NATIONAL CENTER ON DEAF-BLINDNESS

ESTABLISHING ROUTINES AT HOME

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>> HAYLEE MARCOTTE: I think we have the tech stuff figured out, so I think I will go ahead and get started. This is Haylee Marcotte with the National Center on Deaf-Blindness. I want to begin by welcoming everyone to today's session. I'm going to quickly run through some important housekeeping items. To begin with, we have muted all phones, and microphones have been turned off to reduce background noise. We ask that you please keep your phone on mute for the presentation. The question and answer session will occur at the end of the presentation. However, please feel free to write questions in the chatbox at any time, as it will be monitored throughout the webinar. The webinar will be monitored and archived, so please [indiscernible] your writing in the chatbox and refrain from writing personal or sensitive information. The recording along with other material will be posted on their website on our professional development series page which I will post shortly in the chatbox. All right, I think I will start the recording and hand it over to our Co-director, Linda McDowell, who will introduce today's presenters.

>> LINDA MCDOWELL: Hi, good afternoon, this is Linda McDowell and I am the Co-director of the National Center on Deaf-Blindness. As you can see by the slide in front of you, our topic today is establishing routines at home. I am confident that this topic is relevant during these times when home is where students are, more than not. However, I'm absolutely sure this topic has always been relevant and always will be. Routines in the home are excellent learning opportunities and the partnership in this between families and school personnel can only enhance the growth want to see in children.

We are so pleased today to have Dr. Susan Bruce and Dr. Tracy Evans-Luiselli able to bring materials and strategies to us. They've delivered this information individually and together multiple times, and I'm confident that whether you are a family member, a member of the educational team or a technical assistant project staff person, you're going to find the session helpful and encouraging during this time of COVID-19 and in the future, when COVID-19 is not such a threat and we can interact more closely with one another again. Susan and Tracy I am turning this session over to you right now and I thank you again for being with us.

>> TRACY EVANS-LUISELLI: Great. Thank you, Linda. My name is Tracy Evans-Luiselli and I am from the New England Consortium on Deaf-blindness and I wanted to thank NCBD to ask us to be here today I know you folks are very busy and here we are in the middle of summer. But this is information that has been compiled from the New England Consortium of Deaf-blindness that we serve the states of Connecticut, New Hampshire, Vermont and Maine.

>> TRACY EVANS-LUISELLI: We don't have your audio, Susan.

>> HAYLEE MARCOTTE: Susan, if you press #6.... I think you're unmuted, Susan. Can you see if you're...? Hmmm. Susan, I think we can't hear you.

>> SUSAN BRUCE: Can you hear me now? My phone is not working well. I apologize. I am happy to join y'all today to talk about this important topic that Tracy has been developing through her project, and I also want to thank NCDB.

>> TRACY EVANS-LUISELLI: So now that you know a little bit about who we are, we’d like to find out a little more about you folks and your background. So here's a poll that we have up. If you could let us know what your background is and give us some feedback, that would be really helpful as we progress through our afternoon here. I always feel like I’m watching a race as we go through these poll sessions. It's fun to see who people are. All right, so, it looks like we've got some grants folks here, Susan. Some private contractors, teachers. Great to see what we have. Care providers on here today. That's awesome. Parent Educators, interveners, which is great, TVI, TOD, SLP and administrators. It looks like it got a whole host of folks with different backgrounds. So we will do our best to try to reflect their information and have it be helpful to all of you. Okay. All right.

Now, our plan today is to provide a framework for working with families during COVID that supports home-based routines and learning for children who are deafblind. With that we would like to, again, get a little bit more background information from you folks. We have one more poll that Haylee is going to bring up. With this we would like to ask you what topics are most prevalent in our work with families since the beginning. If you can respond to that question, that would be great. Whether it's home routines, communication, tradition, emotional support, literacy, behavioral challenges, play/leisure, siblings and social skills. So it's great, it looks like a lot of you have really been addressing this whole notion of home routines, Susan, that is really important. Communication is really important and we can see as we move forward. Great. Thank you for your input.

Alrighty. I think it's very important that we step back and reflect on where we've been and where we are now. I think it's really critically important that we look at now more than ever how we need to support families and all of those wonderful things that have come out in the literature recently around wellness, practicing wellness and keeping healthy routines and adhering to schedules and having predictability is so important. I think a lot of what we will be doing focused on is how can we support parents to remind them with their day and their demands really significant. Even thinking about taking Zoom breaks, engaging older children and teens within the process. We all benefit from routines and predictability and Susan is going to talk about that later on in the presentation.

This next aspect really resonates with me, I think we've all been inundated by virtual, videoconferencing. And I think there's so many of us who have talked about how fatiguing this is. It's just a new normal for us. Right? I think it's really important that we step up to the plate and think about how we're protecting through that Zoom video lens, if you will, and the whole notion of active listening and friendliness and greeting parents and being positive is so critically important, especially on those days when we are tired, too, we're overwhelmed, feeling really fatigued in terms of using a technology we are not used to using to this particular aspect.

The other aspect is this whole notion of empathy. I'm constantly amazed, every day, since this whole thing emerged in March of what parents are experiencing. And from their perspective, parents have taught me so much. I feel like I've learned a lot. I thought we were kind of focused on the whole perspective and a family perspective. But I feel like we've really needed to change and to adapt more. So really thinking about the family culture, making sure that we have interpreters available so they have access to us in their information. Something that has evolved out of this competency, it has been fun to see more dads involved and siblings. Sometimes siblings are hanging on to the shoulder of a different parent or perhaps projectile, a particular item through the kitchen as you're trying to communicate and connect with families. It is a new normal but it is fun to see extended families and that huge reach.

