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Improving Communication between State EHDI Programs and Hospitals: Strategies, Barriers, and Benefits

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9:41 AM – 10:05 AM (MST)  
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START TIME: 9:40 AM

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[Please stand by].

[Please stand by].

[Please stand by].

>> Okay, we're going to get started so that we can stick to a schedule. Emergency exits there and there. And I'm not going to waste any of your time. Thank you.

>> Hello, thank you for coming. My name is Maddy, and I'm one of the presenters and talking about the saving and Improving Communication between State EHDI Programs and Hospitals: Strategies, Barriers, and Benefits  
  
 We'll just go ahead and get started. This is me. My name is Maddy and I have a BA and MA deaf studies advocacy from Gallaudet. During grad school I was doing various Deaf and Hard of Hearing Deaf educator’s roles and when I graduated I became the coordinator with CHS. It's the Chicago hearing society which is the biggest misnomer. We are statewide services for deaf, deaf blind, Deaf and Hard of Hearing. I'm hearing, and I'm disabled.

>> And I'm Amy K. I'm first and foremost a parent of deaf plus child. I'm an educator. I have experience from third grade up to adult education, and I have subbed in Deaf and Hard of Hearing Deaf and Hard of Hearing programs. I'm a board member with Illinois guide by your side. I'm also working on my master's degree degree in social work. Our objectives for the presentation today are kind of to have you consider different types of disabilities that you may impact in your work with children and families. Gain a deeper understanding of how a disability is connected to accessibility and you can promote accessibility and you will leave with a checklist of strategy to take back to your workplace for promoting accessibility.

>> There are some checklists on your tables I didn't think we would have this good of a turn out so I didn't print that many but they are available on the EHDI Website app. What we're going to talk about today we're going to look at disability through the lens of spoon theory. Spoon theory was created as a way of what it's like to live with an illness. Christine has Lupus and this theory, this thought piece was a disability primer 2013 and the text of that chapter can be found entirely on her blog. I'll kind of explain it today.

What spoon theory is the spoons represent energy, but it's more complicated than that. For most nonstable teed folks, especially young people, you have an endless supply for spoons for each day. You get tired but you have the ability to do most things that you need to do in a day. For disabled people, we often have a very limited number of spoons for each day. Why spoons specifically? It's just Christine had on hand when talking with a friend but it serves as a good, tangible thing to think about. So I brought some spoons because visuals.

Let's say we're imagining we'll go through a daily routine and we start the day and we get twelve spoons for the whole day and once I'm out of spoons I'm out of spoons and then I can't do anything else. And I wake up in the morning and I do not have a fever and it's not a bad pain day and I slept okay so I start with twelve spoons. I get up, dressed I can take a shower but that takes one spoon. Now, I have eleven. I can't get that one back. I can wash hair, shave legs or, but I can't do both. Now, I get dressed. For Christine getting dressed takes spoons too because she has difficulty lifting arms above her head. It's hard to decide what to wear because of factors, bruising, things like that. Now, we eat breakfast.

If we don't eat within 20‑minute hearsay we get exhausted. I can make but it will Costa spoon, and I can skip and it will cost me later. Or I can eat a pop tart. I get to work. I have to get to work somehow I can walk but that will be two spoons. I will take the bus so I decide to do that but the bus is null today and I don't I don't have a physical disability so nobody offers a seat oy so I and that takes two spoons. I'm at the elevator and the he anxiety and the cholesterol phobia so I can take a spoon. There are I definitely can't take the stairs. I squeeze into the elevator and I lose another spoon. By the time I sit in my desk to begin my work I'm down ‑‑ we're really running out here. Let's take away our work spoons I can count. The workday is over and I have three spoons left. I was supposed to call my friend, well supposed to go to dinner with a friend but I don't have the energy to do it so I have to cancel. I have to go to, to store get groceries and I couldn't go yesterday because I ran out of spoons so I have to go grocery shopping and there's fluorescent lights and I have my groceries and I have one spoon, things like cooking, cleaning, making apartment, hanging out with friends, doing thing I enjoy, hard to do because I have one unit of energy left.

Even enjoyable things. Take up spoons. I could borrow from tomorrow's spoons but then I'll have fewer for what I need to do then. Basically when you're out of spoon there's ‑‑ you can't do things you enjoy. So that was an example being a single person living alone so add in anything else. Pet, family, children, all of that takes more energy. What we are talking about here and what she was talking about when creating this analogy. With disabled people real calculations what can and can't do during a day. You can't know what their day has looked like before you saw them so you don't know how many spoons they started with, what happened was beyond their control. Something I was able to do yesterday I may not be able to do today.

As a professional we can be limited in what we see of a child or a family. If you're a nutritionist why do you eat pop tarts every morning? We talked about this it's not healthy, but the energy it takes to make something else. Their lived experience might be different than yours. Spoon theory can help us understand stable teed adults and children are different and require different supports and services. It gives idea that give and take between what is possible and any particular day because disabled folks like me are constantly prioritizing routines, socialization, events for our own survival. That's kind of the concept. What can we use that for?

