

Structure at Home: Let's Build It webinar

CBSS

May 6, 2020

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Sharon Stelzer: Jennifer let us know when you want us to start.

Jennifer Willis: We have about one minute. I'm going to shut down videos and mute everyone so for the recording we can have the presenter and the interpreter big on the screen for easy access. People can stop their own video or I can close those. If anyone has questions at any time and wants to unmute or open your video to sign a question, feel free to do so.

If anyone has a problem with me recording this, please let me know.

Let's see if I can mute everybody and -- there's also a way to get rid of -- I can't see. You know when you find those features and you wonder where that went? [Laughing.] Why am I still seeing -- hmm.

Well, we will -- I don't know how to -- nope. All right, well I'll hit the Record button and turn off my own screen. You guys can take it away.

Sharon Stelzer: Welcome everyone. I'm Sharon Stelzer and I'm a teacher at the Perkins School for the Blind. I've been there a long time and have worked with many different ages. I'm lead teacher doing lots of teacher support and trying to help them all and myself navigate through these difficult times. We are doing something we have never done before. I'll pass it to Kate Beals.

Kate Beals: Hi everyone. I'm excited you are here and we have this opportunity to do this today. I've had the great privilege to work with Sharon Stelzer at Perkins School for the Blind several years ago. I'm an occupational therapist and have a 30 year old son

who has autism. My son does have a lot of OCD and a great preference for things being the same and so I have some personal experience with what happens with him when his life is disrupted and right now everyone's life is disrupted. Sharon and I hope some things we talk about today will be useful for all of you to make life at home with your school aged children or children or grownups, a little bit more calm and peaceful.

Sharon Stelzer: We were thinking about how to talk about this topic. We really were thinking about how we can think about structure and routine during times that are a little bit extra ordinary from what we would normally be doing.

The first question is: Who needs structure? And our answer to that is everyone. You couldn't come to this meeting if you didn't have structure. If you didn't know what time it was, if it was like Jennifer and Donna and all the staff at the Maryland Deaf-blind project said they were going to talk about this but gave you no time or the Zoom link, without that structure that would be chaotic.

When we think of our children, ourselves and our family, we all need a little bit of structure in our lives. For many of our children they can't come up with their own kind of structure so we give them the framework for that.

The first thing to think about, because I'm a teacher I think about why structure is important and what it does for us and what it does for our children. When we have structure, it develops concepts. It helps us think about time, about language, about what we are going to do in building routines. There are lots of concepts we can talk about with structure.

Structure develops vocabulary. When we think about structure, you need some kind of language or way to convey that. Many of our children on their IEPs or in school have some kind of language goals and objectives. That's really what structure helps us do. What happens. What's the name of this thing we are going to be doing and is the name

important or not important? I was just on a Zoom meeting with a team and a parent said "I can't call it PT or speech or math" because PT and math don't happen at home. They happen at school. She said if she called it a different name, like counting or exercise or some other different kind of vocabulary name, then her son was willing to do that because in his mind, those classes happened in a building at a specific time with specific people. Really thinking about that vocabulary.

What else does structure do? Helps us develop anticipatory skills. What are you going to do first? Second? What happened before? Later? All those kinds of things. It's a great tool to think about and develop those skills for our students. Teachers do this in a very purposeful way. Parents probably do it in a more natural way with their children, but really that's what you are building, that big word for a little concept.

Structure helps denote a period of time. Some of our students might be able to say at 3 p.m. "I'm going to do this structure or routine." But some of our children don't know about time. But any activity you do happens within a period of time. What our children learn first is that something happens first and then something happens second. In that period of time, they understand minutes or hours, or they don't and just know things happen in an order.

We'll talk more about these in depth, but structure promotes conversations and it's probably the best thing ever. If you are a parent, sometimes you don't want to have another conversation about what is going to happen, or what you can or can't do, for example. For our children who are deaf-blind it's a great opportunity to practice that conversation. The conversation might not go the way you want. It might be a tantrum. You want them to do something and they throw themselves on the floor maybe.

Structures, schedules, all relay information. If you just woke up in the morning and didn't know what was going to happen next, you would hate it. But if you have structure and information and set up a structure for your child or your students, they are really

thinking about what's going to happen to them and what they will have to do. Then you go back to anticipatory skills, have a conversation about that and do a little bit of negotiating.