Then also, the whole notion of loss of privacy. I think in early intervention, there's been a lot of this. But it's not so prevalent, at least that lens is not so prevalent we look at school-aged consultation and support, that parents really have lost, I know a lot of you on the line today are parents. The whole world is open to what your kitchen looks like. Some of you in bedrooms, trying to get away from other family members and still be on Zoom and capture information. So that's really important.

So our parents have been telling us since this entire process came forth is that they really are on overload. We have really tried to focus, initially, on our intensive TA which is really grounded in the whole notion of coaching and supporting families using a coaching model. But I think that what we're seeing now is families really struggling with that. It's too intensive and what they are saying or indicating in the survey responses that we've collected is that they want really simple, simple ideas and strategies around those particular home-based routines or at least home activities that happened for them. So we're shifting our focus around that whole classroom intervention piece, where classrooms have somebody adults [sounds like] they are able to implement a lot of different strategies and support child. It's very different, obviously, you folks know that, in a home environment. So what we're looking at is a focus on communication opportunities, especially within natural teams and looking at the child's level of engagement in that. So our framework includes the interview process and creation of some templates, and will talk about that little bit later.

Before we kind of dive in, I've been exploring little bit how we can improve the way we match our consultation and technical systems to meet family needs. Some families respond okay in a formal interview process and others don't. But the overall, overarching purpose of that interview process is to gather information and use it to help build a positive, trusting relationship. And, the frequency of those contacts with families really does make a difference. So the more frequently you can connect with families, the richer the information often is, because they get to know you are and they get to trust you. I love this quote down here, I don't even know where it came from. But the whole notion that families don't care what you know until they know you care. So they're not going to be able to take that information that you impart until you really are with them there in a very present essence, I would say. Again, I think from a grant perspective, certainly, or a provider perspective, we really have to think about that dedicated time to get to families and offer open-ended questions and listen, listen, listen and be folks will. Then, going through the PowerPoint, it's a little bit harder for me, but I want to talk about that whole notion of virtual eye contact, because it really makes a difference when you're having a conversation with the parent. If I'm looking over at my phone or looking down typing or regarding different things in my environment, it's the same as if you would be in a meeting with a parent and you are not perceived as being attentive. It's just something to be mindful of as we're moving through this kind of work.

With that, we are going to pull up the next poll. So here's another poll. Which routines -- and this is for families -- which routines do you find go most smoothly in your home? This is a great way to let us know. Wow, that's really interesting. Some folks morning goes really well.

So it looks like after school is difficult, doesn't it?

>> TRACY EVANS-LUISELLI: It definitely does. Morning and evening seem to be better. Anyway, yeah. That gives us definitely some food for thought as he will see as we move forward. So, Susan, take it away.

>> SUSAN BRUCE: Hi. I want to speak with you for a few minutes about the importance of routine in anyone's life, but especially in the life of children and young adults who are deafblind. We are using the word "routine" in two different ways during today's presentation. Tracy will use it when she's talking about morning routines, afternoon routine, the time routines and so forth. I'm also going to use it in terms of activity routines, meaning routines that are within an activity. Whatever kind of activity we are talking about it's very important because it brings order and organization to child's world. We know that children who are deaf-blind are working very, very hard to put pieces of information together into some sort of a sensible and that they are doing this moment by moment throughout their day. So the more that we can bring order to their lives by blending predictability with routine, all the better. Routines give us an opportunity to feature some key vocabulary and build concepts.

I think the most important thing is that this predictability from the routine allows children to have some additional emotional security to what they are provided in other ways such as through their relationships. When we have a predictable routine, it also allows the child an opportunity to perhaps make a comment or refuse or celebrate some aspect of the routine. So predictability lends opportunity for anticipation, because you know what's going to happen next. That anticipation, then, can lead to some intentional communication acts from the child.

Next, I would like to talk to you about within activity routines. So within a single activity, we want to have a very clear, well distinguished beginning, middle and end. And I mean distinguished so the child can recognize the beginning, the middle, and the end. We can help the child understand the beginning through our physical orientation in space, the child's positioning and orientation of materials the different parts of the materials. Not just the beginning but perhaps the middle and very end. Use of touch cues can be helpful. Also, the naming principal. Using a specific name for an activity and parts of an activity will help the child understand what is happening. Again, thinking about your vocabulary, but only conceptual vocabulary, but ideas were specifically tied to the sequence or timing of a routine. So words like first we are going to X, now, one more, all done, or finished. The repetition of these messages like the ones I just shared with you around timing and sequence are more likely to be learned when a child has been repeated in voice, in sign language, in whatever is acceptable to the child.

It is also important to incorporate the use of a finished or all done bin or box so the child understands that something has all done. I think we all want opportunities to ask for more of what we want and be done with what we don't want. Just like we have our to do list and mark it all off, children want to know what's going to happen next so we can help them out by incorporating these activities within mini schedules, perhaps. So we start with very simple routines and we move to more advanced over time.

