>> PRESENTER: Hello? All right. Cool. Welcome to our presentation. Blindspots and barriers and promoting accessibility for Deaf and hard of hearing children and family with disabilities.

This is me. I'm Maddie. This is Evan, that's Amy's son, I worked one-on-one with him. I have a bachelor's in English literature and a master, which I did online because of the pandemic. I have been in a variety of DHH educator roles, including a substitute teacher, paraprofessional, various kind of roles. Started as a volunteer. Now I'm the youth and family coordinator. Despite the awkward name, it's a statewide program in Illinois that provides services and resources for Deaf, DeafBlind and hard of hear kids. We have a Deaf mentor program, the only one in our state, family sign language class, IEP advocacy, family events, the whole thing. So that's what I do now. I'm also disabled, although I'm not Deaf, I'm hearing. I am disabled.

>> I have an education background, I have experience teaching from third grade up to adult education, including substitute teaching in a DHH program through the Northwestern Illinois association. Mostly I'm here as a mom, I have two children, one of them who is Deaf and a parent facilitator for the Illinois resource center.

I'm going to skip the objectives because you know what you're here for.

>> PRESENTER: So I'm here to talk to you about this concept of spoon theory and if you've been involved in disability theory you'll know what this means. But if you don't and you want more, the person who came up with this is Christine Meserdino. And this is available on her blog. You'll have access to the PowerPoint later. One time she was trying to explain to a friend of hers what it was like to live with a disability. And she used a spoon, they were at a diner. And it's a way of understanding disability, and the priorities and cost with living life as a disabled person. So in short spoons represent energy but it's more complicated than that. For most nondisabled folks, you have unlimited amount of energy. You're able to pick and choose what you want to do with no barriers on that front. For disabled individuals, you have a finite number of spoons every day. So, let's think about what that means in like a daily routine. Right? Broad spoon.

So you wake up in the morning, it's not a bad pain day and you slept okay. Let's say you start with 12 spoons. I don't know how many this is 3... 4... 9... 10. Who cares, I think it's close. So you take a shower and get dressed but you have to slow it down. So you can take a shower, that's going to take one spoon. You can wash your hair or shave your legs and you can't do both, and doing either takes a full spoon.

If you just take a shower, that's one spoon. Now you have to get dressed. For Christine, getting dressed take a spoon because she has difficulty lifting arms above her head. For us, let's say that getting dressed doesn't take any spoons because you know, particularly generous. Now you have to eat breakfast, if you don't eat breakfast within 20 minutes, you're going to feel nauseous. You can make breakfast, like a nice breakfast, but that's going to cost a spoon. You can skip breakfast but that's going to cost a spoon later. So you don't have a lot of time, so you make pop tarts, it's easy. Now you have to get to work. You can walk to work, but that's going to take two response. So you decide to take the bus. The bus is full today, so there's nowhere to sit and you don't look disabled enough, so nobody offers you the seat so you're going to stand and lose the two spoons anyway. You worked from home yesterday so you have your computer bag and it has an old HP laptop and it's heavy so you're going to lose an extra spoon. You get to the building of your office, you're at the elevator, your office is on the 4th floor. The elevator that currently there and ready, people are getting on, is tight. So you can slip in but you're going to feel claustrophobic. You can wait for the next one but there's no chairs in the lobby and you can't walk up the stairs. So you decide to squeeze in and you're going to lose a spoon. So here you are, you're at the workday, um... you have already lost a significant number of your daily spoons and you still have stuff to do. You can work um, you know that working a full day of work will take 5 spoons. # if you have meetings. So you know that you're going to have to call your friend and cancel dinner. You are going to hang out, a close friend of yours, not a lot of stress involved. But you're not going to have the energy for that. You know because you're running kind of close. So one, two, three, four, five, that's your workday, done. Now I have two response. This is the rest of the day. I can figure out how to make dinner, grocery shopping. But that's tough, they play loud music, you have to carry your groceries. Making dinner is hard so you know, don't know what you're going to do, you're not able to clean your house, you're not able to socialize with friends or read the book that you've been enjoying, because each of those takes a spoon and you have to use your remaining spoons to be alive and a person.