Structure helps students develop memory. What happens first. Things happen in order. You don't get up first thing in the morning and go right away to school. When they were going to school, they had to get dressed first. It's a great skill to help our students work on.

Some concepts we work on are the language, for example. How much information do you talk about? How do you say it? Do you sign three words together? Sign a full sentence? Do you say one word at a time? Are you using the same vocabulary and sign that they were using in school? You are making very sure your vocabulary is matching.

We can develop turn taking. This is where conversations are so important. I have a turn. You have a turn. It's a skill that many of our students need practice doing because either they want all the turns or they want no turns.

Teachers use this all the time in the classroom. Sometimes you have a reluctant student to do something. The teacher might start by saying "I'll take my turn first and then you can have a turn." This is a great strategy for home. It's a good trick of the trade if you go first and be the model. Then the child starts to anticipate that they won't do the whole thing because mom will take a turn and then they will.

Organizational skills are developed. Things happen in order. There's not chaos. It helps us think about how and what is going to happen and what materials we need. How we'll work on things. I think of organization as a great tool for pre-reading. Things work from top to bottom, left to right. How you think about those things.

Schedule with time. Maybe time is first, second or third. Or maybe it's actually at 1 p.m. for example. In the classroom, we would say "one more minute" and we had a student who would time us. She took everything very literal. We had to work on that. "When I say 'one more minute' that doesn't really mean one more minute."

Concepts help us generalize skills. This is the biggest test of generalizing ever, being at home, working from home. I look at my skills and schedule. Am I getting up at the same time or am I sleeping in a little bit more? How am I generalizing the skills I used when I drove to school?

When we think about schedules, schedules are based on understanding and they aren't based on age. There's no magic formula that says when you were 12 years old, you should be able to tell time for your schedule, do this, do that. That's not how it works. It's really based on how you think and the understanding that our children have.

How we are going to talk about schedules today is by thinking about building a series of routines to make our schedules because that's what our children need the most. They need a variety of routines to figure out what is going to happen in this new world. "Why aren't I going to school? Why aren't I going to the playground?" and those kinds of things. I was talking to Kate about this presentation and in Parade magazine was Temple Grandin and she was commenting on this Covid 19 crisis the nation is.

This line stuck out to me. [Reading quote on screen.] I thought that is so true! Then she gave a bunch of ideas for children with autism. She talked about routines a lot in the article. Jennifer has our PowerPoint and if you would like this to be shared with you, she can do that.

We wrote this presentation initially for children with CHARGE syndrome, but this really works well for lots of students who are deaf-blind. If you think this might not be right for you because you don't have a child or work with a child with CHARGE syndrome, think

about children who are deaf-blind. This is true for many of them.

Children create routines and need to know their schedule. They ask us through sign or they might show us through their behavior. They might show us through facial expressions like a puzzle or they might say you are wrong but they can't explain why. Maybe it's that you aren't doing something the same way their teacher is, for example. Building routines is helpful.

The picture on the left is a little boy who was crying. Kate found this and I love it! On the right is someone smiling and happy because he has a schedule and having schedules help us make sense of our world.

Thinking about what is a routine. What we did is looked up in the dictionary what a routine means. It's a series of actions that are regularly followed. That's pretty simple, unless you have to do it with a student who is deaf-blind. That's more tricky.

The definition of a routine doesn't mention anything about a clock, but it does say a series of actions. How and when you build the routines, it's individualized for you and your students or you and your families. I think this is really important to convey to families that the clock doesn't define the routine.

I had a mom with a 17-year-old son and she was saying she wants to sleep late and she's been letting him sleep late. I said that's fine. Lots of teenagers often want to stay up late and sleep late. That's sort of their internal clocks. I said to her that the routine can be the same if it just starts when he wakes up.

Kate and I were thinking about at your houses for your families, students, children who are deaf-blind. What are you doing now that's working? What do you want to do? And what can you realistically do? Because maybe what you would really like to do isn't what you realistically can do.