Then between the different activities, we need to make sure that we provide clear transitions. One of the most common ways we do that is through the daily schedule which is also known as an anticipation shelf or a calendar system. Again, we are incorporating these with key vocabulary. We are representing the key parts or activities in the daily schedule through that. One of the things I like to empathize a great deal when I teach about this is that every single trip to the daily schedule is a literacy lesson and an opportunity for conversation. The problem is too many people treat it as a tool for transition and the second biggest problem is they are not thoughtful about touch. So making sure the child has enough of an opportunity to gain some understanding of the representations. If you are using object representations, integrating every trip as a literacy lesson will give permission to the faculty and the staff to slow everything down or in the case in the home with a parent, it's a literacy lesson, we slow down and do it well, as opposed to when we think of it as a transition tool. Tracy?

>> TRACY EVANS-LUISELLI: So, as we embark on, think about home-based routines, we go back and look at what's are ready been done. Certainly, all of the work [indiscernible] and his colleagues out of the University of North Carolina and the whole family engagement model was something that's really important. And again, this work is so grounded in early childhood education [indiscernible] but less so with the gang about the whole school process. Thinking about engagement and how we address the whole notion of looking at the child's interest, what they are most motivated by, thinking about their strengths, looking at the number of learning opportunities throughout the day that we can embed into a home routine and then the level of the child's participation, competence and ultimate independence within that routine. This is just, like in another model that we've explored that I think it's important for all of them to know about. Hold on, I just want to make sure I did this correctly.

Thinking about the whole routine-based model, it really has been up there for quite a while. The whole notion of focusing on the child's functional skills within the natural environment, and that includes school, community, and potentially work. And looking at how we defined these activities that occur during certain periods of the day, whether it is daily routine, morning, playtime, and evening, as we mentioned. You should have a handout that we put together and I want to give a shout out to Talia Mango, an educational consultant who has helped me a lot of these materials. We adopted this from earlier work that was done by Dunst [sounds like] and his colleagues to make a little bit more current to give parents ideas of a whole host of routines they can think about related to household chores, outdoor activities, physical activities. If you acquire that list you will see a lot of the ideas that you might want to have discussion with families about what families may want to take a look at, things as simple as going to get the mail. Not every family does that. But many families do. Within that are a whole host of potential learning activities.

So when we looked at trying to put this together [indiscernible] and I talked about how to structure our work if we thought we had a good premise as we looked at their classroom intervention. We decided to refine our model which includes an initial request form that comes in. We conduct an interview, there's a planning form. We generate the template and ultimately, a family routine card. Then there's an evaluation process that we're still refining. This gives you a visual graphic of a conceptual model that we're looking at, again, request, the interview, the planning form. We generate the template and then, we abbreviate the template and make this very simple family routine card. Then, the whole feedback and performance monitoring piece.

Again, the language is very inconsistent when you look at the whole notion of home-based intervention and even activity-based instruction. But just from my conversation today, I look at the whole notion, as Susan was saying, the schedule builds anticipation and predictability. The home routine which could again be morning, school, playtime, leisure, evening, that represents a cluster activities that occur at key points in the day. Such as the morning routine of waking up, bathroom, eating, dressing, and the actual skill stuff embedded within an activity. I have a morning routine. I get up in the morning. I feed my cat. I have my coffee. I might check the weather, the news, sometimes. I might check my email. So it's a whole sequence of activities within my morning routine to give a little perspective there.

So the first step in the process, as I mentioned, is conducting the interview. I think one aspect that we really noted is it's much better right now given the current situation that we're in to give parents a shorter framework, shorter period of time to think about. The whole notion of an annual goal to focus on is so overwhelming. Most of us, let's face it, we don't even know what's going to happen in the next week, let alone the next month or couple of months. Asking them what would you like to focus on between now and the end of the month or perhaps now to the end of the fall will perhaps generate a better discussion because it's really much easier for all of us to grasp onto. Then, thinking about our intense need supports, some parents want a couple of pointers and others are ready to jump into a much more intensive perspective or interaction.

The interview, again, just helps us identify what the routines are. It helps us really take it to that level of targeting very functional, day-to-day life skills. And really helps us think about, are we addressing those aspects of family life that are most meaningful for parents? Too often, I think when we're back in the regular world, we don't offer parents that amount of time to really discuss level. Certainly, the evidence supports that families are much more happy, much more positive in terms of the overall results when it really makes a difference in their day-to-day lives.

So we're going to use the template to identify the schedule, looking for participation in the actual routine within the child's day. Just some examples of what might occur with a particular family, and, you have a handout which is a sample sort of interview form that we've been using, trying to look at. The examples I have up here could be very, very different across the array of families. For example, morning routine, an online school routine or virtual learning, play/leisure and then an evening routine. I will say across the states that we represent, we have states that absolutely, I think the majority of children will not be going back in the immediate fall just based on their profiles. Then, we have other states where the vast majority of those students are going back. So it really depends on where you live. So these schedules and these routines as they present to me look very, very different. So in the interviews, you're going to step back and have the parent think about their typical family routine in the morning. What parts of that routine go well for you and your child? You would tell us what's going well, what’s not going well. Then we would ask you to help us be a little more empirical using a scale of 1 to 5, 5 being good, 1 being not. Tell us how that's going not only for you but your child and family as a whole. Again, thinking it's not just the child and the parent. There are other family members quite often that they've seen impactive. There are very many different levels.

So we go through each routine, quantify or qualify those to the best of our ability and to the information that we have. That that helps inform the next step or the next sequence.