The first way we can do that by prioritizing care. Disabled families are going to be making those calculations every day. Where do they put school, daycare, birthday parties Doctor, appointments, cardiologist, that kind of thing.

Amy will talk about this but when he was an eh infant they didn't do things relate to hearing because they were working on his survival cardiology, other things that were prioritized for his health and for professionals it's like well, you got to get those implants in as soon as possible but that's not taking into account the rest of his experience. The second thing is homework and follow‑up.

When you see a family usually you ask what they've been working on. Have you worked on what we talked about last week, and if I say, did you work on that two finger grab that we talked about, the family feels they failed if they say no, but there's a lot going on with those families, families with disabled parents or disabled children in the family so maybe they didn't work on that two table grab because they spent the weekend in ER, the parent had dialysis or panic attack and let's make sure we're framing, help child's development while being aware of them holistically and as a family and as a whole.

We're assuming the family is doing their best and not just ignoring whatever advice you give them. Try not to jump to them being unappreciative. Not valuing your work. Something I did yesterday maybe I can't do today. I live in Chicago. I live outside of Chicago, and I can drive around my neighborhood, but I can't drive in the city of Chicago. I'm blind out of one eye. It's too much distress difficulty for me. What makes sense to me and what my experience is may not always make sense to you but again assume goodwill. This applies to the kid we work with. Maybe kids being lady today well that's not actual case. They might have other things going on, amounts of energy, that makes so this day is harder to do that task.

We understand listening fatigue. It's a similar concept to that, right? They just get exhausted by the things they have to do to survive so they are not always able to do the extra stuff. Things that are easier or harder are based on a myriad of factors. Environment, supports, that kind of thing. I'm using medicine myself as an example here but disability varies greatly so existed experience with that and spoons and s is different. We just have to be aware of their experiences and be listen to them and be respectful.

>> Absolutely. An important thing I think to remember when considering parents and their spoons is that disability can be a physical like medical disability but we really need to be thinking about mental health. Mental health has a similar impact on spoons as a physical or health disability might have. Trauma can literally affect brain chemistry so a lot of parents who worked with may have experienced trauma and health condition they don't even know about that makes things more difficult for them. What I want to do as a parent paint the picture of day of clinic visit for you through the lens of spoons.

I'm relatively healthy in general. No physical disabilities. I do have anxiety and I have a child with severe physical disabilities. He's had four open heart surgeries. I have definitely experienced trauma. I haven't done ‑‑ I didn't do it with real spoons last year. This should be interesting. On the day of a clinic visit there's four things that I'm kind of approaching. I have to prep for the visit. I have to travel to the visit. I have to experience the actual visit, and then there's the time afterward they have to deal with.

Before the appointment, that wouldn't really affect my spoons on that day but I had to deal with scheduling headaches quite a lot. Often more in the actual medical appointment situation I don't have a choice as far as a schedule. I get a call from the clinic. They tell me when the doctor is available and that's when I'm expected today come.

In a more therapeutic setting, there's more flexibility. A big hospital system where we're from in Illinois had cyberattack which completely demolished the scheduling situation which made it more difficult. I'm going to need to find childcare. Oftentimes, especially during COVID, you're not supposed to bring other children to appointments so that's something I have to prepare. Then I have to take time off. That's an expense. My husband and I both do not have jobs with paid leave. We're not getting paid that day and we are paying to go to the appointment one way or another. Occupant day of the appointment I already lost a spoon because I feel guilty from not going to work and maybe feeling guilty because my son is missing school so before I even gotten started for the day I'm down a spoon because of the mental load that that appointment is carrying for me.

Even though the appointment may be just an hour. It's not an hour. I had to spend time in the morning packing what we're going to need. If you have a child that is on a feeding schedule like tube feeding my son is not anymore but he was. That is a very stressful piece of the puzzle. For me I have to drive an hour to the main hospital in our town, and then do the appointment and drive home for another hour. Many kids on serious feeding schedule three hours is usually the time. I got to try to get that feeding down before we leave. That in itself is very stressful.

I need to make sure I packed emergency meds. Do I have the epi pen? Do I have an inhaler? Is it in the right bag? I don't know how long I'm going to be gone. So far my checklist is all about my son and what he needs. But have I eaten yet? Do I have scene of that accident? Am I going to get hangary? These are all things I don't have the capacity to plan for so a lot of unknowns you might not be able to plan for and like I said I have to pick up and drop off my other child which is just another thing to do.