At the beginning of this whole crisis, if you were on social media there were postings everywhere of sample schedules. "8 o'clock shower, get dressed, breakfast. 9 o'clock academic activity. 10 o'clock, get up and do an exercise. 11 o'clock --." That might work for some families but it might not work for other families. You have to think about what is going to work for you.

I would like you all to take a minute or two and write down on paper activities that are important for you and your child or you and your students. Maybe it's something that's already working or maybe it's something you would like to do. Take a minute and then we'll have a quick share and then talk about some of the routines we came up with. Kate will then take over in a minute or two.

While you are doing that -- it's a beautiful sunny day here in Boston. I heard it's not the best day in Maryland. But they said here in Boston we might have some snow. That's what we are dealing with here.

Kate is it hot there in South Carolina?

Kate Beals: It's crazy. We have had severe thunderstorms for two nights. There have been more tornado warnings in the last three months than ever.

Sharon Stelzer: You all can share in the chat or use your mic about what you are doing right now that's working or an activity that's important to you that you can't live without or something you might want to do.

Jennifer, you are monitoring the chat, right?

Jennifer Willis: Yes, I am.

Sharon Stelzer: Does anyone want to be brave and share something that might be important?

Jennifer Willis: I'm waiting for all the good literacy responses. People wanting to spend time reading with their child or their students. All those fun messy art activities I'm sure everyone is doing at home.

Sharon Stelzer: Or maybe you just have to get outside and run around your house. Or you go outside and have to scream! I don't know.

Michaela in Chat: Being active. Go outside a little bit every day.

Sharon Stelzer: That's really important to get out energy. Sometimes students or children are super active and need to burn off energy. And then we have other children who like to be couch potatoes. It's important to get them off the couch and get them moving in a certain way. Building in activity. If you have students or have children who need that activity built in, there are lots of ways to do that either inside or outside the house.

Thank you for sharing.

We can move on.

Kate and I came up with some ideas, like what's important. Kate put down for herself that she has to drink coffee. That's not important for me because I don't like coffee. But going outside, laughing, learning. All those things that are important for you to stay sane and help to do that.

Kate is going to take over and talk a little bit about how you do that and how you think about the routines and how you can build that in. Kate tell me when you want to switch

the slide. Then I'll take myself off video.

Kate Beals: And I'll be able to tell you when to switch?

Sharon Stelzer: Yes.

Jennifer Willis: We had more comments. Working outside in the yard. Taking time for myself being a mom and also supporting students. And involving kids in cooking or baking.

Kate Beals: Those are great activities.

Sharon Stelzer: I love the cooking idea. You have to get it done because you have to cook meals, but it's a great conduit to teach so many skills! There's reading, math, and science! That makes me very happy and excited. Thank you for sharing that one specifically!

Kate Beals: Cooking is great. You do sequence, measuring, turn taking, OTs like pouring and stirring!

Sharon said you can think of a schedule as a series of routines. It doesn't matter what time you start or what time you end. Those decisions are up to you. What I did here [On screen] and these are easy off the top of my head -- write down things that are typically done in a routine way that might happen in the morning, afternoon or evening. Some people might want to switch bath and shower to morning instead of evening and that's perfectly okay. These are not rules. They are just possibilities.

Activities for routines that can be developed into routines for the morning might be using the bathroom, grooming. That is things like washing hands and face, brushing teeth, combing hair. Then getting dressed.

I can't live without making coffee so that one is for me!

Having breakfast, washing dishes, make the bed. Feed and walk pets. This is a wonderful way to work on fine motor skills, measuring and pouring and also getting some of that outdoor time if you have pets that need to be walked.

I saw a picture of someone walking their goldfish in a bowl in a harness to be able to be outside! [Laughing.]

Any one of those things is something that can be structures in a way that the same steps are followed each time.

In the afternoon it might be lunch, cleaning up after lunch, maybe doing some chores around the house. Play time. I think there are good times to play throughout the day.

Maybe having a snack. Maybe resting. We think of resting as being inactive, but I have read that during this crisis time and these times of great stress, that actually making a point of resting is a really good idea right now. We are all using extra energy right now in ways we haven't had to before. It's a good idea to rest and you don't have to feel guilty about it.

Maybe have snack time, recreation outdoors, these are all activities you can build routines around.