Step two is looking at identifying the activity sequence with a series of steps embedded in the activity. This is where we really get into the task analysis with their specific routines. Again, I am working with families a lot on this. We are looking at routines with the example of toothbrushing, if every specific skill, a beginning skill -- adult guides the child to the bathroom. The adult signs or says brush your teeth. The child looks at the adult and regards the sign or interprets verbal and visual cue. Then, the child locates the toothbrush and grasps the handle. At that point, the adult provides hand-under-hand guidance to place the brush in the child's mouth, back and forth motions to clean the top and bottom teeth, and then signs and gives verbal direction to spit and rinse. Then, finally, the adult directs the child to place the toothbrush on the edge of the sink.

So this is a more advanced situation, advanced presentation for this particular child. The adult guides the child to the bathroom, signs and says brush your teeth. The child is again able to look, interpret the cue for both verbal and visual and the child has those skills already to locate the toothbrush, grasps the handle, place the brush in their mouth to make the back and forth motions and spit out the toothpaste and put the brush on the sink. So again, and much more advanced example and we're looking at the child's levels of independence within that particular morning routine, and that's going to drive how we crafted that eventual routine templates we are going to talk about in a moment.

The next step is where we get really detailed. So I've often thought working in the land of deaf-blindness for many years, how is this different for a child who is deaf-blind? For me, this is the whole core of the work that we do. This is where we step back and look at those individualized communication, sensory, tactile, physical support needs for a child who has blind vision and hearing loss. We are in the process of exploring these planning forms and there is a handout again. I'm going to show you some example. So the providers are going to use this form to work with the family to identify the steps in the activity, the sensory access needs, the communication mode, with receptive and expressive, and then, the level of physical support. And some of this, again, as a family gets really busy, what parents often tell us and we often see is you are there to do for sometimes, then step back and give the additional time for the child to do some of those particular steps and a task analysis, themselves. So it's really looking at those points where we can, again, reflect back on where the child is in terms of their overall independence.

So here's an example of the planning form that we've been exploring. I will give you a sample here of the intervention planning form as it relates to toothbrushing. And here the aspect related to sensory, vision and hearing. Communication has the receptive and expressive qualities noted. Certainly, for some kids there may be different aspects here that we have not included all of them. But we tried to be as inclusive but as general as possible to, again, think about the genes all of us working together with the family and the family giving us input as we basically find the planning form and individualize it to the student.

And then finally, the tactile and physical support needs that would be indicated for that child. This is a situation where the child has cortical [indiscernible] impairment and we are looking at the materials being adapted or at least indicated with the red toothbrush in the yellow cup and the before types of strategies that would be used, there's a tactile cue for placement. Joint attention is probably one of the most important things. Dr. Jennifer Gresham and her colleagues at the University of Kentucky have worked with us on, it's probably the most important thing that caregivers and parents of service providers can work on, really making sure you engage the child's attention before you proceed through the activity. This is an example, you maintained close proximity to provide auditory access. Receptive to sign and say brush your teeth. The child would grasp the brush from the side of the sink. There's a little bit of hand-under-hand guidance. As the child brushes there's some touch cues for thoroughness. As the child spits and rinses the child mimics these putting ways and as a parent I can't tell you how many times I did that with my son. Sometimes it worked, sometimes it does not. But providing a touch cue on the shoulder to lean forward in the process.

Finally, touch cue to indicate we are all done using sign and verbal cues and touch cue at the back of the wrist to place a brush on the side of the sink. You can see it's a whole big sequence and it is specific to that one activity.

This is another example of the planning form that is evolving as we speak. And I will say this came out of a conversation I had last week with a service provider said to me that great, that's great routines, I'm all for home-based routines but tell me how it ties into the IEP objective and learning standard. And it was a big aha to me because I thought we hadn't thought of it from that perspective, or at least not to that level of detail. So we are going to be working on that moving forward and really working with families. Because I think this level is going to make it or break it. It's got to be able to tie in the IEP and learn standards on some level to really make sure that this work is carried back if the child moves on and hopefully returns to the classroom.

Again we are creating a template so now we've got the information there in that planning form. Now we have defined it to create that template. The template, think of it as a lesson plan. The template really outlines the materials, the steps, and then you're going to award success. How are you going to know whether it's working, whether the parent feels confident in terms of their child learning and their ability to implement the different steps within the process. So you have a handout in terms of the actual template.

Here's an example of the templates we're using. So again, the steps would be indicated one, two, three, four. I should have that on the form and I don't. That the outcomes, we would calculate the fidelity of implementation across those identified steps.

Then finally, working at using a goal attainment scale for the child's generalization across settings, across materials and across people. This is a much more advanced level. This would certainly be in a case where we have parents who are willing to engage in a much more intensive process and perhaps we'll see more families that are interested in engaging that level as we move to the fall. I would say in month or two months ago, it was very, very sparse in terms of the families that we were seeking that really could go to this next level. Here's an example of templates we created, an example of one around getting into pajamas and outlining the different pieces that come from the planning form, the different materials, and again, steps within that particular process and AT [sounds like] devices used in that situation. The adult says time to get into your pajamas and then provides assistance around the whole sequence of getting into PJs, whether it is with the pants and top. The final piece here that is expected of the child is at the actual take those clothes and put them in the hamper the end of the activity and then the adult provides praise. So again, it's all scripted out very, very specifically.

I will say one thing I should have also indicated, it sounds simple and it sounds trite, but the fewer words you can put on any template, the better. The more concise you can be, cryptic if you need to be, I think most parents get the general gist of it, at least they've indicated that. But it's just the more words we put in the template, the harder it's going to be for families to grasp all the nuances.

Here's another example of eating cereal. Again, the adult prepares the whole process, provides the cue and is providing all kinds of support as the child begins to eat cereal. And the major goal at this point is the child actually get the food into the mouth, chew it and then swallow it. So just an example of a particular routine.

