

[MUSIC PLAYING]

AMY
HOUTROW: Thank you, guys. It's a pleasure to be here. I am going to be talking about optimizing health and well-being for children with disabilities, and the alternative title is "We Have a Lot of Work to Do, People." And that kind of theme is going to come up throughout the talk.

To start out with some disclosures, I have some funding from net federal organizations. Much of this funding I won't talk about, in terms of the research that came from that, so nothing directly related to this. And this is the actual disclosure. So this is what we, in pediatric rehabilitation medicine, have dedicated our lives' work to. And for me, in particular, that happens through direct patient care certainly, but it also comes from programmatic development and education of the next generation of providers and then also the work that I'm going to talk about today, which is about looking at the bigger factors at play for the population of children with disabilities.

So we had some objectives, and they are here, but what we're going to talk about mostly is what's going on in the trends of childhood disability, looking at access to care and understanding some of the disparities that are at play here. And then throughout the talk, I'm going to spend some time reviewing some of the findings from a recent report that we published last summer from the National Academy of Medicine.

And so this is just the title and front book cover of that report. And in 2016, a task force, or a consensus committee, was put together by the National Academies, which I was lucky enough to chair, to look at opportunities for improving programs and services for children with disabilities, thinking about how we can help children with disabilities have the best health and functional outcomes.

But I want to start back here. So some of you might be familiar with this. This was published in 2004 while I was in my residency training. And it was really instrumental to me in terms of understanding child health from a much broader perspective than what I was experiencing as a resident, kind of from the very medical base perspective of a quaternary care hospital with a lot of illness and high acuity.

And the thing that comes from this that I think is very important for us to just hone in on and localize ourselves with is this definition of child health, which is the ability of a group of children or a child to be enabled or able to develop and realize their potential, satisfy their needs, and develop the capacities that allow them to interact successfully with their biological, physical, and social environments. And if you're a rehabilitation person, the word "capacity" really resonates with you because that's a lot of what we're thinking about doing is helping kids become more able to do things.

And in fact, this definition of child health is exceptionally well-aligned about how we think of the interactions that are at play when we think about disability. So disability is an umbrella term for things that are happening at the level of your body part or body system. Those are impairments. And then we're also thinking about how that affects the things that you do day to day. Being able to walk, to get yourself dressed, those are activities. And the term that we use in the disability world is "activity limitation."

But ultimately, what we want for children is for them to be able to fully participate in life in the way that they want to, and so that's participation. And so when we put it under the umbrella of disability, that's participation restrictions. And we know that it's not just a medical model that influences your ability to do things. It's not that you don't have a leg that makes you disabled. That alone is not enough. That there are interactions with your own personal factors and your environmental factors.

So you should be able to walk even if you don't have a leg if you have a prosthesis, right? So you might not have an activity limitation because you don't have a leg. You do have an impairment because that leg isn't there, but you should be able to fully participate in society. Although there is, unfortunately, a lot of stigma around disability which limits that. So those are some of when we think about environmental factors.

So in our health care space, we spend a lot of time in the impairment space, thinking about body structures and functions. And the work that we do in medicine is very well-localized there. But the work that we're doing in pediatric rehabilitation wants to extend that thinking well to the other side of this graph, so thinking about participation, how kids are doing in school.

And so when we were working on a big report, nationally representing how children with disabilities were doing, we actually reconceptualized the definition of disability to take into account the International Classification of Function, that schematic that I just showed you, and the Children's Health and Nation's Wealth Report and their definition of child health. And this is the definition that we put forward for childhood disability, really thinking about the interaction effect of what's happening in a child's environment and what's happening with their health condition that plays out over the course of their lives in all of the things that they do.

And for children, when we think about participation, we're thinking about being able to play, being able to go to school and learn and all of those things that kids do in their day-to-day lives that many of us don't really get to experience and understand because we see them here when they're acutely ill and they need extensive services.