In the evening, maybe the actual cooking, maybe setting the table for dinner, eating together, cleaning up. Again, feed and walk pets. Maybe evening time is good for some quiet activities. Maybe some child or student choice activities from an array of quieter more calm things to do.

Planning for the next day. I'm going to come back to that in a second.

Bath or shower, brushing teeth, getting ready for bed. Maybe there's a story in there or stuffed animals that need to be arranged a certain way. Or goodnight routines. There are lots of ways to build routines during the evening hours as well.

I'll go back to planning for the next day. As you develop your routines and put those routines in an order that becomes a schedule, you can set up your schedule for the following day. "First there's sleep and then in the morning we'll do this and this and then in the afternoon this and this and in the evening this and this."

Depending on your child, you might want to set up only the morning schedule first and then when that's complete, you set up the afternoon schedule and when that's complete, set up the evening schedule.

Again, those are just ideas. You will have your own and your own are the best.

Sharon, do you mind changing? Thank you.

I divided routines into three different categories: Self-care, recreation, and household chores or household work.

Self-care examples. Washing hands is a super important one right now and you are probably spending extra time with that. [Reading bullet points on screen.]

Each of those activities has multiple steps to it. The way you put those steps in order and how much of an activity you expect the child to do is what shapes your routine.

Recreation or leisure activities are things like getting outside to walk, swim, dance. You can do some of those things inside too. I was talking with a friend whose son is

obsessed with Titanic and he was playing Titanic in the bathtub. [Laughing.]

Riding a bike, listening or playing music, games, color/draw. Here's your literacy Jennifer. Reading stories that don't have to actually be books. You can use story boxes or activity books. Actual activities your children have done with you that you create yourself. Arts and crafts. As an occupational therapist, the first day of OT school, they taught us that the process not the end product is the most important.

Household chores. Oh gosh, there are so many possibilities. All the parents who are joining us know this list is very small and there are so many more. Things children might be able to be involved in.

Dishes, table, laundry. [Reading bullet points on screen.]

I think dusting furniture was my first chore I was given as a young child.

A child doesn't have to be involved in cooking on a hot stove to be participating in preparing a meal. They can wash lettuce and put it in a bowl.

[Reading remainder of bullet points on screen.]

Children like to be productive. We all have our couch potato moments, but children like to feel comfortable and competent at doing things.

Sample routines. I put together routines in each of these areas. Remember these are merely samples. You will have your own and develop your own that reflect your family's priorities, needs and preferences and that reflects whatever support your child needs to participate.

Sharon Stelzer: I learned something from the families I work with that's related to that.

Our school is a residential school. We have a large population that just comes for day school, but we have a large population that stays at the residence. As teachers teaching remotely from home, a lot of our residential staff were sending their routines home.

One mom said that the routine of their child putting their clothes on a chair isn't possible at home because the bathroom is so small that a chair won't fit.

We really need to listen to our families and parents. One teacher said what she started doing is asking the parent to take a picture of the environment so the teacher could help the parent set up a routine.

I don't know what their homes look like. They might be in a big house or a tiny house. One family lives in a hotel. So you really have to keep all that in mind.

Kate Beals: Thank you for adding that. That was important.

Before we go into those sample routines, I want to say a word about active participation and why it is so very important. Whether the child is able to participate a little bit or a lot, it doesn't matter as long as they participate and are given the time to participate.

This is so critical. The way the brain works. My slide says "the child" but it applies to everybody. We have to do in order to learn. When babies are born -- I give my friend Danielle credit for this quote, "babies are born without a lot of wrinkles on their brains." Experience builds the wrinkles and pathways so the child learns and becomes more adept at performing skills as the time goes on.

Doing builds the pathways in the brain. This is one reason we don't use hand over hand facilitation. Because what happens? If you hold the child's hand, the first thing they will try to do is pull away and then you have conflict. The other thing that can happen is if

they don't pull away you take the child's hand and move it through the activity. Whose brain is working then? The grownups! The child can't learn by being passively moved through an activity or action.

This is why we use hand under hand facilitation instead. You support the child and gently guide, but they have a chance to remove their hand and eventually because they don't feel threatened by having their hand grabbed, they will begin to do some of that exploration on their own.