Once you're out, you're out. You can borrow from tomorrow but that's going to mess you up for tomorrow. So that's the -- the idea of this is, you know...

Sorry, what I'm getting at and what Christina was getting at, for disabled people there's real calculations going on on what you can and can't do. You have to prioritize everything involved from self-care, work, family, to relationships, you know and this is one person. If you've got you know, other kids, if you've got um... a family to support, if you've got pets, all of that stuff is going to take more energy, also. Um... so as a professional, as somebody homeworking with anybody, or just has a person in a coffee shop, you don't know what somebody's day has looked like. You don't know how many spoons they started with, what happened that was beyond their control, what choices they had to intentionally make to decide what they can and can't do that day. Something they were able to do yesterday, they may not be able to do today. Right? Well, you know, you drove out to the office yesterday, can't you just come in again today? No. I need to recovery time. Now I have to go grocery shopping so I can't use those spoons to get on the bus and come to work. Relationships, how well you sleep, physical and emotional stressors, that impacts how many spoons you start with. As a professional we can be limited to what we see. It can be harder to see the whole picture. For example, in the example that I gave you, we didn't eat very well. We had pop tart, maybe we had something for lunch and maybe we through something together for dinner. If I'm a nutritionist I'm going to look at that and be disappointed. Don't they value nutrition? Don't they know how important it is for your whole well-being to eat well? Why aren't they following my instructions? What they don't understand is making a healthier breakfasts costs spoons, I can't get my brood drawn, these real consequences and priorities, I can't take my kid to his baseball game because of the energy involved. But that doesn't mean I'm not grateful for the nutritionists work that I don't appreciate their expertise. It means that there's other stuff going on. So spoon theory can help us understand disabled adults and children that we work with. It gives us an idea of that give and take between what is possible on a particular day, and that disabled folks are prioritizing routine, socialization and events for their own survival.

Okay, so what can we takeaway from this? The first we can understand and be understanding by prioritizing care. So disabled families are going to make these calculations and choices every day and they are going to have to prioritize some things over others. Amy talked about in the beginning when her son was young and had serious medical emergencies, they were prioritizing those. Now he is in school, his health is relatively stable and they are prioritizing school over those ancillary appointments because you know, he has a limited amount of energy. He has a limited number of spoons. And so does the family involved with that process. They can only do so many things and not visit, you know, take a toll on them. So... the second thing we can talk about is homework and follow-up. When you see a family, you're going to ask them what they have been working on, have you worked on what we talked about last time, how has the progress been, how are things going? Let's be contentious about how we phrase that, how we frame that and what implications it has if I say did you work on that two finger grab we talked about last week? Then the family has to tell me "no" if they weren't able to get to that. But maybe they didn't work on the two finger grab because they spent the weekend in the ER. Maybe the parent is disabled or maybe they didn't have the spoons left to do that homework. Let's make sure we are framing our services in as understanding way as possible. We want to help the child's development, but we also want to be aware of them holistically and not put judgment on them.

And assume good will. Assume that the family is doing their best and making the hard choices and trying to do all the things they need to get done. They are just not able to do every single thing for their team all the time, because they have a limited number of spoons, a limited amount of energy. Try not to jump to them being unappreciative or not valuing or understanding your services. It's not an issue of you, you know, "Let me explain more how important it is that we get that implant on right away."