So for that report that we did in 2012, one of the things we did was we looked at disability trends. And so this is just across time from the 1960s to the end of the decade 2009, 2010. And in the beginning, the rate of disability, the percentage of children with disabilities was 2% of all children. And this is disability that's recognized by having an activity limitation, so things like not being able to walk. And by the early 2000s, what we're seeing is a rise to 8%.

On this graph is examples of important legislation related to children with disabilities. And this is not intended to show you cause and effect, but this graph is intended to show you a massive rise in childhood disability.

We actually wanted to dig a little deeper, so we looked at 10-year trends, so the beginning of the 2000s to the end of that decade. And what we wanted to examine was what's explaining this rise? What are we seeing underneath that rise?

So we used the National Health Interview Survey, and in that, parents or the caregiver respondent identifies whether their child has an activity limitation. And then they're asked does that activity limitation, is that related to a specific health condition? And then we classified those conditions into these groups-- a physical health condition or a neurodevelopmental mental health condition or something that we couldn't classify, just it wasn't a single entity.

So a physical health condition-- the most commonly disabling physical health condition for children over the course of that 50 years is asthma. And you don't think of asthma as disabling, but asthma is incredibly disabling, especially when it's not managed and it's severe. So children cannot run. They cannot play. They don't go to school. So uncontrolled asthma, it really is a very important cause of disability. And then I'm sure you can think of all of these various neurodevelopmental and mental health conditions, and some of them are certainly on the rise, like autism, for example.

So in that decade. We saw a 16% rise overall of childhood disability. So that brings us to nearly an additional million children in one decade. And what was interesting in the study is that the highest rises were among children in households with high incomes and among educated parents, and we can talk a little bit about why that might be.

What I want to focus on is the big shift. So this is a table from the paper, and what it shows is the number of children at the beginning of the decade who had physical health conditions associated with their disabilities, an actual drop. And then for neurodevelopmental and mental health conditions, what we see is a massive rise over the course of 10 years. So this is a 21% increase in the percentage of kids who have neurodevelopmental disabilities over the course of the decade explaining their disability. And we're going to dig a little deeper into that to look at some of the disparities.

So what I'm showing you here is the change in the percentage over the course of the decade. So in the beginning it's just the beginning of the decade, and on the other side of the slide, it's the end of the decade. In the blue line, I want you to point out, that's just the overall population rate of increase of neurodevelopmental disabilities in the population. So a 21% change in the prevalence.

And the other lines that I want to show you are that we have this big rise among Hispanics. So Hispanics have the lowest rates of disability overall, but towards the end of the decade, they had a big rise, bigger than what we would expect based on the overall average. And also, up here, I want to show you African Americans. So at only one time point in the decade did they not have the highest percentage of kids with disabilities. And they also had this relatively big uptick right here at the end of the decade.

If we do this same graph but we're looking at it by income, so the blue line again is that 21% rise that's true of the whole population. And then, I've graduated by income. So the lightest green is the least amount of money, and the darkest green at the bottom is the most amount of money. So we're doing this by federal poverty level.

What I want you to notice is that, first of all, that lightest green at the top is much higher than all of the other lines. So those are children who live in poverty. So poverty and disability are linked. Disability is a cause of poverty, and living in poverty increases your risk of disability. And you're also much more likely to have other family members who have disability. So I think this is interesting.

I had told you that there was this big rise among families who live well above the federal poverty level. And I think some of us might be able to think about why that might be true because people who are much more well to do have better access to get services that identify their child's disability. So if you're trying to get your child in developmental pediatrics for a potential diagnosis of autism, it could take six to nine months. But if you are more well-off, you might be accessing those services more quickly and be getting a diagnosis. And you need a diagnosis to get services, so there's probably something about recognition and ability to access care.

But I also want to point out here in the middle of the decade this kind of steep rise that was much more prominent among kids in poverty. We don't have a good explanation for that. But it was interesting that we saw kind of similar but not quite at the same time point, rise among Hispanics. But this one I think is what the major take home point was for us that we were surprised about because this is data that is not done longitudinally with the same families. We can't explain exactly why this is the case, but it is something that we're paying attention to because I think it relates to access to care.