I encourage you to try not to make your routines too complicated and not go too fast. Allow some extra time for the child to initiate an action that you have requested. And then you can provide some help.

I learned this from taking some classes by Millie Smith, who was absolutely brilliant and if my house ever catches fire, I'll be taking her phone number with me.

The brain becomes active at the initiation of the movement. The brain is less active when the activity is winding down. So you want the child to initiate and at least begin moving at the beginning of the activity. That is where learning happens and the pathways are built. You want to have the child be actively participating as much as possible and you manipulating their hands and body as little as possible.

This is a sample routine for self-care [On screen.] I chose washing hands because that's very important right now. The steps of that routine might look like this.

[Reading steps 1-6 on screen.]

Then this might be a new one for you in this routine. Right now, especially, leave the water going. Get a paper towel and use the paper towel to turn the water off. This is because you have a dirty hand that turned on the faucet and you have washed your

hand with soap and your hands are clean, but if you touch the faucet to turn off the water, you have recontaminated your hand if you turn off the water with a bare hand. Use a towel to turn off the water.

Some children like to put their thumbs under the faucet and water squirts everywhere! I have worked behind a child and I turn off the water while they are washing their hands. Sometimes you have to be sneaky if you have children that like to play in the water.

I have had children where the step they could do was put the paper towel in the wastebasket. That was their level of ability, that they could put in. Put in is a fine place to start. You can have the child involved in whichever steps they have the most ability and then build the skills for the other steps.

Jennifer Willis: There's a question in the chat box about hand under hand. "What if a child has apraxic/dyspraxic disabilities?"

Kate Beals: That's okay. You still want them to initiate. I would use hand under hand and have them initiate the muscle action. I would still not move them from the top. I would guide from underneath. Does that answer the question?

Jennifer Willis: We shall see. Yes, there were some good responses. "My child usually takes my hand to engage in certain activities. She will take my hand to guide." People have been using the hand under hand which is good.

Kate Beals: You want the child's hand on top, not the grownup's hand.

This is an idea for a recreation activity. [On screen.] Setting up an obstacle course with things you have on hand, if there's room. Chairs or a stack of books or a ball or a laundry hamper. You can use any kind of materials that you have available. You put those in an order and decide what you want the child to do at each step and you

demonstrate it.

As an example, maybe you put a piece of tape down and start there. [Reading steps on screen.]

You can also as children are more able, have the child decide on what the obstacles are and what order they want to do different movements in. And we will talk more in a little bit about how to modify things. But this is also when for this sort of recreation activity, if you are encouraging movement, if you have a child who likes to do puzzles, you can have the puzzle at one end of the room and you have the pieces and they can come to you for the pieces, and crawl through a tube to go back to the puzzle. That gives you some movement for doing a puzzle.

This is a sample routine for doing laundry. I had older kids in mind for this but it doesn't have to be. There are so many different steps. Who doesn't have kids that like to dump stuff out! [Laughing.] Maybe turning the hamper over to dump out the clothing and then sorting by color. Put one load in the basket, carry that to the washer. Open the lid. Maybe there's a child who can open the lid and then they can participate.

Close the lid, choose your settings. Grownups might want to do that until you have some special tactile markings for a child that's vision impaired. You start the washer, put things in the dryer, remove, folding, hanging and putting away.

There are lots of steps in doing laundry. You can choose one of those steps, all, or just a few of these steps for the child to be involved in. It's up to you. Those are your routines.

Jennifer Willis: We have a comment that their child likes to pull out all the clothes and get in! [Laughing.]

Kate Beals: I love that! I used to put kids in the basket all the time when I was doing OT! Does she try to get in the washer or dryer or the basket? Oh, the basket, whew! Don't let the child get in the washer or dryer.

The basket is great. I always had a laundry basket when doing OT in schools. Especially children who are deaf-blind can figure out where their bodies are better if they are in a small contained space. Her child might want their very own laundry basket with pillows! I'm serious. I have a picture of my son in the basket with books. Getting into small spaces is a therapeutic strategy. [Laughing.] That's cool!

You will probably run across this happening as we do as teachers and therapists. Sometimes you have a great plan for a routine and it doesn't work. [Laughing.] That hasn't ever happened to you Sharon, right? [Sarcasm.]

Sharon Stelzer: Never! [Laughing.]

