

>> Good afternoon. My name is Cathy Hickey, program coordinator for Mass Family Voices, a project of the Federation for Children with Special Needs. We're so glad you are able to join us. Today's webinar is entitled "What's Out There?" and we'll review publically-funded services and reports that your family can utilize, regardless of income. This webinar will be recorded and archived at a later date on the Federation's website. A few technical pointers. Please be advised that everyone will be muted except our presenter. If you have questions, please use the webinar toolbox that allows you to type in questions. And we will answer them either during the presentation, or I will collect them for the Question and Answer portion of this webinar which will follow the presentation.

This webinar will be presented by Sophia Johansson, who is both a child and parent to an individual with disabilities. She is passionate about empowering families to imagine better for their loved ones. Sophia has presented to service providers, state agencies, and family members across the state of Massachusetts. She works directly with families in both her roles as the Assistant Northeast Regional Coordinator for Mass Families Organizing for Change and as a Mass -- and as a Family Outreach Consultant at The Arc of Massachusetts. This webinar is being done in collaboration with The Arc, Mass Families Organizing for Change, and Massachusetts Family Voices. And thank you to our IT director, John Sullivan. And here is Sophia.

>> Hi everyone. I hope that you're all doing well and comfortable. We'll be spending the next hour going through all of the publically-funded services and supports that exist for families of children with special healthcare needs, developmental disabilities, and/or chronic illnesses up to age 22. I'm really happy to be here on behalf of The Arc, whose mission is to enhance the lives of individuals with intellectual and developmental disabilities and their families, as well as to be representing Massachusetts Families Organizing for Change, whose mission is to provide sustained advocacy and leadership training in pursuit of high-quality, individualized community support and service options including family support for people with disabilities and their families.

I am here also doing work that is directly connected to the Massachusetts Alliance for 21st Century Disability Policy. The purpose of this is to advance full participation -- I'm sorry. Full community participation for individuals with disabilities and their families. There is an approximately 10 to 12 page manifesto that was created in the early 2000's. And it's a really spectacular guide. And it's called Implementing a 21st Disability Policy. And everybody here will be getting a link to that document. It's a really, really great document that outlines the guiding principles and the system barriers, as well as the policy recommendations and actions that individuals and advocates and organizations can take to further advance the community participation of individuals with disabilities and their families. This was a document that was worked on by pretty much all of the major statewide advocacy organizations, including the Federation for Children with Special Needs and several others. So let's get down to business.

So what exactly is out there? To begin we're going to be talking about some definitions that are really important. So what do I mean when I say "publically-funded"? What I mean is, really money that is coming from some sort of government body, whether it's federal moneys or from the state or distributed by municipalities -- so a town or a city. And I'm using this to really -- I'm using this term really, extremely broadly. It just refers to money that comes from taxpayers.

Then, What do I mean by "services and supports"? So I actually mean a huge range of things here, from the most formal type of agreement where, you know, you are going to see a doctor or you have somebody come to your house. And as informal as just a neighbor inviting you over for a barbeque, or you inviting a neighbor over for a barbeque. And that being a kind of support for your family. Just -- you know, because community interaction; that's supported, right?

Then the last piece is, What am I -- who am I talking about when I'm using the term "special healthcare needs, developmental disabilities, and/or chronic illnesses"? The Maternal and Child Health Bureau defines special healthcare needs as "those who have one or more chronic physical, developmental, behavioral, or emotional conditions. And who also require health and related services of a type or amount beyond that required by children generally." So that's actually a pretty broad definition. And a lot of diagnosis, and some children that don't have any diagnosis, fit within that category.

The second definition that I'd like to go over is the definition of developmental disabilities. And that, according to the Developmental Disabilities Assistance and Bill of Rights Act, is defined as "a severe, chronic disability which originated at birth or during childhood, is expected to continue indefinitely, and substantially restricts the individual's functioning in several major life activities, such as self-care, receptive and expressive language, learning mobility, self-direction, capacity for independent living, and economic self-sufficiency." Chronic illnesses also refers to individuals whose health status would have the same impact that a developmental disability might have.