So basically, what helped frame our project, our consensus committee's work was that we knew that disability was on the rise. We also knew that the conditions that were associated with disability for children were changing and that disability is associated with markers of social disadvantages. So when we were thinking about social determinants of health, these are the kind of conditions that we're seeing. It's the social circumstances in which these kids live contributing to the increased likelihood that they'll have disability.

So I want to switch us over to access to care. So it is clearly demonstrated that when you have high-quality health care, it improves your health outcomes. But it does matter who you are, where you live, what type of insurance you have, how much money you have, and the type of care that you need. So our care is not distributed equally amongst children based on their need. It is not, in fact, anywhere close to that.

And so this is the Aday and Andersen model of health care access, and one of the things we spend a lot of time talking about is characteristics of our health care delivery system. You heard me say the word "system," but we'll get to that later because I think that's the wrong word. But there's a lot of factors that are at play here. There's health policies that influence how we deliver care. There's characteristics of the population at risk. And I'll show you some of those examples of why this becomes much more challenging when we think about delivering health services to kids with disabilities.

So taking in the work that the previous National Academy's report had done, the children's health, the nation's wealth, also thinking about the international classification of functioning, this is the schema that we put together for our report, thinking about both external and internal factors that influence outcomes. So you have a whole bunch of programs and services, which you know have demonstrated efficacy to help improve health and functioning for kids with disabilities, but those things really are happening in a milieu that includes what's happening at the level of the child and the family but also all of the environmental context, which includes social contexts, such as stigma, includes policies and how we finance our health care delivery system. And so although we know that there are things that we can do that improve outcomes, our ability to really achieve those is hampered by a whole bunch of other things happening in the environment.

So I think this is obvious. In order to benefit from the high-quality care, you need to be able to get in the door. You have to have access to that care. And so we looked at how well children with disabilities are able to access care that they need. And so we profiled children with disabilities with other children with special health care needs.

So I think most of you are familiar with the concept of children with special health care needs. These are children who have a health condition that has lasted or will last greater than 12 months, and it is associated with something such as a need for increased service use, therapies, behavioral services, prescription medication, or having a limitation in your ability to do the things that other children of the same age can do. So those children, those children who are limited in their ability, those are the children we're talking about who have disabilities. And then we're going to compare them to all of these other kids who have special health care needs. So these already are kids who have chronic conditions.

So what I'm going to show you is a couple of graphical representations of unmet need. The way it works in these national surveys is that a parent is asked if their child needs a particular service. And then they are asked if they needed it, did you get it? And if they say, no, we didn't get it, that represents an unmet need.

And so we're looking at comparing these kids with special health care needs who have disability to all the other kids with special health care needs on a whole bunch of different things that they might need for their health and well-being. And the way I have displayed this graphically is that each point is the odds ratio, and each line around that point is its confidence interval. So for you to know that something is statistically significantly different, the confidence interval cannot cross that big white line, which is one. So if a confidence interval crosses one, the odds ratio is not significant.

So this is just a way for you to see graphically how different the unmet needs are for children with disabilities. They're much higher. So they have higher rates of unmet need for prescription medication, specialty services, mental health care, therapy services, medical supplies, DME, not respite care. If you have identified that you need respite care you're just not getting it, it doesn't matter who you are. And I think many of us who try to get kids respite care know this very true in our own clinical experience.

They also have more needs for home health care, mobility aids, communication aids. And so the take home message here is the likelihood of you having an unmet need is almost four times as high if you are a child with disability than if you are a child with another type of special health care need.

We also wanted to look at whether or not there was another thing going on. So you can't get in, and we know these things relate to poverty, not having enough money. These are kids that have the most trouble getting the care they need, children who live in single-parent homes that are headed by a mom, a family household where the highest educational attainment is high school or less, or if their disability is particularly severe. I don't know what this kid has, but it looks bad. But you are eight times more likely to have unmet needs if you have a severe disability. So the kids who need it the most are the least likely to get it.

We examined also in this project how kids were doing in achieving the various core aspects of the medical home. So the primary care, family-centered medical home is our standard of care in pediatrics. All kids should get this.