As you think of the example templates that I just showed, there's a lot in them. There's we have to do both in terms of our goals, objectives and learning standards. So what [indiscernible] and I have been thinking of is using a family routines card and perhaps even sending these in the mail with a magnet they could put on a fridge or putting in a little ring if we've got several of them. But really just outline for families with the particular routine that's targeted, here are the materials and here are the key steps you have to think about as you go into the process. We're trained to keep this as simple and user-friendly and fun as we possibly can.

So we have another poll here at the end of this piece here. Haylee is going to put this up for us. And we asked the question of what are the routines for which you’d like additional support in the home. So we'd like to get some feedback certainly from families. We left this open-ended for a reason.

>> SUSAN BRUCE: If you're aware of family needs, it might be fun for the professionals to also indicate the routines you've been asked about by families.

>> TRACY EVANS-LUISELLI: Hillary, in the chat, from Texas, had a great idea about an extended template that will allow the instructor to easily gather data related to the goals and objectives within the routines when they can observe it. Absolutely. We may be focused on one goal objective but you may refine for about that covers another area that we to think about. So, bath time. Ready to do learning activities. You know it's interesting, I think our fields focus so much on activities of daily living from years and years and years ago. For students who are deaf-blind, I think we've really stepped away from that. It's probably one of the biggest areas parents ask us for support on. Especially toileting. We've been trying to do a lot of investigation about where folks are around strategies for children who are deaf-blind around toileting. A lot of the literature is extremely old. Thank you. That's really helpful.

Okay, alrighty. Then finally just, this again is a work in progress thinking about shifting. I do think that a lot of parents give us rich information just in basic interview question and answer, what's working, what's not. Some families have offered videos and sent those in. Sometimes it works great. Sometimes the consistency with that is a little hard given what we're doing. Then, some of our formal data collection. So again matching that approach to the individual needs and desires of the families that we work with. We're looking at coaching, it started off in that direction. But again we are trying to figure out how to modify and some of it for families given where we are right now.

Really quickly, think about with impacted school, I think if families and providers can thinking those skills that occur in both settings, I have a child who can't get on the bus until they lift that knee up onto the front step, and he has kept many a long line of cars behind him and sometimes kept his mom from actually getting him on the bus. So if that's the skill that's really important to get him to school, think about how that can be performed or at least addressed at home if he's at home right now. So just thinking of how to make that bridge back to school, hopefully, when that comes in the fall. So, Susan, why don't you take this away.

>> SUSAN BRUCE: All right. Thank you, Tracy. So I'm going to talk to you next about schedule which certainly relates to some of the earlier slides. Schedules represent the activity, selected activity of the day. And like routines, they help bring predictability to the life of the child who is deaf-blind. And this predictability, then, creates a greater sense of emotional security because you know what's going to happen to you. So each of us have a different tolerance level, I think, the range of tolerance levels among us if you will, for how much surprise we appreciate in life. But we probably wouldn't want as many surprises as many of the children who are deaf-blind experience on a daily basis. So deaf-blind and emotional insecurity go hand in hand.

So when you have a daily schedule or anticipation shelf or calendar system -- three terms we use in our field -- it helps you know what to expect. It helps you know when your preferred activities are going to come into play in your day. Just like you and I create a to-do list and some of us put all the difficult things in the beginning. That's not a good thing to do with a child who is deaf-blind. But interspersing those activities, but knowing when those are going to happen is helpful to all of us in our day-to-day work life, for example, or in school or home life. It is easier to practice self-regulation skills when you know what to expect. So if you know a preferred activity is coming and you've got to do two more things that you don't like so much you might be able to control yourself a little better because something wonderful is coming up very soon. Aside from the reinforcement that the parent or teacher may have built into a particular activity, our schedules are literacy lessons we can practice left to right, top to bottom, if you use two rows within your schedule, sequencing, which relates to literacy and concepts such as now and then and had finished. And all of the words and representations, whether they are objects or pictures within the schedule.

So schedules are a good time to work on key vocabulary. We want to make sure that we select our vocabulary carefully, that we label representations with that vocabulary so adults do the right thing, meaning that adults will do the same thing so we are consistent to support the child's learning. Repetition is very beneficial for the children we serve. Creating, setting up the schedule with each child and doing the of whatever you preview of whatever it is you're focusing on, whether it is a schedule within the school or for that a particular routine as Tracy talked about today. It's good to preview it and it's nice to review the all finished/all done box which we rarely do. The schedule provides us with daily opportunities for conversation about the daily activities. I love this memory when I approached one of my students who is deaf-blind many years ago. She had taken off a bunch of markers off her daily schedule. I paused and I recognized she had taken all of the independent lessons off her day and she had kept all of those which were interactive with other people. It's just such a meaningful memory to me. Then I had to figure out what to do. That part of the story wasn't so great, but it is still a meaningful memory.

We have now and finished as a beginning point then maybe we add another step and at now and then or next and then finished. We could do a larger sequence. We can build concepts and make the vocabulary more complex over time. And we know that we can use objects, partial objects, pictures, line drawings and so forth, print and Braille being very important in our schedules. So this picture is an example of a first and then board with the child first goes the bathroom and then the Legos.