So how are we going to talk about this? I am going to give everybody here an incredibly comprehensive overview. So the great thing about that is we're going to be going through a ton of systems and all the programs, kind of, within those systems. And all of the options. But the downside to that is that we're really taking a bird's eye view. So it's going to be a very, very, kind of -- we're going to be dipping our toes in the water of a lot of different tide pools, so to speak here. There will invariably be a resource that many of you are probably very interested in and attracted to and found very useful that I will probably miss. And at the same time, I will probably tell you about something that you've never heard of before, or maybe you heard it once a while ago and I'm reminding you of it. Primarily everyone here is going to leave with some tools or techniques that are going to help you -- I'm assuming -- sorry. I'm going to back up for a second. I'm assuming that I'm talking to mostly family members who are raising children with some sort of special needs or disabilities. So I'm sure that some of you are also probably people

working directly with families or people working directly with children. That being said, I'm really going to be speaking as though I'm talking directly to families and empowering them with some tools and techniques to help describe what you need. And again, you know, just to really reiterate the overview, we are going to be discussing initial resources that will inevitably lead you to others, should you pursue them.

So to begin, again, we're going to look at some really helpful terms. What are rights? They are best practice and what we should expect. But there is not funding or legislation in place to protect these all the time. You know, I think of a sibling -- or I think of one child with special needs being placed in a school that's not their neighborhood school. And I think of a younger sibling. Now when we think about "what's right," and we think about the community relationships and the kind of community that's built around school, we think of, you know, Is this sibling's right to attend the same school as their older brother or sister if they're placed out of their neighborhood school? However, there is not necessarily any type of mandate or guidance that really ensures that this will happen no matter what. So that's an example of that. But then, you know, there are other things like the Bill of Rights, for example, that is an example of legislation that, you know, really states what we should expect.

Eligibility means that you might apply for something on behalf of your family or your child, and while your child meets the criteria, services may not be offered. And this is because usually services or supports are partially-funded, which are based on state and federal budgets. But they're not totally funded, so that means that they leave a certain amount of families, kind of, out in the cold so to speak.

Entitlement is another example of the types of -- the types of services and supports can fall under entitlement. And they are when you meet the criteria and your services are guaranteed. So MassHealth is a great example of that, where if you fit -- if your child and/or your family fits the criteria for -- to be eligible for MassHealth, you are guaranteed to receive health insurance through MassHealth. And despite the fact that services are guaranteed, you know, you still really do need to advocate for funding.

So what exactly does this mean in practice? So for families, I think it's really important to always ask for what you need. You're not going to get it unless you ask. And I think that you should always believe that you and your children and your family really deserve what you're asking for. And unfortunately this does involve being persistent. And certainly a big part of that is trusting that you're an expert at knowing what you need. And while you might need assistance describing it or you might not be up-to-date on all of the jargon that's used to describe what you need, you definitely certainly do know what you and your family need.

So where does this all start? At home, right? So children with disabilities have a right to live in a family home with loving parents. Now I am using the term "family home" very loosely, as well as "loving parents." Historically, children with disabilities were taken from families, sometimes from the minute of birth, other times from the time

when the disability was diagnosed. And really taken out of a home environment and sent to live in an institution. And no child deserves to live that way.

Children also have a right to services and supports in the most natural setting. I think the greatest example of this is really Early Intervention, where you have therapists coming into the home, and other types of providers coming to the home, to help a child -- to support a child's development. Really utilizing what's in their natural environment and helping to build the skills of their primary caregivers.

And then finally, families have a right to access all of the services and supports they need to keep everyone in the home as happy and healthy as possible. And, you know, again, just harkening back to the terms where we began, these are all rights. But certainly these are not guarantees. But I think that we all know and all intuitively understand why these things are important.

So certainly when you've got a lot of balls up in the air and you're juggling a lot of different things, it can be really difficult to balance everybody's needs. So it's super important to figure out how to assess the need. And I remember when my family -- when we were receiving Early Intervention services, we had one EI specialist say to me, "You know, if things feel out of control more than 50% of the time, they probably are." And, you know, I think that one of the most challenging things as, you know, a family that is really at the whim of a lot of services and supports that, you know, we really need and might not always get. Families have a different definition of crisis than what somebody who is, kind of, I don't want to say "doling out," but distributing or allocating the services and supports.

So for example, if you are a family and you're struggling every single day to get dinner on the table because you can't separate from the kids long enough to cook and prepare food and put the food down, and then you can't get enough people to the table to eat a full meal, and then you struggle with cleaning up afterwards because you're juggling too many things -- that's certainly an example of crisis. It's not a huge, acute crisis, but I would say that that's crisis in terms of a family definitely needing more support.