So in the blue is children who have disabilities. In the green are all other children with special health care needs. They don't have disabilities. You want everything on this graph to be 100%. So the Maternal and Child Health Bureau tells us in order to meet specification for the medical home you need to have a personal doctor or nurse-- we're doing pretty well for both groups on that-- a usual source of care for ill and well care, family-centered care, so meaning a partner being listened to. We're not doing well. We're doing worse for children with disabilities, but we're not doing well overall for children with special health care needs.

They also look at being able to get referrals if you need it and then adequate care coordination, which we're also not doing that well with. We're doing much worse for children with disabilities, in part because they need so much more care coordination.

But what that means is that less than a third of children with disabilities are receiving care in a medical home, less than a third. So we have some work to do, people. And don't you think if we could give these kids the care in a medical home, we might be able to improve their access to care? If we can improve their access to high quality of care, we can improve their outcomes.

That brings me to this idea of the health neighborhood. So to me, the medical home is a concept that does not adequately meet or could be expected to meet the needs of children with disabilities because a primary care practice cannot alone give those kids what they need.

They need specialty care. They need services in their community. They need-- so if this is their medical home, they need access to a quaternary care facility that has the kind of specialists that you need to take care of them. They also, unfortunately, need to have transportation to get there, and we all know that is a serious problem. And so if this is our health neighborhood, it actually looks pretty good for a kid, but it looks really bad if you live out here in a rural area. And so we know kids with disabilities who live in more rural locations are really struggling with access to care.

So the data I had showed you was from several years ago. So I'm going to just quickly jump in with some new data from 2016 about how we're doing on these metrics now. The population is sliced slightly differently, and we'll talk about kids with health complexity more, but kids with health complexity have disabilities. And the more complex you are, the more likely you are to say that you didn't get the care you need, so five times as likely as kids who don't have complex chronic conditions, 20 times more likely to say that you have an unmet need for mental health care, 20 times.

And why is this a problem? It's a problem parents are reporting for a number of reasons. They can't get their kid in. The kid's not eligible. The service isn't available. They're having some difficulty getting an appointment. There's a problem with transplantation. Or it costs too much.

Let me tell you how much it costs when you get a new wheelchair. A new wheelchair, a fancy one, can cost \$20,000. And if you have a copay that's \$2,000 and you make an income of \$24,000 a year, how do you pay for that? So no wonder there are services that people don't get because of cost.

We're going to switch over to a slightly different population-- kids who are medically complex. And just to kind of orient you to this, these are the kids who are our highest utilizers. We're taking care of these kids all the time, here at Children's.

We already know that there are big disparities. So that children who have markers of social disadvantage, like poverty, and then there's also racial/ethnic disparities for kids with special health care needs, and as I had showed you before, children with disabilities. But what we don't know is how having a complex health condition really relates and interacts with those aspects of social determinants of health.

So just to start out, a kid with special health care needs, these are 20% of the kids in the population. These are our kids who have asthma, and they are doing relatively well, but they need increased services. And then kids with disabilities, these are our kids who are limited in their ability to do the thing that other kids can do. And I had showed you the data that's about 8% of kids.

The kids who are medically complicated, those are about 1% of kids. So medically complex kids, not only do they have disabilities, but they also have the need for multiple specialists. They have all sorts of high utilization markers and high need markers. And they often are getting care in a center that has a complex care program and then multiple other specialists available to them. And the middle one is one of our patients. Isn't she a cutie patootie?

So when we look at unmet needs, I'm just going to compare children who have medical complexity to all the other kids who have special health care needs. And the medically complex children in this graph are the darker purple. And you want them all to have zero unmet needs, which 77% of children without medical complexity have zero unmet needs, but that's not true of the kids who are complex.

And so what you can see is this sloping decreasing as the number of unmet needs go on. But what we have is that nearly half of children with medical complexity have at least one identified unmet need and a quarter of them have two or more. So this is very clearly that we're not giving them the quality care that they need.

