right or wrong answer here and I would argue that the point here is not to determine what's right and what's wrong but to try to figure out how we can help the family move through this. And some of you are saying we can't help this family if they don't wanna be helped and I think that is in some cases very possible. Someone said to check in with them regularly. So I think that's extremely important because the last thing that we wanna do is alienate the family. So someone commented in the question and answer that, "When we have parents of children who use cochlear implants or hearing aids and they don't make progress because of lack of parental involvement and follow through with recommendations, we don't report them to CPS." And I would say that's true in some places and in other places, people take a little bit more of an aggressive stance in terms of child protective services. But the point here is to try to think through the ethical dilemma so that we can help the family to try to access that care. And these situations are so challenging.

So good points here about documentation, we need to document what opportunities the family were given. And we became audiologists, I hope, to help people and many of you are talking about how we can try to help the family provide other types of support, keeping in touch, maintaining those lines of communication and access. Those are all great answers but as some of you've pointed out, we can't help people who don't necessarily want to be helped, so this is a challenge. Alright, I think we're ready to move on. So one of the important distinctions that I wanna make is when an ethical issue becomes a legal issue. So if you think about a Venn diagram where you've got a legal problem and an ethical problem, not everything that is a legal issue has sort of a root in an ethical problem, but sometimes when audiologists get involved in a legal dispute, it'll start out as an ethical issue. And this is something that when I was on the board in Nebraska, there was almost always sort of an initial ethical issue that then eventually manifested into a legal issue. But as you saw in the response to the question about neglect, the law and ethics, we hope that they line up sometimes but that's not always the case where you can have a problem that's an ethical dilemma that doesn't have legal implications and you can have legal issues where you don't have that. And if you're thinking about as a clinician, how you protect yourself legally from some of these ethical considerations, what I would suggest is just having this framework that we're talking about for legal and ethical decision making can help to provide some kind of legal protection because then an outside person who looks at what you did in a given situation can say, yeah well, they acted in a way that was very transparent and supportive of the family and that was in the family's best interest. And the reason that that's important is I think that sometimes when we think about the law, we think about it sort of being black and white and we forget about the fact that one of the key legal standards that gets applied to malpractice or other sorts of disputes that may occur that involve audiology is what's called the reasonable person standard. And this is important because oftentimes legal judgements in these issues come down to an issue where it's a question of what a reasonable person would do or say. And in the current political climate, it's hard to imagine what different people might think about what constitutes a reasonable person in terms of different political perspectives but that's still a legal standard that we have to consider. And using this kind of ethical framework can help us to sort of substantiate our thought processes and our approaches using common ethics that most people I think would agree.

So someone put into the comments that they had to report to CPS on a child who would not follow up on getting hearing aids for educational purposes and it helped motivate the parents to sort of make a decision and get involved in. So that's a good point. I think sometimes we think about child protective services as sort of that they're gonna lose custody of their children and I think many of us who've worked in child and family services for a long time recognize that that's not the most common outcome, at least not where I work. In most cases, child protective services can help and try to provide resources to try to support the family and that's something that is an option that's there. So someone asked the question about that, "Was the motivation to try to help the child or was it fear?" That's a great question and that would require us to engage with the family to sort of understand, you know, hopefully it would come from a place of helping to figure out that it's a serious and that we wanna help their child but that can be really challenging to do that. And another person commented that neglect is the most common form of child abuse, and yeah, it is and that's one of the hard parts about working with children and families is that that whole dynamic and the vulnerability that we see with children in particular makes a lot of these ethical dilemmas really, really challenging. Great comments. So when it comes to legal issues, I wanna be really clear that nothing that I'm saying today should be constituted as legal advice. I am not an attorney. I'm not licensed to practice law anywhere and I'm not trying to give you legal advice. That being said, if you feel like you are in a situation where an ethical issue could become a legal issue, you want to make sure that you have access to legal representation and that you have great documentation. And I'm sure many of you who are a part of larger organizations like I am, I have a team of attorneys at my disposal, but if you're a private practice owner, you may not have access to the same legal representation and I would just encourage you to think about what you would do in that situation and develop a partnership because oftentimes legal advice can help to resolve these situations.