Whereas I was speaking with an intake coordinator from DDS and she was describing a family who had -- she was giving me just an example of one of the crises that she had encountered, which was a family that included three children with severe and very complex disabilities and medical needs. Both of the parents were in a car accident and they were in the ICU. And so that was an example of really, major, code red crisis. And so for them, that rated a lot higher obviously than a family that's having -- that's struggling around daily routines. But I think as a family member, it's really important to definitely remember and acknowledge that crisis is just if things feel out of control more than half of the time.

So when we think about how to assess need, we're also going to be talking -- we need to be figuring out, like, how we're going to break this down. So the first piece that we're going to go through is, What type of health

care does the child need? And we're going to primarily be starting with the child or children that led you to watch this webinar. However, sometimes siblings fall into this category. And sometimes parents or primary caregivers don't always realize that until they get partially through thinking about their child with special needs or their children with special needs.

So when we talk about health care, we're definitely talking about affordable care. Health insurance is a huge piece of that. And then financial assistance to cover expenses that aren't covered by insurance. So, you know, I have the most experience with autism spectrum disorder. And I'm thinking of floor time or relationship development interventions that are examples of therapy that might not be covered by health insurance, but are deemed very valuable. So those alternative therapies really do, you know -- they do -- they can fill a really much-needed place in somebody's life. But there is definitely a need to -- for certain families to really get a lot of financial assistance to cover those.

The third key piece of affordable care is great practitioners who belong to a strong network of providers, particularly because people are having so much trouble getting referrals outside of network these days. I've heard of that coming up a little bit. But then also it's really important to, you know, if you're seeing a doctor and the only doctors or specialists that they know are outside of network and they can only refer you outside of network and your health insurance isn't going to cover it, that's certainly not an example of affordable care.

So then the second thing is help with activities of daily living. And I like to break this down into two categories, medical or physical and behavioral. So when I think about medical or physical assistance, you know, I think about kids that might rely on technology to get through their daily functioning. For example, G-tubes or ventilators. Or sometimes there are children who are unable to dress themselves because of an issue with their fine motor skills or an issue -- other types of issues with their body.

Whereas behavioral is really -- this could range from, you know, an emerging mental health issue to just not understanding the expectations that are associated with any types of daily routines, like eating a meal or getting dressed or anything like that. But the individual or the child is usually physically capable of doing it; they just might not be able to do it. So, you know, if a child is anxious and they're not getting out of bed or going to school in the morning, that's certainly, you know, an example of their activities of daily living, you know, needing more support around getting out of the house.

And then finally, you know, coordinating care between specialty, medical, and therapeutic providers is a very, very big piece of managing health care. And, you know, it's very, very important to make sure that everybody is kind of up-to-date on what other people are working on and how they need to be involved.

So when we talk about, first, affordable care, there are definitely going to be families -- there are definitely going to be children out there who do have special health care needs who may not qualify for MassHealth. But I am assuming that most of the people who are on this webinar probably do. And you become eligible -- there are two types of MassHealth that are -- that apply for our families. But they really, kind of, all come out in the wash to get you the same benefits.

On the left we see MassHealth Standard, and that is a MassHealth benefit that's a version of MassHealth that's really based on income. Whereas CommonHealth is based on just the disability. So if you qualify based on income, then you have MassHealth Standard. If you qualify just based on disability but you don't meet the means test for MassHealth, then that means you're going to get CommonHealth. And you're usually expected to pay some sort of a premium every month to CommonHealth. And, you know, it's certainly up to you and your family to figure out whether or not CommonHealth is a good fit, but I don't think you should discount it if you're not pursuing that benefit. I think that having the opportunity to have MassHealth pick up your copays at any facility where MassHealth is accepted and more is just -- it's a really helpful benefit.

And then of course, having either MassHealth Standard or CommonHealth will open you up to some of these four programs below.

So Personal Care Attendants can help with activities of daily living that are related to medical or physical challenges.

Then there's Kaileigh Mulligan, which provides a certain amount of support and care that a child might receive in a nursing home. But it's actually more cost-effective to deliver that same care in a child's home. And that's a -- and Kaileigh Mulligan is available to everyone regardless of income.

Premium Assistance is also a benefit that's really important to know about. And this where MassHealth looks at your child's situation, they look at your employer-sponsored health insurance plan, or they look at the -- your child's individual healthcare plan that perhaps you may have purchased from the Connector. And they look at whether or not it is more cost-effective for MassHealth to simply pay the premium on that health insurance, than it would be for them to foot the bill for all of the services that you would receive when you use your MassHealth as your primary insurance. I'd definitely look -- I definitely recommend looking into Premium Assistance because it can open up a lot of options for families.