What we wanted to look at was this relationship between typical disparities issues and medical complexity as a variable. So this is we're doing it by race and ethnicity. And so each couplet here is by a race. So the first one is white, the second one is black, third one is Hispanic. In each of those couplets, we're comparing children who are complex first with children who are not complex.

What you want is the blue bar to be as tall as it can possibly be, 100%, because that's zero unmet needs. And you want the red bar, which is one unmet need, or the green bar, two or more unmet needs, to be nonexistent or as small as possible.

So what you can see in each of these is for each racial categorization, the children who are complex have more unmet needs. And if I do it by poverty status, you see the same relationship. Children who are complex in each income group have more unmet need.

I'm going to stop us and look at this one, the 300% or 399% percent of the federal poverty level. Those kids who are complex have really high percentage of unmet needs. And that is, at first, somewhat shocking because these families have a lot more income. But what happens for these families is they are on private insurance with high deductibles that don't robustly cover their services.

So the children who are a little more poor have Medicaid. And we know there's problems with access to care with Medicaid and obviously, as a health system, how much Medicaid reimburses. But if you are in this middle income category, you don't have a ton of disposable income, and your health insurance isn't very robust. You don't actually have-- you have health insurance but it's not adequately meeting your needs. So these are the kids that we really start to worry about as health insurance becomes more and more restrictive in terms of what your benefits are.

So to control for various factors that influence your access to care, we did a mixture model Poisson regression. And it's an incident rate ratio, and I don't want you to get caught up in the idea of how this is different than a regular regression. The reason that it is a Poisson is just because of the distribution not being normally distributed. There's just a long tail that I showed you a couple of graphs ago.

But what we did is we looked at the kids who are not complex. And what I'm going to show you is that when you are a minority status, you have more unmet needs compared to children who are white. And what I am not showing you is that that's statistically true of children with medical complexity. They don't have-- the p-value here is not less than 0.05. It's not statistically different. If you're complex, it's not your typical sociodemographic markers of disparities that drive.

I could show you this exact same table for income, for insurance status, for language spoken at home, for education in the household, and it would be true for every single one of them. That the drivers of disparities for children with medical complexity is the fact that they are medically complex.

So this is something as people who think about how to provide health care that we have an ability to tackle. I mean, I don't have good mechanisms to really address pervasive racial disparities, but we do have mechanisms by which that we can move the needle in terms of providing better and more robust care to meet the needs of children with disabilities or complexity.

So I'm going to shift us, and one of the things that I wanted to be able to share with you today is how some of this data gets used in and outside of the clinical setting. So how it gets translated or doesn't get translated or informs policies.

So this is pre-publication. So don't go disseminating this everywhere, but we're sharing it with you early because it is particularly relevant. So the question that we were asking are, do children on SSI have more health problems and more needs than other children with special health care needs on Medicaid?

So just to give you a little bit of background. SSI is cash assistance. It's a program that you have to become income eligible for, and the child has to have severe enough disabilities to qualify. And so it provides this cash assistance to the family. It's about \$650 a month for them to pay for things that they need. It doesn't have to be for medical care. It can be for something like having a car to get to appointments or paying for your heat, which of course are obviously, very important to health and well-being.

But as you may have noticed, like many programs that support people who are poor, the SSI program is under a lot of political scrutiny and actually in the lay press as well. And so the question is, do they really deserve, are they disabled enough to get the benefit? And there are many people, including the president and many people in the GOP that would like to line item, cross out SSI for children with disabilities and just eliminate it entirely.

So we were and did make the argument that these kids do look different. So we know that kids on SSI, these are kids with disabilities, are older. This is true for all kids with disabilities. They're more commonly male. This is true for disabilities. Boys are just way less hardy than girls. They're more likely to be black. I showed you that data for that whole group of children with disabilities.

They're more likely to live in single-parent households. They're equally likely to live in urban versus rural locations, and they're more likely to live in something more like extreme poverty, so less than 100% of the federal poverty level, which is \$24,000 for a family of four.