Kate Beals: It's okay if things don't work out as planned. Relax and breathe if that happens. Actually, let's all take a deep breath right now. [Breathing.] It's okay to modify routines because you made the routine and you can change it! We modify activities by changing one or more of these three things. We change the task. And you if you are parents, probably do this and just don't know it has a name. But I'll tell you the name for it.

You change the task or you change the environment or you change the child. Most people when they hear "Change the child" are horrified. They say absolutely they will not change their child because they are perfect and they accept that child with all their special gifts and challenges.

Well, here's the deal. There are ways to change the child that helps the child participate in a meaningful activity and learn a skill. You don't change the essence of the child but

you can change the child's strength. We work as therapists on strengthening activities to change the child's muscles. We manage the child's muscle tone to make it more or less stiff, depending on whether that needs to be increased or decreased.

We all have probably learned something about sensory integration and therefore are aware you can change a child's level of arousal in order to be ready to participate or ready to learn, we sometimes call it. If the child is hyper and super active, we want to do something to provide calming sensory input to help them get organized.

If they are very lethargic, we provide a different type of sensory input to get them more excited and ready to participate.

We can change the environment by changing the space or the materials. I have found it fascinating if I have a child working in a bin of sand or dry rice with their hand, if you add a cup, it changes the environment.

You can change the task by increasing or decreasing the complexity. You can change the number of steps, size of materials you use. Lots of ways.

It's okay if things don't work out exactly as planned. You'll find ways to work around that and make a routine more workable and functional.

You can make simple changes, modifications. If the child doesn't like washing their hands -- we all have bumped into a child like this. I worked with a child who was very tacitly defensive. She wouldn't let her mother wipe her hands and she wouldn't put her hands in the water. We ended up taking a Tupperware pan of water and some colored foam and toy fish and put the fish in the water and had her pick which color foam. I didn't call it "soap." She washed those fish all afternoon! So you can call it something else. You can call it making bubbles, washing the toy cars. You can clean up the foam. Maybe the foam has gotten onto something "by accident" wink wink. Maybe the child is

more willing to take something off rather than putting their hands in, though they are functionally doing the same thing.

If they are washing plastic Easter eggs instead of their hands, their hands are still getting clean.

If the child doesn't like the obstacle course, that's okay. You let him choose the items, the order. Have a box they can crawl through. You can use a smaller box to make dice. You can draw a picture of an animal on each side. The child throws that and whichever animal picture is up, you move like that animal. There are simple changes you can do with that.

There are lots of times when the child has a way better idea than mine. So, listening to them is really important in developing these kinds of routines.

Simple changes for the laundry routine. Heck, let them choose something else! It was my idea to have them involved in doing laundry but you might rather they wash the vegetables that will go into a salad. Choose what is interesting, meaningful and motivating.

Whatever task you choose, you can reduce the number of steps the child is expected to perform. If you have a child that grooves on counting and really enjoys that, it takes longer, but they can count each piece of clothing. You can also use a first/then system like "First we'll put the clothes in the machine and then we'll go for a walk." You can sandwich a non-preferred activity between activities the child likes to do.

Sharon is moving slides for me because of the way the computer is set up. Actually, it's your turn!

Sharon Stelzer: Perfect. So you are thinking these are great ideas and there are so

many things. But you are home and your child or student doesn't have all the materials. How we want to help our parents or ourselves is thinking about how your child communicates. That's the first step. Do they use pictures? Objects, speech, sign language, gestures? Sometimes our children communicate through behaviors. You start with the level your child is at now.

"But I don't have things they had at school" is what they might say.

Kate and I try to brainstorm about what we can do and how we can communicate at home.

You can communicate by showing my turn, your turn. You can show them materials or objects. Objects is a very concrete way to show any child anything. Even if they are reading or if they use Mary Johnson [sp?] pictures, you can always show them the objects.

You might demonstrate by modeling what you want the child to do. It might be turn taking. Maybe the first time you do the whole task. "Look at Mom. Mom is going to do this." Or you might have a brother or sister model it.