And then finally Community Behavioral Health Initiative or CBHI is certainly a type of behavioral support that can help with activities of daily living.

So the way that you get onto MassHealth is you need to complete the application and then complete the disability determination form. And certainly Mass Family Voices and Cathy Hickey and Tracey Rooney are some excellent, excellent options for getting through that process. The Autism

Insurance Resource Center is also an appropriate resource for families who have individuals on the spectrum.

Then Community Behavioral Health Initiative, just to go more in depth to the types of support that they offer. Outpatient therapy, in-home therapy, intensive care coordination. If you are in any of those, you will also be eligible for in-home behavioral health services, a therapeutic mentor, and access to a family partner. And then also Mobile Crisis Intervention is through Community Behavioral Health Initiative. I recommend looking this up if you need any sort of support for your family or the siblings in your household, so that they can receive some support around any type of behavioral health issues. Again, Mass Family Voices is really a great resource to learn more about what's out there in terms of these types of supports.

And then there's also Parent/Professional Advocacy League. And they really specialize -- they are a state-wide family organization dedicated to improving the mental health and wellbeing of children, youth, and families. And they just have some really great resources and great trainings out there. But certainly mental health and behavioral health is their specialty.

So then we get into the Department of Public Health. And under the Department of Public Health there is Early Intervention and the Division for Children with Youth and Special Health Care Needs. We'll start at Early Intervention. And there is the Regional Consultation Program. And I believe that they're in five regions across the state, but there may only be four. I apologize for not looking that up before doing this. And, you know, the role of an RCP is to serve the Early Intervention and childcare programs so that they can build community capacity for inclusion of infants and toddlers with complex needs. They work together with providers and families to really meet the developmental needs of children with multiple disabilities and complex healthcare needs. And state-wide, they have a vision statement that all the RCPs have really signed onto and act under. And that is that all children are born with possibilities and should have access to inclusive settings to learn, play, and interact. So RCPs can be a really great resource for families with children who have really complex medical needs.

Then within Early Intervention there is also the EI or Early Intervention Parent Leadership Project. And that is a really great organization that is run all by parents. And their main goal is to promote lifetime advocacy, leadership skills, and the development of an informed parent constituency, which will encourage Early Intervention services to be increasingly family-centered. They also have an amazing amount of resources on their website, which you'll see in the lower left hand corner, that can help with the transition from Early Intervention. It can help just to build those basic advocacy skills, particularly early on, which can be really important.

Then within the Division for Children and Youth with Special Health Care Needs, there are these programs that I've listed, which is: Care Coordination, Catastrophic Illness in Children Relief Fund, Health

Transition information, Pediatric Palliative Care Network, and Public Benefits Training, as well as MASSSTART.

MASSTART is a really great resource to just keep on your radar, particularly if you have a child with some health needs that might go easily misunderstood. Or you're worried about folks at school not being able to support a kid medically. And it's a closed-referral system, so you're going to need to look this up and figure out who your best point of contact will be for, kind of, getting into that. But what they can do is they can really provide you with a great -- they can act as a support to the family and the school to help the school understand how to effectively deliver any type of medical care that a child needs to access the school day.

And if you look on the left, you see the Community Support Line. That is a support line run and funded by the Department of Public Health that can definitely help you access all of these benefits that I described on the right.

So then when we get into the Department of Developmental Services, of course there are family support programs. You can read more about all of these family support programs listed here in the Family Support Directory. And a link to that will be provided in the handouts after this. But certainly anybody -- regardless as to whether you've been determined eligible for services from the Department of Developmental Services, anybody can access the Family Support Center and the Autism Support Centers. When you start looking at the other programs, they really go back to supporting the health and wellbeing of everybody in the home, whether it's medically-related or behavioral health-related.

To get into DDS, or to be determined eligible, you can see on the right we have a description of birth to age five. There's got to be a substantial developmental delay. And five to 21, there's closely-related developmental conditions. And you can call -- there are four DDS regions across the state: northeast, metro Boston, southeast, and central west. And every region has an eligibility coordinator, and you just do the intake referral directly to them. And then they will send somebody out and you can finish the paperwork and everything like that. And get set up with DDS.