You wanna document everything. And we have had situations where we have a sort of unbiased observer present for interactions if the family approves, and sometimes that's someone within our organization from Child Life or social work, sometimes that is an early intervention provider if the family provides permission for them to participate in the process, and sometimes it can be a mediator or other neutral observer to help avoid misunderstandings about situations. But we always have to think about privacy and making sure that if someone else who is not central to the clinical decision process is gonna be involved, that the family actually has the autonomy to accept or reject that opportunity. Alright, so scenario five. You're serving a child or a family of a child with a bilateral hearing loss and has used hearing aids for several years. The family has had considerable financial challenges and the family asks for a personal loan to help with expenses to avoid being evicted from their home. So in terms of questions, what are the issues related to justice in this situation and what remedies might you have available to help the family? So these are difficult situations. We're already getting some good answers on the remedies. So a good point here about the fact that these financial considerations might influence how the family accesses services. Sometimes if a family is in this situation, the child's hearing is not an important primary concern. And even as an audiologist who cares deeply about promoting hearing aid use and access for kids with hearing loss, I totally understand that. And with some of the economic impacts of COVID-19 and the pandemic on families, we're seeing more and more of these issues where families can't access care. The thing that makes me feel good though is I'm seeing your answers to the remedies and it looks like there are lots and lots of resources that you have at your disposal to try to help with these situations because we wanna make sure that we're providing support, that we're able to get social work involved, figure out what other kinds of programs might be involved. I'm glad that no one is suggesting to loan the family money. I know that seems absurd but I have used this scenario in a live ethics discussion before and had people, audiologists, argue with me about providing financial support for their patients, and I would just say that is a problem for a lot, a lot of reasons.

So thank you for not. And I'm not meaning to minimize that if anyone actually feels that way and just isn't comfortable saying that but it's just not a good plan for so many reasons. We had a situation like this where the child wasn't consistently wearing the hearing aid and they came in for the appointment and they came into the appointment without the hearing aids and one of our audiologists was kind of indignant about the fact that the child wasn't wearing their hearing aids and it turned out that the reason the child wasn't wearing their hearing aids is that the family got evicted in the middle of the night and had to leave their amplification and many of their possessions in this home where they were evicted, and those are the types of situations where it can be really challenging. And so we just have to be, you know, we have to be thinking about the backgrounds that our families are coming from in those types of situations. So great answers there. So someone said, "Thanks for the example. We don't live our patients' lives and we shouldn't be passing judgment," I totally agree but I consider myself to be a highly empathetic person but it's funny how sometimes you get into a pattern of thinking and interacting with patients. And we often think that, when we think about families who are at risk or families who are in poverty, we often think it will be very obvious who those people are when they come to our clinic. And I think one of the things that I've learned after working with families for a long time is that sometimes you can tell when families are struggling financially and sometimes you can't. And so it's just I think, you know, the good news is you're here because you're interested in learning about how we can better serve children and families so I'm preaching to the choir but it is important for us to remember that sometimes we can't tell where, you know, what family circumstances are and so we just have to kinda approach those situations and support families the best way that we can. So some of you are noting that you have fundraisers to help, that's awesome, to have those resources. Most of the hospitals in our area have financial assistance for people who can't afford care. "You shouldn't assume, asking questions and finding out family challenges are more important," that's right.

And we also have to understand that some families are not gonna be comfortable disclosing personal financial challenges to us and so we have to approach the situation sometimes without knowing what the true financial situation, and we shouldn't make assumptions that, you know, I worked with an audiologist for a long time who would get really frustrated because a person would come in to an appointment and have an iPhone or something with them and then also struggle to pay for their hearing aids or something. And I just think unless we fully know all of the details on those situations, our goal is to try to help the family and not to pass judgment but it can be challenging because we often don't have all the information. Alright, so I think we're ready to move on. So this issue of sort of supporting families has to do with our professional boundaries and the influence over decision making. And so we have to think about if we're providing support to the family, does that change their autonomy at all? Does that give them less control over decision making? But you also have to balance that with beneficence where if you have a family that's extremely vulnerable, we need to make sure that they have the resources to try to help them to weather that vulnerability and giving them the opportunity for justice so that they can work through that issue. So a question came through, "I have witnessed other professionals personally paying for ear molds or hearing aid batteries for families that could not afford them. Does that present an ethical dilemma?" Not quite alone but on a smaller scale. So what do you all think about that? And you can enter that in the Q and A box if you want. Does personally paying for an ear mold or batteries for a family create an ethical dilemma? So I think it does and I think we should always strive, and that's just my opinion, I think we should always strive as professionals to make sure that we are giving families access to resources that are not personally tied to our own. So some of you are saying, "Yeah, that's kind of a slippery slope." Some people are saying, "I don't have a problem with that," and that's okay, like, again, these are highly personal and situational things.