Haylee, would you go ahead and put up a poll 6 for me, I missed one. This one asks have you already implemented a daily schedule for a child who is deaf-blind? This could be in a home or a school setting. Wow, look at that. I will wait for responses. Okay. So it looks like 84% of you have, roughly, and implemented one and roughly 15 to 16% have not yet had that wonderful opportunity but you will soon. Thank you, Haylee, I appreciate it. First and then is one type of schedule. Another type or another part of the schedule that's important is the finished/all done bin. Please use the term that the family prefers. I have met families that highly preferred finished and others the highly preferred all done. We should use what the family prefers.

This is an example in this photograph of a schedule using objects. You might prefer to mount the objects before you place them on the schedule board, individually mount them. I will tell you that mounting helps some families distinguish when an object is an object and an object is a representation. If the child also has autism or autistic characteristics that may be particularly important. You may have to think about children who also have autism using a vertical rather than a horizontal display. Otherwise, visual impair, we tend to go[indiscernible] as you have so much experience I'm sure you know already.

This one is using the term routine more as Tracy has been using it today with morning or evening routines. You can see they have paired the [indiscernible] line drawings with color and object or presentations, as well. Perhaps this child is transitioning from one type of representation to a more abstract repetition. So we see something that combines forms or modes of representation in this slide.

This next slide do something a bit more unique. It shows a couple of activities, four activities, actually, and it uses top to bottom, not just left to right, which could be for some children [indiscernible] easier for access and engagement. Then they have added more and help so the child could use those representations when needed.

So that's about making schedules. And I said for your child because I was thinking of parents. But these ideas apply in schools, too. The quality of the schedule is actually pretty important. How we construct it is important. So we want to create a schedule that is at an appropriate level for a child so it is appropriate to begin with a now and then or now and finished and add to it as the child gets knowledge and skills. Keep it simple but appropriate to the child. If you're in the family home, use materials from your home. If you're using glue to fix things please be careful you don't have a lot of gluey-ness or messiness so when you're integrating into touch you will associate the touch of glue with the objects. We want to remember when we affixed objects whether we are doing it through mounting or any kind of a mounted surface, it changes the nature of how you experienced the touch because we've lost little bit of that three dimension. So we want to be thoughtful about what it feels like, thoughtful about touch.

So again, we could start with now and finished and become more complex. We might consider mounting things or representing them on high contrast background. We night need to consider slanting the schedule or putting it on a tabletop to consider the child's field of vision.

Then I want to hit the concept of saliency. This is one of my things, I will tell you that. Saliency means we turn off our own perspectives and we really observe the child. Sometimes our vision distracts us. We tend to think about what's important about an event by what we experience. Oh my gosh. What we thought. No, no, no. Saliency is about what was emotional, what was exciting, what was the child most engaged in? It's from the child's perspective that we then select a representation, whether it's for an experience bucket -- which I will talk about in a moment -- or for the schedule. Make it real from the child's perspective. And if you select from the commercial options that are available, you will select based on saliency and augment with some that are teacher or parent made [sounds like] then.

So using the schedule in the home same as the school, you set it up with your child and then the activities. Then you guide your child to experience the daily schedule and the left to right sequence. Begin at the far left every time. You cannot take the child's hand and put the child's hand in the middle of the schedule because then you have lost that sense of the day goes from the left and right. Basically, what the child will begin to understand is that the first thing that they've touched is the thing they are going to do next. It will just be about level for quite some time and that's fine. And we will use consistent names for each activity. We will allow time for the child to handle the representation of the activity, because they're trying to figure out what it is and what it needs. They can take the representation with them to the next activity and return with that representation in place it in the finished box. I'm not suggesting they're going to hold onto at the whole time, maybe even have a little place on their wheelchair or on the table for them to put it to place and while they're doing the activity and to then they take it back if there, in a separate room and return it to the finished bin. Each trip to the daily schedule is an opportunity for a conversation. Each trip to the daily schedule is a literacy lesson, not just a transition tool.

I provided you with some links to some nice video resources that were done by various teachers at Perkins and they show various different kinds of anticipation shelves, daily schedule calendar systems, that I think you will gain a lot of information from. You may have discovered them before I did. These are really, really well done.

Parents, then, I want to talk... before I do that, we want to do another poll. Thank you, Haylee. Poll number seven, do you feel ready to implement a daily schedule for a child who is deaf-blind? Wow. Everybody feels ready. You probably were ready before you heard the talk, but I am glad to hear this. This is good. We can always improve our implementation though. The numbers are changing a little bit.

>> TRACY EVANS-LUISELLI: I think it was percolating about a bit. Now people are just adjusting their frequency.

>> SUSAN BRUCE: Early in my career one of the common questions parents would ask even if it's in regard of the common settings. The question was do you have to show all the activities? The answer is no. It's too much to have 20 activities, especially if they're in an inclusive setting. Some people do an a.m. and a PM when they’re at the school and at the end of the day they do a review. And of course you can have many schedules within a routine like a play setting.

>> TRACY EVANS-LUISELLI: We have a question here I don't know if you can answer. That's still having difficulty choosing objects or modes of representation for the calendar. Do you have any advice on that?

>> SUSAN BRUCE: Saliency would be the number one thing. Considering I think the child and any issues they might have preferences around the touch would be another. Thinking about textures and so forth. Diane, do you want to tell us a little bit more in the chat about what you're asking? What the difficulty seems to be? She's typing. Tracy, did you have something you wanted to add while Diane is typing?

>> TRACY EVANS-LUISELLI: I really think your whole notion around saliency is where, again, but in order to get to that point, you have to do a lot of observation and a lot of interviews, a lot of questioning around why is the child doing this or not doing that. I think the whole notion of saliency is really important.