But again, the biggest challenge I think that families face with the Department of Developmental Services is if you go back to the different types of rights versus eligibility versus entitlement, is that none of the supports and services offered through DDS are entitlements. They are all based on eligibility. So a lot of families do have -- do encounter challenges getting access to everything that they need. And a large part of that is directly related to funding. So there is a really interesting campaign going on right now called the Supporting Families campaign, and that is to add more money into the Family Support Line items. So if you're interested in that or if you're a family that has really needed a lot more support than what you have been getting, you might consider sharing your story through The Arc of Mass website.

So then of course the second big consideration for the child that led you to watch this webinar is, What does this child need to be able to access school, learn, and be a part of the school community? And when we think of the school community, I think initially physical access. So what does a child need to actually get to school physically? Not just -- oh, we have a question? Yeah, sure.

>> Okay, so I'm going to interrupt for a question. We have: "Could you tell us more about closely-related developmental condition? What does that mean?"

>> So what that really -- good question. So what that really means is let's say -- I'm going to go back. So closely-related developmental condition. I'm going to think -- I'm thinking of one child I know who has -- he has a lot of involvement with apraxia of speech and has a lot of involvement -- he's just got a significant array of learning disabilities that are really impacting his access to the material in school. So that's an example where, you know, it's not as cut and dry as an autism diagnosis or ... I'm trying to think of another one. Or, you know, some of the other just general -- Global Developmental Delay. But it's certainly something that -- it's a closely-related developmental condition whereas multiple -- you know, this kid is not developing along his same-age peers. And it's clear that he is going to need multiple supports when he gets older. So he's really going to need involvement to, you know, keep up with supporting himself, and community-based services. That type of thing. And of course, you know, the best way to get this question answered too is to also just call the Intake Referral Line because sometimes there are kids that get referred and, you know, the psychologist will review the paperwork --and you might not think, "Oh, well, you know, he's probably fine." Or she's probably fine. And then the psychologist reviews the paperwork and they're like, "Actually," you know, "this kid totally qualifies." It's not a very arduous process, so I do recommend doing it.

So we're going to continue on with, What does a child need to be able to access school, learn, and be a part of the school community? So when I think about physical access, I think about a child getting to school safely transportation-wise. And then also, like, whether or not the child has had enough food to eat that day, in addition to just can the child physically maneuver the building. I also think about extracurricular activities, in terms of, you know, What are the kids doing after school? Whether or not it's a school sport. Or is there some place or program that all of the kids are going to after school? Whether or not that's, like, a swimming club or, you know, YMCA, or any type of town-based soccer program, stuff like that.

Then I also think about support to stay healthy while in school. And, you know, I really have to give a shout out to the school nurses here because I feel like they are as valuable a resource as a primary care physician. And they can really fill in a lot of gaps for some kids if you have, you know, the right school nurse and the right relationship.

I recommend families looking up and into individual healthcare plans. I haven't found a particular -- I haven't found one particular resource

that I think is really spectacular, so if anybody knows of one, I look forward to receiving it. Receiving more information about it. Because individual healthcare plans, they're kind of like an IEP, but it's all medically-based. It's all based on the child's -- just what they need to stay healthy. And I think that this is an opportunity where families might be able to get needs met that might not be met with an IEP. So for example, in our situation, one of -- you know, my son has a lot of trickiness around eating. And we've actually worked out a way to address that in the individual healthcare plan as opposed to the IEP because we want to focus on something different in the IEP. So it's just something to keep on your radar.

Then there is also, you know, modifications to their curriculums. So what about their curriculum needs to be changed? And that would certainly be addressed in an IEP. As well as, you know, accommodations. But that might come down to more of a 504, kind of, relating more to physical access.

Then of course there's language access. And, you know, Mass Law Reform has a language access attorney, Tere Ramos, and you can find more about the work that she does at masslegalhelp.org. But I think she's doing really, really important work which is all related to civil rights stuff around families whose primary language might not be English. Or who's -- who are most comfortable reading and writing in their primary -- you know, their primary or native language, but they might be proficient in English. Just really making sure that the families have access to all of the support that they need to be -- to play an equal part in their child's education.

Then we have social/emotional support. What kind of support a student needs to get through their day.

And then finally summer camp. A lot of people are like, "Well, why didn't you put extended school year services on here?" And it's because, you know, every kid goes to summer camp, whether or not that's a really formal summer camp where you go away for several weeks, you know, and hang out in the woods, or if you do something, you know, for a couple of hours a day in your community. Every kid really needs a summer camp experience, and figuring out how you can do that is really -- is, I think, really important for every child's development.