So this is the same sort of unmet need graphical representation that I had showed you previously. So what you want is the confidence interval not to cross one to demonstrate statistical significance. And so this is what we're looking at, is are the kids on SSI? Those are kids with severe disabilities.

Do they actually have severe disabilities compared to other kids on Medicaid? And they do. They have much higher numbers of functional difficulties. They have the interference with their ability to play, interference with their ability to participate in organized activities. I'm going to stop there and just point out some of our other works demonstrated that it's actually being poor is a bigger driver of your ability to participate in organized activities than anything else that we looked at, including disability.

So if you don't think disability and poverty go together, I hope I have shown you that they do. And if you don't understand that poverty itself is, in fact, disabling, I hope that I am demonstrating that it is.

They're also much more likely to be frequently affected. All the time, their health condition impacts them, and a great deal they're impacted by it. They're also much more likely to have unstable health care needs, which means they're coming to the doctor more, and they're struggling more.

Which is fascinating that they're not missing more school due to their health condition. And I'm going to point out here that this was particularly important data that we gave back to the House because there was a bill in the House that wanted to tie SSI benefits to children to truancy. So if kids weren't showing up to school, their families didn't get the money. So of course, operationally, that was a ridiculous thing to ask the Social Security Administration to do, but it is also entirely real irrelevant to the experience of disability, whether you're truant or not.

Obviously, we want kids to be able to be successful in school, but punishing families by taking away the cash assistance because their kid isn't in school doesn't make any sense from the health or social policy perspective. And we use this exact data to say no, that information that they're just missing more school isn't, in fact, accurate, and we have nationally representative data to demonstrate that. So that didn't leave-- it never got voted on in the House.

So now, I spent a lot of time thinking about how families are impacted by disability. And so some of the family impacts here are they're spending a lot more time providing direct medical care, a lot more time coordinating that care. And then, of course, this makes sense they're having to cut back or stop work. So if you are poor and you're cutting back and stopping work, what does that do? Entrench you deeper in a cycle of poverty.

And these families, kids who are poor, their families are more likely to spend more than \$1,000 a year on their child's health care. That is a lot of money. And of course, that means it's causing financial problems for the family.

We looked at their overall health care needs and unmet needs. So as you would expect, just like other kids with disabilities, just like kids with medical complexity, these kids have more needs for every service that the survey measures. Interestingly, they did not have more unmet needs. So perhaps this is evidence that giving families some resources helps them access the care better.

I showed you before we're not doing so great with access to care anyway. So it's not like this is a great win. Similarly, this is not a great win. So these are the markers of a good, high-quality health care system by the Maternal and Child Health Bureau. And really, kids who are on SSI, so kids with severe disabilities, they're not doing that different in terms of their outcomes on these quality indicators.

The one I want to point out though is adequate insurance. One of the things that being on SSI does for you is in 35 states it puts you automatically on Medicaid for three years, automatically. No gaps in your insurance, which is one of the aspects of having adequate insurance is that it doesn't have gaps. And so without gaps, I think that makes you more likely to have adequate insurance.

The policy implications were very real. I talked about how it was very important in terms of the truancy law. But we are actively using this data when we meet with House Ways and Means and Senate Finance to talk about what would happen.

So first of all, the SSI program is doing the thing it's supposed to do, which is give kids who are poor with severe disabilities cash assistance. That's the purpose of it. And if we were to take that away, it would make the situation, which is already not good, much worse. They already have work lost. They already have financial instability. We would just be making that worse. That further worsens the cycle of poverty, which I told you is a major risk factor for disability, which ultimately, then costs our health care system more money.

So we know that we have work to do. It's not enough. It doesn't fix the problem for children with severe disabilities. But if we were to cut SSI, it would entrench families much deeper into poverty. And also, it's impactful because they lose their direct enrollment into Medicaid.

So one of the things that we took away from this report that we developed based on the evidence is that what we're really trying to get at is what is it that we can do to take things that we know work and enhance them? And then how do we do a better job with things like dissemination? So you have a great program that has great outcomes, and then it gets reproduced or not reproduced, and that's what we need to really work on in terms of the science.