That's probably not the issue here. Be aware of you know, families and children as whole units. The last thing is new day new spoons. Something I could do yesterday, I can't do today. I can drive at night but it's more difficult and often gives me a migraine, takes up more spoons. Maybe I was able to meet at a library at 6 p.m. last year but not this, maybe I had to drive two hours to Lansing for a presentation and I don't have the spoons left over to do this thing that I was able to do the week before. Be understanding that somebody's ability may fluctuate. This applies to the kids we work with too. This week she is barely doing any. Maybe she's grouchy. Maybe, but we might find that she had a CAT scan, had to work extra hard in PT, she had a social event. All those take spoons and they are also important things. Let's be understanding of what kids and adults and falselies can do now and not do maybe at another time.

Um... we understand that listening fatigue, we understand listening fatigue better than we did before and we can apply that here too. Take energy, take spoons, and disabled kids aren't able to do the call cuelation I did for you earlier. I can do this but I can't do this and this. They might just say I can do this and this and then out. So how do we support them when they are figuring out what their limitations are? Disability is environmental dependent. Things are harder or easier based on a bunch of factors. Back to driver, I live in a suburb of Chicago, I can drive in the suburb, I can't drive in Chicago. There's a lot of pedestrians and bikers and I don't see out of one of my eyes. If I met someone out, you know, by my home, they might assume we have a specialist appointment in Chicago, you can drive there and I may have to tell them, I can't drive them. We have to go on the public transit line. And that would be confusing to them if they were thinking, you can drive here, why can't you drive there? Those things take different amounts of spoons and energy and those disabilities are environmentally dependent. I'm using myself as an example. Disability vary so everyone's experiences are different and what uses spoons, what doesn't. So be willing to listen a family as they express taxpayer needs and assume good will as they navigate a world that is inherently and systemically more difficult for them than it is for you.

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>> PRESENTER: What I'm going to do is kind of walk you through a day in the life. So if you weren't in the previous session, I have a child who is 4, with extensive medical needs and I also have anxiety and Maty convinced me it's a disabilities.

Maybe it's my anxiety saying I'm not disabled enough, but I'm coming to you from that lens. On a clinic day there's a lot. The prep work, the travel, the appointment itself and then after ward. If you look at this whole chart, the appointment is only a small portion of the actual experience and the energy and the spoons that are required to get through that day. Not even that day, but that experience. So before the appointments I have to tackle scheduling. I'm often giving little or no choice as far as when the appointment can be. The more specialized the professional, the fewer choice I get, as far as schedule.

And the time of day, it can be problematic to drive at certain times of day and often within a scheduling department, we are not given any choice whatsoever. Childcare, in the first place, because of COVID, understandably, I cannot bring any other children to my son's appointments. So not only do I have to schedule the appointment, take care of my own work obligations, if I'm working, I also have to find childcare on top of that. And then the time off of work, it's an expense to take off of work. My husband and I work jobs that do not have paid time off. So in order to have an IEP meeting it's something that costs our family hundreds of dollars because we not able to work and have to do that instead.

It's also a sacrifice to his education that we have to pull him out of school for these things. There's a lot that goes into the energy and the spoons that we have to sacrifice just to make an appointment go on the calendar.

So there's packing required. I have to pack up things for myself, I often -- I live about an hour from the children's hospital in our city in Chicago. So, I have to pack for myself, I have to pack for him, I have to pack energy medications. When he was tube-fed that was a significant amount of packing on top of it.

Not to mention the scheduled feeding situation, which is obviously not a part of the scheduling office at the hospital. I need to make sure I have all of his emergency medications, it's an unknown amount of time that I will be there and I have to pick up and drop off another child. So with anxiety on top of that, I'll often lay awake in the middle of the night wondering if I have his EpiPen, should I make sure I have the inhaler, what could happen if I forget the bag? And that phrase in itself is 3 spoons. Gone.

So, this is our clinic day. This is our boy banging on the door at 5:15 in the morning. And now it's 5:15 and I have two children up and ready to go, while I'm trying to get myself up and ready to go.