Then when we think about the Department of Education, there are three, kind of, pieces of the Department of Education that I think directly relate to our kids, which are early education and care, elementary and secondary education, and higher education.

Up at the top here, the Coordinated Family & Community Engagement Grants, these are really, really wonderful grants. They have actually been funding a lot of the playgroups and music classes and stuff at the local libraries. Or some communities use them to run regular playgroups at some of the preschool programs that they might have. And it's just a really, really great use of that money. And it's likely that you probably live in a town or community that has been given that -- given one of those grants. And so you might want to just keep an eye out for any free offerings in the community to build literacy and social/emotional skills.

Then there's also preschools, obviously. For kids who are exiting Early Intervention or who have a documented disability, it starts at age three.

So of course special education also. With IEPs and 504s, impacts elementary and high school transition services.

But, you know, the really great thing about the Department of Elementary and Secondary Education is that their mission is to strengthen the commonwealth's public education system so that every student is prepared to succeed in post-secondary education, compete in the global economy, and understand the rights and responsibilities of American citizens. And in doing so, close all proficiency gaps. So I think that's really important for us to all hear and really reflect on, in terms of job-readiness and inclusive concurrent enrollment, which is an opportunity for students who did not pass MCAS to participate in a college-type program.

And then we also have job readiness skills, which can often be provided on a limited basis through the Massachusetts Rehabilitation Commissions. So if you have a student that's approaching transition or in transition, I definitely recommend looking up whether or not that student would qualify for supports and services through them.

Of course, you know, the expert on all things related to education is the Federation for Children with Special Needs.

Mass Advocates for Children is also another great resource to know about.

And I also really think that Program Quality Assurance is a great resource as well. They don't just collect complaints, but they actually have education consultants that you can call. And often times you just call. You don't need to get -- you don't need to give your name, you just need to give which district you live in. And then you can speak with an education specialist and ask them anything. And there are people who are trained really well in the law. So I think of that as a really good resource to kind of keep in your back pocket if you have any -- if you need any -- if you need to ask any clarifying questions about anything related to your child's IEP. Or even getting onto an IEP.

So then the third piece is, What are the ways that a child, teenager, or young adult make strong relationships, experience similar rites of passage, has hobbies, and regularly-scheduled fun activities? So when we think about those, we're really thinking about how this child, teenager, or young adult is connected to their community. What exists in the neighborhood? Is there a spiritual community that they can, you know, connect with? Or that the family has connected with. And what is the accessibility like around town? Or, you know, close to them? What are people doing for fun? Not just recreation, but, you know, actually just what makes this person happy? And then of course, like, paid employment and/or volunteer work. These are all [INAUDIBLE] for young people, particularly in our culture.

So when we think about the community, the possibilities are incredibly -- I mean, this is just a sample of them. We'll start with the Massachusetts Rehabilitation Commission again, where they house a program called REquipment that passes along durable medical equipment to its -- you know, one family's done using it, they pass it along to another family. It's usually free of charge. It's certainly a great resource to know about.

And then in terms of local government, this is something that a lot of people don't seem to be aware of. There are often times disability commissions or disability access committees or commissions for the disabled in nearly every municipality. And they can be a great resource for advocacy because they are actually appointed by either the selectman or the mayor, depending on whether you live in a city or a town. These are members of the community that are appointed to represent the needs and interests of individuals with disabilities who are living in the municipality. And they also, you know -- sometimes they have access to funding, so they might actually be able to support a program. But most often times, they just have -- they are just expected to weigh in. Similar to a SEPAC or a Special Education Advisory Council, they are expected to weigh in on community issues the same way that SEPACs are expected to weigh in on issues relating to special education.

Then another piece of every municipality that a lot of people don't seem to know about is there is an ADA Coordinator. So let's say that you have a child who is in a wheelchair or has a lot of trouble navigating space. You know, can't climb a ladder. Can't climb a slide. Can't go down a slide. That type of thing. And you have a playground in your neighborhood. And your child actually can't access that playground because there's nothing that accommodates their disability. An ADA Coordinator is going to be a great contact for you, particularly if you see or hear about any new plans to develop a playground. Because if you have a child who cannot access the playground, the ADA Coordinator would be a great resource to help you work with the town to make sure that that play space or other play spaces are accessible to children with disabilities.