>> SUSAN BRUCE: Yes. So we're thinking about a representation for using the bathroom, we would want to think about what bathroom time or bathroom routine means for child and it's a good presentation, a piece of the Depends, or do we not put that on the daily schedule? I think people use tiles, but a tile isn’t helpful if a child doesn't touch the tile when they enter the bathroom on a regular basis. It's about what they touch or they see. You think about this through all the modalities, I think.

So Diane is asking, what my daughter understands the object to be. Ah, you have hit upon one of the great debates on the field. This could take us the rest of the time. I can't go into it too much, but I would love to have a conversation with you, Diane. We could have a Zoom meeting on this. We have people within the field of special ed and even deaf-blindness right now are promoting the idea that you can use their abstract representations with children who do not understand abstract representations and they believe that with practice all children can learn those representations. Other people do not believe that. So that, in a nutshell, and I hope I didn't sound too biased, we never want to use what we believe about somebody's level of communication to limit their opportunities, so I'm not suggesting that, at all. But that's like a topic for another time, although it certainly relates. So I would invite you to send me an email. I would be happy to have a one-to-one chat with you on that one, then you can make up your mind on what you want for your daughter. Okay? All right.

So parents are critical to building experiences. Like an experience record, if you will, for the child. So we share a story at school where the parents share a story or, this has happened to me when I was teaching in the classroom, the psychologist wants to come in and wants to do a reading assessment, well if the child who is deaf-blind hasn't had that experience, thinking of the text whether they are reading it for themselves or experiencing at auditorily. Children need experiences and it's the families that provide that, much more than we do at school. And during those experiences, the child needs to be as actively engaged as possible. This needs to happen from the time they’re born, from infancy. And we need to think about the vocabulary that we use, certain vocabulary are repeated. That could be in a pause before and after a key vocabulary word -- and when I say word I mean it could be assigned. It could be voiced and signed. It is important, also, that we think about how to share these experiences later with the child and not only in an accessible but engaging way. I’ll talk with you in a moment about experience books which can be created at home or in school, and I know many of you have done that already. But I would suggest as parents, ideally would keep a record of experiences their child has had and think about that in terms of literacy. That information would be extremely helpful to school professionals to know about the child.

We're not able to share video through Adobe, and I have shared this video before in some talks. Haylee was kind enough to get this set up on YouTube and we had mom's permission earlier to share this. So I invite you to take a look at this wonderful video, a favorite of mine, of Colby and his mom what I think he was 8 or 9 at the time and she worked with him on the concept of small, smaller, smallest. Big, bigger, biggest in the context of him pumping up a balloon with a balloon pump. I'm in the background with a camera hoping this thing isn’t going to burst when it gets to the biggest stage. But the point is parents are the ones that ground these concepts that all these extra things this mother did over the year and long before we were doing some of them in school, she didn't just reinforce, she introduced ideas, they were so critical to his learning. So she kept him actively engaged and experiential. So it's not just words or eventually learning the Braille for the words. It's feeling the balloon get big, bigger, biggest and small, smaller, smallest. I invite you to take a look at that. It's on YouTube. You can use that in teaching for families can use it to think about experiences.

So that segues into talking about experience books, sometimes we call them experience stories. These are books that are individualized to a level that understandable and useful to the child, but they are also personalized. Separate out those ideas of individualization and personalization. Personalized means it is about the child's experience. The child's lived experience. And again, this concept of saliency, what the child's perspectives are, not ours. What was the trip to the park about for the child, not for us? We create these books with the child or young adult and we think about sequence, we think about representations in much the same way we think about them when we use them in the daily schedule. And relabel and print in braille for the child or young adult so that other people who are sharing the book with the individual who is deaf-blind will be consistent in their use of language, which will help the child to gain communication and language skills.

These personalized books are important because they are triggered memories for the child and also, I think, helped to build memory in the child. We want to share these experience books in environments other than where the experience initially or repeatedly took place, because this will help them build something we call concept of distancing. Learning to use object representations will not take you to language, in itself work to be linguistic. It does not. You must also be able to have conversations and think about things a distance. So abstract representation is part of it but not the whole piece of it. So the whole of it involves being able to have communication, share communication with another in a separate time in a separate place from where events occurred. So this is what distancing is and we can very systematically help the kids who are just deaf-blind to develop distancing and this has been written about by Warner and Kaplan, renowned psychologist. Van Dyck attended to it at little bit but not so much as they initially did. This is really important for someone to build and embrace [sounds like]. The child should increasingly assume more responsibility for reading and writing overtime. Initially it might be gathering the objects and putting them into the book and fixing them to the page. We should also store these experience books that are highly personalized in a place where the child can locate them. If the child has some means of independent mobility, then the child will want to go and find them and perhaps bring one to mom or dad or to a teacher to share with them. So knowing where they are is helpful to the child.

Then, I have some sample they just happened to find in Google images. Here's one on a tree with leaves and their actual leaves, not fake leaves from the fabric store. Then, this one is a sample page from a book about the seasons. It says, "And I wear my sweater because it is cold." The next one, "I celebrate my birthday." This would be a good representation only if the child had an opportunity to touch a candle. Maybe the child helped a parent place the candles on a cake or cupcake -- hopefully not when anything was aflame. But the point is, what represents the birthday must be meaningful to the child, so candle is good only if they experience the candle.