Still before the appointment, three slides I haven't even left for the appointment yet. In these pictures this is an actual clinic day. In the first one son up and banking on the door. That cut into my own time to get ready for the day. I try to get up before my kids so I can manage my own self‑care and my own anxiety and have a little bit of time to get ready but that cut me off because at this stage we thought it would be fun to bang on the door and our hearing sister does not sleep when people bang on the door. The door started early that day. Then we're packing and getting ready to go.

On this particular clinic day I wasn't feeling good either I have a whole box of tissues so I had additional self‑care for myself so I am halfway down on spoons already and we haven't left the house. On this day it was winter so I'm driving to the appointment running a little bit late and I'm stressed and, again, feeling guilty because that's part of how my anxiety is affected. I'm feeling guilty I'm running late to drop off. I'm feeling guilty because my sister has to watch my daughter. I'm worried about being late in the first place. So there's lots of stress. And then as she mentioned before I'm driving straight in the sun. Luckily for me I don't have issues with migraines or vision, but it's not comfortable. If there was anything that I had on my plate that was affecting me way I have more challenges. S once we get to the appointment I find the larger the facility the worse the parking situation is.

Parking in itself is often spoon lost. We have a handicap loss but at the big hospital I haven't been able to get a handicap spot. Traffic is unpredictable so I don't know when I'm going to get there. I know that makes me look like the mom getting late but sometimes you can't help it on the highway and that's what it looks like.

One of the most frustrating things my sun uses a wheelchair. This is the door to one of the office there's no handicap button so just trying to get in the door I lost a spoon because I'm doing gymnastics with my leg and trying to fan able my way in. I've got four left. Then we're in the doctor's office and we're weight our turn. This particular picture was when COVID was more concern can. COVID is still concerning, but depending on where I'm at, stressful, is he going to end up, if there's a diaper the bigger he gets the harder it is to deal with. Doctor offices are not easy to maneuver a wheelchair so space is a consideration. How much time do I have until I have to pick up my other kid and am I going to get marked late. A lot of things that could be in the way. During the appointment, I'm at the point where I got about four spoons during the appointment. I need spoons to be able to listen and pay attention.

Especially if this is an important appointment, not that they are all important but let's say cardiology I need to be on top of game I can lose all my spoons in one appointment. I'm going to for sure use up at least one. Getting an interpreter could also put me at zero spoons. Most places bigger places have a video interpreter but that is often going to make the appointment longer. I have to run my risk reward if I'm going to just get through it and not provide my kid access which makes me feel like a horrible person. I just lost spoons right now. Or do I want to get it done and go home because that's what we need to do.

I'm way down on spoons and I need to be paying attention which is challenging. I'm at two maybe less, depending on how the appointment went, if he's in a bad mood or nervous, which is definitely a thing with trauma, medical trauma at the doctor's appointment my kid is going to cry no matter who it is to be honest I'm going to be empty.

Let's say the person gives me homework, I'm not going to go home and remember what that homework was. Let's say that if there's a big thing I'm self‑aware enough to know they need to write it in the after visit summary thing so I have it in writing. Not all people are aware to ask for that to ask for what they need. Just the information piece of it where I have gone to get to this point I'm not retaining very much information and notice there's no mention of anything else that I have going on in my own personal life. Did I fight with my husband? Am I having problems at work? And none of those things are impacted so I can be even further behind. One thing people say as far as kids who have a lot of appointments, make it fun go out and get ice cream, stuff like that. By that point I do not have the capacity to do something fun and connect with my child and make a positive association because I'm done. I'm burn out. Out of energy.

Sometimes we're just going to book it and get home as far as we can. On this particular day, when I got out to the car in a handicap spot a friend decided the line space was their prerogative to take on so I'm already spoon less and I got to the car and I was really happy. Thankfully my son gets in on the other side but not the best choice but I didn't do anything questionable because I can get him home.

How does this provide to if you're a ‑‑ having somebody in my home is very spoon depleting because I'm feeling judged by what my house looks like, by what I look like, by if we're ready, by if we've done our homework, by what it looks like if my other kid is watching TV in the other room and am I the mom puts TV on for kid?

A lot of prep pieces are taken away when I have services in home there's still plenty to replace that and deplete my spoon as a parent in order to engage in those services. One thing I also think of my sister is EI provider. A lot of parents drop the kid in the other room, I know EI is family centered service but you do not know what brought that person to that point that day and they may not be able to mentally engage in that situation.

Sometimes that's an information piece, sometimes parents just need to know this is not a drop and go I want you involved. Sometimes it's really just what they need and it's their only choice that day. The moral of the story kind of is that the families you engage with may literally be running on empty. That can look like lack of engagement, lack of follow through, the person that lashes out at you, just giving a picture of what goes into getting to the point where you are seeing them. And so thank you so much for listening, thank you for engagement, thank you for all that you do, this is Maddy and I's information and we're happy to chat with you.

[Session concluded.]

END TIME IN YOUR TIME ZONE – 10:09 AM (MT)

START TIME: 10:05 AM

END TIME: 10:09 AM