Then the last one in terms of local government is local law enforcement. And I say this very, very -- with a lot of caution. This has to be really specific to your family and specific to the child in question. And so what I am encouraging people to do is if it feels right, sometimes police can help de-escalate things. And so The Police Pocket Guide published by PPAL is a good thing to know about.

The local resources and organizations on the right are excellent opportunities to just think about ways to further connect with the community. We're going to breeze through the rest here because I want to leave enough time for questions.

So when we think about what siblings need to be happy and healthy, a lot of times it is the same thing as children with special needs. But of course there are some things that are specific to siblings. And then when we think about the needs of the parents or other relatives, What are the things that everybody needs to sustain their involvement and to sustain

their health and wellbeing? And this slide will be in the handouts that I will be distributing.

So when we think about all of these -- thinking about respite, strong supportive relationships, good information, and guidance. And these of course are all of the options that can exist. Or just some of them that are out there.

And then in terms of workshops, conferences, webinars, and all of the -- and then the support that you need with navigation, advocacy, getting extended trainings, whether or not that's family leadership training or trainings like what the Federation does with their Parent/Consultant Training Institute. These are certainly opportunities to learn more and participate in your community and become a better advocate on behalf of your child and family.

Okay. Let's take some questions.

>> So we have a question. "My family is in crisis, who do I reach out to? I've tried reaching out to our team and no one is paying attention."

>> I think the best way to begin with a big question like that -- and of course you're welcome to respond to this answer partway through if you'd like to chime in with more detail -- is it depends what crisis you're fielding. If the crisis is directly related to the child's disability or if the child -- or if there is a crisis directly related to the parent's capacity or the family's capacity to care for the child with a disability, or, you know, is the crisis directly related to the child's experience at school? That would be where I would go. If I were personally in that situation, I would probably call somebody like the -- my regional coordinator with Mass Family Ties because -- actually, or Family Ties of Massachusetts. And the reason is because those are not only your resource mavens, but they are also going to be people who -- I just really like everybody who works for them. And I've known that they can really help talk people through things. And can help, kind of, parse out the issues and the challenges and help make priorities. But of course, if you have a more particular situation that you want to get into detail -- and you want to get into more detail, you're welcome to email me and I can work with you a little bit through -- as a Family Outreach Consultant for The Arc.

>> And the next question is, "How can I find specific information about who to contact in my community?"

>> So when you look at -- I'm going to flip back to this slide here. So when we look at local resources and organizations, you know, it's really going to -- it depends on what types of resources you need or want. If you, of course, need further assistance identifying activities for your child to participate in, the Recreation Department or the YMCA is an option. If you need -- if you want to learn more about what might be out there in terms of extracurricular classes, I mean, usually town websites are a good resource. But, you know, I think that really just Googling and asking around and asking your neighbors is a good way to do that. But again, you're welcome to email me as well, because it's a pretty broad

question. So, yeah. If you want to get into more of that, definitely reach out.

>> And the next question: "How does a child age five who has autism get into summer camps, but doesn't have the financial funding to register?"

>> So I think of that as being something that can be just an all-around challenge that a lot of families deal with. I want to go back to the resources in the community. Sometimes rotary clubs or chambers of commerce or other places in the community sometimes offer scholarships to meet this exact need. Another option is Flexible Family Funding with the Department of Developmental Services. If a child has been determined eligible for DDS services, Flexible Family Funding might be an opportunity to help subsidize the cost of that. But again, if you have a specific situation that you're really trying to work through, you're more than welcome to email me and we can figure that out.

>> Another way would be to post that question on the listserv -- the Mass Family Voices listserv because other parents may have been in the same situation and found a scholarship available. Or even to directly ask the camp if they have financial scholarships available. And Family Ties of Massachusetts is another good source for those types of resources.

So the next question is, "I know you stated that through MassHealth a family can access CBHI. Is there a difference between that and ABA services?"

I'm going to tackle that one. CBHI is a behavioral health services for children needing behavioral health services in home. ABA is Applied Behavioral Analysis. And they are different. It's probably enough information there for a whole 'nother webinar. But I can -- if you email me offline, I can send you information and we can talk about the difference between those two.

And the next question: "Do you have specific contact numbers/emails, to reach the MassHealth four programs that you mentioned?"