Think about the resources that you have. If you can use internet pictures, if you have a printer you can print those out. If you don't have a lot of ink and that's expensive, you can show the child the picture on the computer if their vision can access that. If you have siblings or family members and are thinking you don't have time to do that, most of the people we know are at home and you might have another family member in another house and they might have time to look at pictures. Say you need a picture of a brownie box, eggs, a bowl and spoon and have them send it to you because you don't have time to do that yourself. Think about who your resources are and think about asking people for help.

Remember that we are building a series of routines. These are tricks you might want to say. You will use general labels, like cooking, art, maybe chores. You are going to help Mom or help Dad.

You have all this energy at the beginning of the day and you say "We are going to make a complex dinner recipe" or "We're going to make a cake." Well, your child has an awful day. You are trying to juggle work. You had an unexpected meeting. By the time 5 o'clock comes around, you are tired. If you said to your child "We are going to make cake today" and you don't end up doing it because you are tired and your child is tired and it's just not a good day for cake, well if you had called it "special dessert" you could put sprinkles on ice cream instead. If you keep the labels more general, you are still successful.

Same with art. You thought you were going to do an art project. You needed toilet paper rolls. You start looking for those and your partner recycled them in the trash. But if you are doing art, you can come up with an alternate activity on the fly. It's a way to think about things in a different way to still be successful.

When you talk about the schedule, I think keeping it simple. Remember if something doesn't work, it's not a failure. It's a learning experience. What did you learn from the lesson about why it didn't work? What could you do differently next time? And thinking about schedules.

I have some examples of some families that I work with and the mom is working. She has to go into a hospital setting. Dad is working from home. The older brother is finishing his semester in college. The mom said their morning routine is great. They can take time with their deaf-blind son and help them with his routine. Their evening routine is great because they have time to work individually with him instead of a few minutes here or there. But she said during the rest of the day, the routine isn't great because they don't have time to be with him one on one because their schedules are

busy earning money so they can stay in their nice house and have their son finish college.

During those times, thinking about what their other son can do independently. He likes to sit and look on his iPad. He's a very social guy and he's missing people. His mother felt bad, but I said, "Look what he's doing." He found pictures of houses he could take a virtual tour of. He likes to visit people's houses and go see what other people's houses are about so that's what he likes to do. I said to put that in his routine. Call it "house visiting" or whatever he likes to do. So his routine during the day is less structured and has more things he likes to do and that he can do by himself. Especially if they are on a conference call.

I have another student. The parents are working and her sisters are in school. When the parents do have the time, they are trying to help the other children with school and Zoom schedules. The mom said that during the week they are so strapped and so anxious about doing the things they have to do that there just doesn't seem to be time to do things for her daughter who is a very complex learner who is deaf-blind.

What they figured out is that they can do some the teacher's activities they are sending, doing those on the weekend.

Really thinking about your schedule. Routine doesn't have a time affixed to it. It's just a series of activities in a row. To do some of those school activities, maybe they do crafting or reading a story, on the weekends. Thinking about how you can change those things around and helping our families change those things around and it's really okay.

When things have to change, we talk about this a lot, many of our students and children aren't good with change, especially some of our children who have CHARGE, who are deaf-blind. They are a little bit more rigid sometimes. You have to acknowledge there's a change and that change might be hard. Meaning you might have a little tantrum

about that. You have to plan for change. If you were going to cook and ordered from the grocery store and the ingredient didn't come, you say "This is our backup plan because there was no brownie mix at the store but we got muffin mix!" You have that backup.

We need to teach our children that if something needs to change and we can't do it now, when can we do it? If you were going to do a nature hike outside and it's raining and you can't go outside because it's thundering and lightning, reschedule it and let our children know when that's going to happen. Put it in their schedule. It's all about communication and that's what they want to know.

Other tips and strategies. Make the schedules and routines fun. Kate, you didn't wear your hat today. It's Wacky Wednesday. Have a theme for your kids or say if you are doing a Zoom lesson, say "It's going to be Wacky Wednesday so wear a crazy hat." Or you might have Fun Fridays with breakfast for dinner and dinner for breakfast, for example. Think of fun ways to spice it up and have your children look forward to that. You build routine around that.

Think about balancing activities for active versus restful activities. You don't want to do everything so active and busy and everyone is so exhausted the next day. You want a balance of doing things that are active versus restful.