Pay attention also to what excites them and what their emotional reactions are. We tend to remember things that are more emotionally charged. This third page it says, "In the spring I plant flowers." In this case they did use some artificial flowers because it's probably not practical to use real ones.

So here are some experience books and then we will do a poll. Experience books ideas during COVID. You can create a book about walking in the neighborhood. I noticed there are some people doing books about wearing masks. Visiting the Park. Maybe something about sharing a Zoom session with parents and helping children understand or visiting with grandparents is different, now. You can have a story about building something in the home so it relates to something that was very active and the child was engaged in. You could have an experience book around the home routine or a favorite evening activity. You can have a book about a visitor in your home. You can have a book about a trip in the car perhaps to a favorite location. You can have books about going to the dentist or going to the doctor to help prepare your child for those kinds of experiences. Haylee, could you go ahead and put up poll number 8 for us and I will go ahead and take a look at the chat here.

Megan I see your comments about that dangerous topic stepped into a little bit. I just want to acknowledge that. [LAUGHS] It's around professional and parent decision-making, I think. So, do you need more information on experience books. Oh.

>> TRACY EVANS-LUISELLI: It looks like they've got good background here, that's good to know.

>> SUSAN BRUCE: Yeah, it looks like 80% feel in their ability to implement or at least create experience books and do not need more information and about 20% do. Thank you. Haylefe, could you go ahead and end that poll, then? Okay. And Tracy, I'll turn it back over to you for the final thoughts.

>> TRACY EVANS-LUISELLI: Sure. Again, as we progress and kind of go into this new journey into the school year and the fall, I think our focus is really how we can develop a collection of home routine templates that really can be utilized across a variety of children's situations, families and cultures. So that's a real major goal of our work moving forward. Then, newly thinking about how we can put parents in the driver's seat as their children returned back to school, I think as parents feel confident around the use of consistent home routines, that they're going to be able to provide such rich information back to the educational team as the child transitions back to the school setting. So those are our dreams as we move forward, for sure.

This next item I think, I know I'm preaching to the choir on a lot of different levels here, and I know how time-consuming it is. But we certainly know that collaboration with all of the key team members is so, so important, to really make sure that we provided that structured, individualized support around those different categories that I mentioned. Your TVI, your TOD and your SLP I think right now are certainly, I'm not going to call them the holy trinity, but I would say they're extremely important as you move forward and we individualize instruction. Then if folks could really take away, I would say, is to keep it simple, as simple as possible and concise and really trying to encapsulate over shorter period of time. Then any final thoughts, Susan, that you have around daily schedules and experience books that you would like them to [indiscernible]?

>> SUSAN BRUCE: When I think about the daily schedule, I try to emphasize with you the idea of being thoughtful about what you choose as representation. And, being thoughtful about how to support families in creating daily schedules and mini schedules are good, too. And experience books, let me pause there a minute, I think sometimes about how often as hearing, sighted people, we hear shared stories and see photographs or videos -- for those of us who are young enough to have had videos made of us, I'm not in that group -- children who are deaf-blind do not have as many of these learning opportunities to hear and see these experiences represented. So, to me, these experience books about their own lived experiences are very critical in terms of building memory and in terms of sharing with others and also to this whole process of building distancing to support them to develop language and become linguistic. Tracy?

>> TRACY EVANS-LUISELLI: So with that, with final thoughts, again, I would just like to thank the families that we've encountered over the last several months. You are our heroes. If to say lot along the way about where we were going and where we need to go now. Because I think we can't continue to operate in the same way. But I think that the material we talked about today will really help put parents in a more sort of front view as we look at supporting children, learning and growing at home as well as in schools. To you, again, special shout out to Talia Mango, who has helped me with a lot of these materials. Haylee Marcotte, you've been wonderful supporting Susan and I and thanks again to NCDB. We have references here for you.

Then, a fun poll to end the day with if Haylee can bring this up. We want you to come away with a smile on your face and think about what’s the first thing you're going to do when we are safe and COVID is over? We'd love to get an idea of what folks are going to do. That would be great to get your thoughts.

>> SUSAN BRUCE: I just posted an email address because I think there’s a chat that I might have missed and we might get cut off before I have a chance to answer, so please do feel free to email if you have questions. And here's our final poll, what's the first thing we are safe and COVID is over?

>> TRACY EVANS-LUISELLI: Beach party! I'm with you there, Susie. And a beach vacation. Hugging a family member, I am going to hug my daughter.

>> SUSAN BRUCE: It looks like vacation and hugging.

>> TRACY EVANS-LUISELLI: Red Lobster. You can come right up to me to Maine, right on the side of the ocean. Susan and I keep talking about going on a whale watch.

>> SUSAN BRUCE: Last year I broke my shoulder [sounds like] this year it's COVID.

>> TRACY EVANS-LUISELLI: Thank you everybody, this is a real treat.

>> SUSAN BRUCE: Thank you so much.

>> TRACY EVANS-LUISELLI: Don't forget the evaluation quiz.

>> LINDA MCDOWELL: Thank you Susan and Tracy, we appreciate the information. A lot of people are voicing that in the chat. We are going to leave it going for a little longer so you can see how grateful people are.

>> SUSAN BRUCE: Thank you.

>> TRACY EVANS-LUISELLI: Okay, Linda. I think we will get some feedback and we'll move along. But thank you so much, NCDB and all of you for guiding us through the process and the technology and such and like I said, it was a real treat.

>> SUSAN BRUCE: Thank you very much.

>> TRACY EVANS-LUISELLI: Goodbye, now.

[END TRANSCRIPT]