I want to frame what we were starting with as important considerations. This is obvious to me, but it is not obvious to everyone. The goals that we have for children with disabilities are the same goals that we have for all children. We want them to be healthy. We want them to be able to participate fully in their lives. We want them to be productive, engaged adults in society. It's a lot harder for kids with disabilities to get there, but the goals are the same.

And then there just is not a system of care. We call it a health care system, but it is not because a system indicates coordination and organization and thoughtfulness. It is a bunch of bull-- loney. The other thing that is really evident is that there's a lot of different definitions of how we define disability and then that means that eligibility, which parents identify as a problem, is a barrier, which should be relatively easy for us to fix.

While we were doing this report, we were looking at the important federal programs that set the stage for delivery of services for children with disabilities, and I've been talking a lot about Medicaid. But as we were doing this, we were facing not even having SCHIP reauthorized and massive cuts to the Medicaid program, which the president is still working kind of behind the scenes of how to gut Medicaid without congressional approval.

We're also seeing attacks on IDEA, which is the Individuals with Disabilities Education Act. And of course, what I just showed you was attacks on the program for supplemental security income for children.

And the data about these programs is that these federal programs improve health and functional outcomes for children with disabilities. So we hand that data back to House Ways and Means and Senate Finance, and then they can use that in the dialogue when we're talking about why we shouldn't gut Medicaid, why we shouldn't rescind all of the disability regulations in IDEA.

So basically, when we concluded our talk, we thought about what makes an effective program? And here, I'm a pediatrician, so I use the ABCs. It should be accessible. It should be based on individual needs. It should be coordinated. Obviously, it should be developmentally appropriate. It should be evidence-based, and it should be focused on the child in the context of their family and goal-directed. And that means aligning short-term goals with our long-term objectives. Our long-term objectives are same objectives that we have for all children, for them to be happy, healthy, well, to become productive, engaged members of society.

But we have a lot of barriers to success. We've spent a lot of time already talking about disparities in access. I've hinted at this idea that we really have challenges to navigate. We have difficulty with implementation. We certainly have an insufficient workforce and a lack of preparedness for transition.

And this issue about coordination and continuity of services is a real concern. We're going to spend a little bit of time here and here. So challenges to navigate-- so Kristen did this representation of her child, Giovanni, her son who has a complex medical condition and multiple needs, of all of the different types of programs and services that they're using.

Down here in blue is health care. It has kind of a dotted line to some of the other stuff, but that line is not very direct or organized. And I want to put here in your mind that there's a whole bunch of stuff in red. Those are the school-related things. That's really important, and we need to pay attention to school-related things, and we don't do that very well in the way we think about delivering health care.

And then I'm going to talk to you a little bit about workforce. So I'm in a field that's very small. There are about 250 pediatric rehab doctors in the country. We are lucky that six of them are here.

And when we did a survey last year, most people thought locally, the access for kids with disabilities to them was pretty adequate, but nearly every single one of them thought that nationally, access was inadequate. And that's true. And one of the reasons that's true is because our distribution of rehabilitation doctors by where they are in the country-- so that's in green-- doesn't map to our distribution of children with disabilities, which are in blue.

So let's just look at the Midwest. We are flush with pediatric rehab doctors in the Midwest, but I can tell you right now, we have an access problem here. And the access problem that they have in the South is astronomically worse.

40% of children with disabilities are living in the South. Why? Because that's where people who are poor are living. And there are very few pediatric rehab doctors there, and we have barriers to get them there.

So with those barriers in mind, we had opportunities to improve, and these are some of the things that we pointed out. And I want to just spend a little time here on being creative about workforce development and partnering with families. So this is a project-- how do you solve a problem like Maria, something that's really complicated?

So how do you do both workforce development and work with families? When I was at UCSF, there was a demonstration project through Medicaid's waiver that allowed families to be a paid provider for their person, whether it was their child or their spouse or their parent who had disabilities. They needed in-home supportive services.