So I wanna be really clear, it's easy to sit here in a presentation where we don't have a family sitting in front of us who can't afford food and say, well, this is what we should do or what we shouldn't do. But I think we have to think about how those decisions impact a family's autonomy and their ability to make decisions, and I think this is an example where it comes from a really good place and we wanna make sure we exhaust all of the potential resources that we have at our disposal before we would do that. And the responses that I'm getting suggest that there's not a lot of agreement on that, and that's okay. Again, if it were all really straightforward here, then this wouldn't be a very interesting discussion to have. Alright, so the other boundary challenge that we run into is that we become very, very important parts of our family's lives that we serve. So I have a child who was one of the first people that I tested, I did an ABR when he was a baby, and now he's an adult because I've been practicing long enough that that's something that has happened. And so this person is now an adult and in college and they invited me to come to his high school graduation and I've been invited to weddings for patients and it can be really challenging because some people might take the position that we don't wanna provide gifts or other things to our families or receive gifts from families, but it's important to recognize that how do we set those boundaries when oftentimes we are a really significant part of these people's lives and are for better or worse gonna be sort of indelibly linked to a pretty significant part of their identity. I mean, the mom of that child that I mentioned who's now an adult still remembers everything about that identification of hearing loss and it's just a very significant and salient event in her life and it's a positive thing, but you can imagine how it could also be viewed negatively. So the goal of an ethical decision making framework isn't to develop a tool that will allow you to apply decisions to every possible situation, it's to say, if I'm gonna approach this decision, how do I set boundaries in a way that's consistent and ethical? So one comment is, "I'm an educational audiologist and have a large stockpile of batteries and I've started sending out to families in need. I don't feel like this is an issue. By the time I am back providing home visits or seeing students in a center-based program, the batteries might be dead." I totally agree with that. A friend of mine is a teacher in Omaha and in a school that has very, very low socioeconomic status and she takes donations for students for hygiene items because they can't afford them and I think that is providing support because you're providing it to everyone and it's more of a donation-based framework, but that's how these things can be ethically challenging because there's no clear answer to every situation. And you have to decide for yourself as a professional where those boundaries exist and I would guess that some of us are much more comfortable on one side than on the other.

So for our sort of last scenario here, we have a family of a child with hearing loss and they express noncompliance with hearing aid use due to religious reasons. So the question is, what are the threats to autonomy? What are the threats to beneficence? And then what are the issues related to justice in this listening situation? So you're identifying a lot of those great threats to autonomy, that's awesome. So a good point that, "The family has the right to refuse care based on religious beliefs but they need to be made aware of the consequences," that's excellent. "It's a threat to the child's autonomy if they can't hear," that's probably true and they don't get other intervention. So we're thinking about lots of opportunity and beneficence, limited learning and future growth. A really excellent point about how negative outcomes in this process might create sort of a crisis for the family in terms of their religious beliefs. If the child has a negative consequences, what does that do for the family in terms of their faith and their belief, the family dynamic. Lots and lots of good, good answers here. So another sort of little area of the ethical consideration here is that sometimes it can be helpful to learn more about the aspects of the religious or cultural objections so that we can try to help the family maybe to identify an alternative approach to intervention that isn't in conflict. So for example, if the family's religious objection is to do that, what are our options that are available alternatively? So moving onto the next. So we'll move on to the next slide here. And so what are the options that are available for treatment that are compatible with their religious views? And then thinking about that issue that we touched on earlier about maintaining contact for the family that didn't wanna participate in treatment versus alienating them, so thinking about that. So what are the options that are available for treatment that are compatible with their religious views?