There he is in the middle with his coat and stuff and sister is helping and he's in the good mood but his mood is about to change. And there's my messy front seat of my car with all the stuff I have to pack. This is a good day, but I had a cold at the time so I had to bring along the tissues as well. And on that appointment I feel like COVID regulations changed so often, lately, that I was making a lot of phone calls because I was worried about getting turned away if I was coughing and sneezing. So, a lot of pieces.

Then we are driving there. I'm running late. I did have to make a coffee stop because I have to sort of... bribe myself to get through the day and do it. I drop off my older one at my sister's house and then I was thinking of Matty in this one, considering the time of day, the sun is blasting in my eyes as I'm going down the highway. And I don't have any -- well, I have normal vision concerns.

Once you get to the facility, I feel like the larger the facility, the worse the parking. And I do have a handicap pass. At the hospital in our area, I think that there's one time in five years that I've found a handicap spot. Um... the bigger the place, the harder it is. Traffic is unpredictable. The time I arrive is unpredictable. Sometimes I'm coming in hot through the hospital because if I'm 15 minutes late, technically they can turn me away. Thankfully that's not happened. But I may have to give myself cushion time to set up a tube feeding and sometimes I'm sacrificing sleep or something, in order to get there.

And there are a shocking number of doors in medical facilities that are not handicap accessible. This is the vain of my existence because I have to do acrobatic thing to get it open, get my leg in there and get both of us through the door. Which is a little crazy to me, given that it's a facility affiliated with a children's hospital. Once we are in the actual appointment, there's a lot of stress in the medical waiting area about germs. This is a boy who has been admitted to the hospital 9 times in a calendar year before because of having the common cold. Some medical waiting areas share them with urgent care, which I can't even say because it makes me want to spray myself with Lysol just thinking about it. There are diaper and toileting needs, space for a wheelchair and the unknown amount of time for any child to sit in a waiting room and behave. And then late policies are often not scheduled to be compassionate about any of these things. Like I said, many clinics have a 15 minute policy, thankfully I've never had it enforced on me. I've been put on the no show list because. --

Sorry I'm going a little quick. During the appointment, I have to focus. So at this point I haven't really calculated my spoons, but if I'm at of spoons as a person with anxiety, by that point, it's like if you're physically out of energy, my mental energy is minimal. And these are important things that I really need to be able to focus on and listen to and engage in. And sometimes if I'm not showing up with this spoons I need to participate fully... we are there to check the box and an appointment but I'm not present the way I need to be. So after the appointment, do we stay and eat or head for the hills? A lot of times on a feeding tube it was going to be another 30-45 minutes that we would be at the clinic doing a tube feeding because I can't do that while I drive. Oftentimes I'm so mentally spent that I want to go home so badly and I want to drop everything to do that. Is there time? Can we make it back to school? Can I get a few more hours of work in? What time does childcare close for the other one? There's a lot of facts after. And then there's the association. A lot of people who suggest when you have a child that goes to a lot of medical appointments, to make it fun and go out for ice cream after that. And mom just does not have anymore energy to get to the ice cream place to do that. Not to mention we have anaphylactic milk allergies, but that's a discussion for another day.

On this particular clinic day if you could see the picture clearly, I'm in the handicap parking spot and someone without a handicap pass is jammed to the space next to it. Thankfully on this day it was on my side and not on my sons side and he's a small guy so I could make it work.

I knew I was taking pictures for this presentation and did this person T me up for this day. Even though they are not cool, thank you stranger for this opportunity.

So what about early intervention providers who do these services in-home? Many of these pieces apply. There's the stress of feeling like your home is on display and I don't know if that's my anxiety or if every mom has that. I feel like every time an early intervention provider came to the house I was being judged and we had great relationships. So there's a lot of stress on that. Keeping the other child occupied. Is my child going to participate in therapy and will they judge me if they don't? So a lot of these things apply even if you're not in clinic. The most important I want you to remember is that the families you engage with may will running on empty. And like Matty said you don't know what the day has been like, you don't know how many spoons they have spent preparing for the day after.