So what we did is we said, well, if a parent provides that or another family member, is it somehow going to make them sicker? Are they more likely to use the emergency room? Are they more likely to have a hospitalization? Because this is a way for us to demonstrate that if you pay parents, you're helping the workforce issue, and you're giving them adequate care. And most parents actually do want to be able to take care of their kids. They just also have to have income to survive.

So the quick answer is that compared to a trained non-family member provider, both for kids and adults with disabilities, there is no difference in the rates of hospital use, no difference in emergency room use. So when we linked all of that data, we gave that back to the state so that they could say, yes, there's good evidence that the care provided in the home by a family member provider is equivalent to a paid provider.

And so now, California allows families to be the paid provider. So direct policy implication for helping families do the thing that they want to do, which is to take care of their loved one and not suffer the consequences financially to do so.

I'm going to shift us really quickly to well-being taking us out of the health care space into the community. And this is some of the work that I've been doing with Tom Hagerman, and so a bunch of this work is his slides.

So you guys are familiar with the concept of ACEs, so adverse childhood experiences. They have both near and long-term consequences to health. And we have three different groups of kids-- kids who don't have health conditions, kids who have special health care needs but don't have disability, and in orange are the kids with disability.

And so here are the various ACEs that get asked in the National Survey of Children's Health. So trouble getting by on the family's income, much higher percentage of families with disabilities say that, having a divorce or separation. Having a parent or guardian die is much more common among children who have special health care needs, both those with and without disabilities. And having time in jail or being the victim of violence or being racially discriminated against, all higher among children with disabilities. Or seeing domestic violence or living with someone with mental health problems or drug and alcohol problems.

So I want you to just hold onto that for a moment. So these are kids who are already not able to do the things that they should do in their day-to-day life. They have disabilities, and they're living in social circumstances that have long-term negative consequences on their lives.

And even after we control for things like income, family structure, the child's age, their race, all of those things, kids with disabilities are nearly three times as likely to have three or more ACEs than other children. Are we asking about that in our clinics? Probably not. And should we? Probably.

We also looked at housing and food insecurity. So these are, in the green is kids who are not affected very much by their health condition. In the orange, it's either they're sometimes or always affected by their health condition. So the proportion of kids who have unstable housing and food insecurity is much, much higher for kids who have disabilities, markedly higher. And that's after we control for things that drive that, like poverty.

So even after we control for their poverty status, kids with disabilities are much more likely to live in unstable housing and be food insecure. And we probably should be asking about this in our clinics

How about bullying? So this is the kind of same sort of breakdown. Kids with disabilities just have much higher rates of their families reporting that they're bullied. So this makes me think about what we're doing in our health neighborhood.

So maybe it's more about thinking about what's happening at the school and in the community because this is really affecting kids' lives in very negative ways and affects their long-term health outcomes. So it's not just the quaternary care health facility. It's not just they have a primary care medical home. It's all these other things because kids with disabilities are getting bullied on the bus, and kids with disabilities are not living in secure situations. Their families don't have enough to eat. They don't have stable housing.

So there's a lot of work to do, people, and a lot of that extends much farther past our walls. And maybe we should start thinking about kids in the way that Fred Rogers thought about kids, so not just in our health care space but in all the spaces that are important for kids to live in.

So Mark Del Monte, who was in charge of federal affairs and is now overseeing the American Academy of Pediatrics, shared with me this analogy, which is something that I wanted to leave you with. Which is this idea that even though we have a lot to do, and it seems like these are problems that we can't fix-- there's a stone or a child or a group of children being pushed across the ice. And here we are with our broom, sweeping, sweeping, sweeping. And sometimes it doesn't seem like we're making a lot of progress, but you can get that stone closer to the circle by doing that sweeping.

And that's exactly what we all are doing is we're sweeping that ice super hard to alter the trajectory. Sometimes we're altering that trajectory in profound ways, curing them of their leukemia. Sometimes we're altering that trajectory in a very small way but getting them something that the family desperately needs, plugging them in with social resources so that they do have stable housing, so that they do have food to feed their family. So while we have a lot of work to do, people, I want you to know that we all have to keep sweeping. All right. That was it.

[APPLAUSE]