Think about if your child has a lot of things. I loved Kate's idea about puzzles. You could put your puzzle piece at one end of the room and the child has to go back and forth.

Maybe you use their siblings, each sitting on one side of the room and you have your deaf-blind child going back and forth trading objects.

You can use your child's teacher as a resource. We encourage "Tell me what it's like.

Could you take a picture? Could you describe how it is?" Some of our students can't turn on the shower water. In school they can do that independently. Then they take a picture of their shower nozzle and it's hard.

One mom said "I never have time for my child to pick out his own clothes, so we are trying to take time for these things we never had time for when he was going to school." She asked great questions for the OT and the teachers. "He can put his shirt on his head, but how do I make sure it's not backwards?" She's really using the resources she has by asking.

Things are different and our kids know that. They are expected to do things at home that they weren't before.

Remember you aren't stuck at home. You are safe at home.

We'll open it to questions in one minute. On this form we have all kinds of resources. Jennifer you can probably share with everyone, but we have all kinds of resources. We write down what you can find on those websites here [On screen.] We have everything from stories in Spanish with slower audio. ASL books.

Kate put in something from the --

Kate Beals: World Health Organization.

Sharon Stelzer: The National Center on Deaf-blindness has great resources. The CHARGE website has great resources, even if your child doesn't have CHARGE.

We also have our contact information on there.

Jennifer Willis: People can put their email address in the chat and I can send it out or

you can email me to request a copy of the PowerPoint with the resources.

If people want to unmute to ask questions or start their video, feel free to do that.

I'm going to stop our recording. Before we finish, there also is a poll to complete for our evaluation purposes. I'll launch that now for everyone to complete, if you wouldn't mind.

Sharon Stelzer: Jennifer, do you want me to stop sharing?

Jennifer Willis: That's up to you. Sure.

Sharon Stelzer: I'd like to thank the person who did the closed captioning and our interpreter for making our PowerPoint accessible to everyone. Thank you.

Kate Beals: My last word is be kind and gentle with yourselves.

Jennifer Willis: Definitely. People are saying thank you for sharing, great resources. This was wonderful, great information and examples. Many thanks to all.

Kate Beals: It was a pleasure to have the opportunity to share. Thank you.

Sharon Stelzer: Thank you for coming and taking time out of your afternoon.

Jennifer Willis: Anyone from Maryland, the governor declared that schools are closed for the rest of the school year. So online learning will continue. So please come back and join more of our webinars!

Sharon and Kate, thank you so much for this information. I want to take lots of these key points and really emphasize them. You talk about that we learn by doing. And also for parents, it's whatever they can do in this moment to create -- we give them so much

of an expectation. If they feel they can't meet that, they don't even start because they feel overwhelmed. Giving that approval we can do with what we can in the moment and that will be enough.

Kate Beals: Absolutely.

Jennifer Willis: Someone asked where our webinars are listed. They are on our website. I will post that in the chat but it is marylanddb.org. That's our website. And all of the links to the current webinars as well as past webinars that were recorded are on there as well.

Sharon Stelzer: Jennifer thank you for inviting us and thank your whole team.

Hi Donna!

Jennifer Willis: You will be able to see the PowerPoint later. If your email is in the chat box, I'll send that out. Either way this session was recorded and will be posted on our website at some point so people can go back and watch it again if they need to.

Donna says "Hi ladies. You both are so cute. Stay well. And hugs."

Yay to Wacky Wednesday hat!

Kate Beals: Sharon invented that.

Jennifer Willis: We did a feeding webinar and someone has a donut group. I'm going to incorporate that one!

Sharon Stelzer: That sounds lovely!

Kate Beals: That would work well with my coffee routine!

Sharon Stelzer: I just want to make sure I can get through the door! [Laughing.]

Jennifer Willis: And margarita routine too!

Sharon Stelzer: I'm in!

Kate Beals: Yes!

Jennifer Willis: I appreciate everybody's --

Thank you both very much. We really appreciate it.

Kate Beals: Thank you. Should we say our goodbyes?

Jennifer Willis: I guess so. We are good to go. Thank you both so much for your time.
Stay safe and healthy.

Sharon Stelzer: Thank you.

Jennifer Willis: Thank you.

[End of webinar.]