So someone commented that, "These types of issues occur frequently." So asking the family what they want, that's so important. Getting to the bottom of the objection. So maybe the device is the problem and maybe sign language is not a problem, and I don't know if a religion where that's an issue, I'm just using that as an example. The specific case example that this was based on, the whole religious and cultural aspect of it was really hard to unpack because it was about accessing care overall not related to a particular part of accessing care, it was almost like treating the hearing loss itself in any way was sort of a problem. Some great options. Using ASL, learning about their religion and what might be allowed, that's a great point. Great questions. See, so you all really didn't even need to attend this today because you all are very thoughtful in how you approach these things and I appreciate that. Alright, so to kinda wrap things up here, I just wanna hit on the key concepts here. So again, we're thinking about autonomy that patients and children should have the ability to make informed decisions about care. We wanna make sure we're maintaining beneficence. We're not doing harm, and we're thinking about benefits to the patient and to other people who are involved and that could include our institutions, it could include us, it could include other people who are not immediately apparent. And when we think about beneficence, we don't just wanna think about benefits but also loss of opportunity. And in terms of justice, we wanna think about what are our vulnerabilities and how do we avoid coercion. So the key other take home messages here are that ethical dilemmas occur in all areas of our practice and not just in pediatrics. And if any of you are participating in Dr. Jackie Clark's session at this time next week, she's gonna cover some of those additional areas of practice as well and I'm looking forward to that. And then I'm hopeful that you, it seems like from your responses that many of you had a good ethical framework to start with, so that's awesome. And using that combination of evidence-based practice and ethical principles can take us a long way in figuring out some of these challenges. I just wanna share some ethics resources with you. So the American Academy of Audiology has a Code of Ethics that describes a lot of these situations. The American Speech-Language Hearing Association, I provided a link there to that as well. Many of you live in states that have excellent state level resources that are provided either by your state speech and hearing association, your state academy of audiology or the licensing board. There's also a great book that talks about communication and ethics by Thompkins called "Practicing Communication Ethics" that I think is helpful in terms of applying these frameworks to how we communicate with families and children who have hearing loss.

So I hope these resources are helpful as you start to explore because as we experienced today working through these examples, there are no clear cut answers and something may happen to you at work this afternoon where we don't have the answer for how to approach this but hopefully these tools will give you a framework to help you work through and think about some of these things. So I have some questions pending that I'm gonna answer, but if you have questions and we don't have time to answer them in the last few minutes here, you always are feel free to email me at this email address and I will do my best to respond to your email if you want me to respond to the email or you can just tell me anything that you want about the webinar for feedback, I look forward to that. So moving into the questions, someone asked, "Is it legal that we can make deals or agreements with cochlear implant companies?" And it's an interesting area of legal practice but the short answer is that most of the time, institutions can enter into agreements with device manufacturers similar to buying groups that provide them with discounts for reaching certain levels of, and so those things are typically judged to be legal. The difference between something that would be legal and illegal or at least ethically questionable in some areas is if the persons who are involved in negotiating that agreement on the institutional side receive some sort of benefit personally as a result of that. And that's why in my institution, the people who are involved with negotiating those contracts with implant companies are not surgeons or audiologists but rather business folks, not that they don't have their own conflicts of interest, but those at least then will not affect the patient care side of the equation there. So that's a great question. We have participants right now from all over the world involved in the webinar, so my friend Serita from Cape town, South Africa, it was great to see you too, thank you and some others.

So let me know if there are any other questions, feel free to type those into the box in the few minutes that we have left. "Did we discuss what non-malfeasance refers to?" No, we did not specifically, but I'm happy to elaborate a little bit. So the issue of non-malfeasance is sort of the flip side of beneficence. So it's not just about what the potential benefits are, but also identifying non-malfeasance. So another way to say non-malfeasance is to say that we wanna do things that are not harmful to our patients. So the concept of beneficence and non-malfeasance are sort of two sides of the same coin, one refers to the benefit side of the equation and the other refers to harm, but medical ethicist will often separate those two concepts. So that's a great question. Other thoughts or questions?

- [Moderator] Dr. McCreery, I just wanted to come on and say thank you so much for an amazing course. I really appreciated the interactiveness for the participants and thank you to the participants for doing a great job of responding. I really feel like we've got a nice open discussion going in a online format. So thank you, Dr. McCreery, for your time and expertise and thanks to everyone else as well. We do look forward to feedback on the course evaluation and absolutely look forward to seeing everybody next week as the Salus course series continues with Dr. Jackie Clark. Thanks so much, Dr. McCreery, have a great day everyone else.

- [Ryan] Thanks everyone.