>> So I will be sharing some of that information in the handouts. But really, that Community Support Line with DPH, which I'll flip back to it now, is going to be an excellent resource if you're trying to get more assistance and learn more about all of the options that are available through MassHealth. The Community Support Line would be a great first starting point.

>> "Where can we see The Police Pocket Guide?"

>> Oops, sorry. You can see The Police Pocket Guide on -- if you go to -- I'm going to go back all the way here to ... If you go to ppal.net you will see on their website they have an option for Guides. And it is on that link. And I am looking for it now. I will give this to you now verbally, but it will also be in the handouts. So it's ppal.net/wp-content/uploads/2011/01/ppg-abbreviated-version-final.pdf

And really, if you just Google "ppal 'police pocket guide'" it should bring you to the website and where that PDF is.

>> And someone just posted that on the question section. So you can see it there.

Our next question is: "Twice I have reached the top of the waiting list to receive a voucher for after school programs, but trying to find an agency that is equipped to care for my non-verbal child, I always have trouble. Are there any agencies for a non-verbal eight-year-old for after school programs?"

This is something -- I would also post that question on the Mass Family Voices listserv to get answers from other families who have dealt with this issue. But, Sophia, you may have another answer?

>> No. I would definitely agree with that. I would also consider calling the Family Support Center that's local to you. You can get that information from the DDS Family Support Directory. You can just Google "Family Support Director Mass.gov" and it should get you there. But usually Family Support Centers will have that type of information. Particularly there's usually the people who oversee the medically-complex program with DDS. They should also definitely know of resources like that.

>> Okay. And, "Whom would I contact regarding financial help with weekly social group for a 19-year-old on the autism spectrum?"

>> I think of one option as -- let's see, if the child is enrolled in AFC, which is Adult Family Care/Adult Foster Care, and depending on your family's circumstances, that child or young adult really, might be eligible up through the end of this fiscal year, which ends on June 30th. That young adult might be eligible for some Wrap funding, which would be utilizing Flex Family Funding through DDS to cover the cost of social skills. Of course, if the child is in AFC, then it would have to be part of a care plan and you'd have to kind of go through the Transition Coordinator with DDS. But if you're just looking for general help, I think that calling your local Family Support Center and speaking with the director, or calling your DDS Service Coordinator to ask them about that, would be really helpful. If the young adult has not been determined to be eligible for DDS, then I would just ask the Social Skills Group directly. Or I would look at some of the other options that might be available through community-based organizations.

>> Okay, we have time for just two more questions. Any other questions that we do not get to, we will email answers to all at the end of this.

So the next one is, "How does one get PCA help?"

So to get personal care assistance, you would need to be on MassHealth and get a prescription from your primary care doctor. And take that prescription to a PCA agency. And they would come and evaluate your child to see how many hours they would benefit from having a PCA. We also have a webinar on how to get a PCA on the Federation website. So you can go

through that to get the specifics of how to get a PCA. Or you could also post that question on the listserv, and many parents I'm sure would be happy to share with you their experiences.

The next question: "I am a mother of three young children with autism. My husband works out of state and returns home two weekends a month. I need support, resources for respite, activities of daily living support in the simple things such as taking one child to another therapy appointment while the other one is home with ABA. I am overwhelmed. We have several hours of PCA time per week between the three children, but it is very limited in scope of use and I don't have the financial resources to pay for respite. DDS has nothing available. Any thoughts?"

>> Yes. Email me and we can talk. Because what I can do is I can walk you through some other things that might be available. And if you email me, we can set up a time to talk on the phone and talk through some of that stuff for sure.

>> And Sophia's email address is on the PowerPoint, which I will be emailing out within the next half hour.

"Are there agencies that can help look over your child's IEP to make sure they are getting the right type of services for your child?"

>> So I would say that the best resource for that is actually going to be SPAN, or Special Education Advocacy Network, sometimes do IEP clinics. Folks at the Family Support Center might know of IEP clinics. But the Federation for Children with Special Needs also has some opportunities to support parents like that. In general, it's going to be really, really difficult to get that type of support at many agencies just because it is so time-consuming. But, you know, there might be an option. If the child has been determined eligible for DDS and has some Flex Funding, you can spend up to \$500.00 on an educational advocate.

>> Okay, thank you. That's the end of our webinar today. Thank you for joining us. I will be emailing out the copy of the PowerPoint as well as an evaluation that I hope everyone will fill out and submit to us. Thank you, John, for helping us with this. And thank you, Sophia.

>> Thank you. It was my pleasure.