Back to Basics: Down Syndrome

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- [Amy] Once again, welcome to our webinar today, Back to Basics: Down Syndrome. Our presenter today is Dr. Theresa Bartolotta. She's a professor of speech language pathology at Monouth University. She's an experienced pediatric SLP who specializes in working with individuals with complex communication disorders, including autism, Down syndrome and Rett syndrome, and her courses are always excellent, so we're very pleased that she's back here today to talk to us about Down syndrome. Theresa, welcome.

- [Theresa] Thank you very, very much, Amy. I'm really happy to be here again. I love working with SpeechPathology.com and all of the attendees and I'm talking about a topic today that is really very close to my heart. I've worked with individuals with Down syndrome over most of my career, and I'm really excited to see the interest in this topic, and I'm so pleased that there's so many SLPs on today's webinar. So, I'll begin by talking about, I have a financial disclosure and then I'm receiving an honorarium for today and I don't have any non-financial disclosures. These are the three learning outcomes I've identified for our participants.

After this course, you'll be able to list the characteristic features of communication disorders in individuals with Down syndrome, talk about the influence of motor planning problems on acquisition of speech and identify effective treatments for speech and language disorders in this population. So I'll begin today by covering just some basics of Down syndrome overall. I'll talk about health and wellness issues, some principles of communication challenges and then we'll spend a good amount of time on intervention, and I'll end with a case study about a young woman who has Down syndrome who is now 19 years of age and who I've had the pleasure of working with since she was just about one year old. So, to begin, let's just review. Down syndrome is the most common genetic cause of intellectual disability, and, as a review, the cause is a genetic error. There is a, an error occurs during the early cell division when extra material, either an entire chromosome or a partial chromosome gets added onto chromosome 21, and so the other name for the disorder is Trisomy 21. So the prevalence is estimated at being occurring anywhere between one in 1,000 to one in 1,100 live births worldwide, so it is fairly common, certainly not as common now as we see autism, but there are other syndromes that we as SLPs deal with. I work a lot with Rett syndrome, and Rett syndrome is fairly rare. It occurs in approximately one in every 10,000 female births, so that's an illustration of how much more common Down syndrome is.

There are some risk factors for Down syndrome. The primary one is increased maternal age and the risk really jumps up as the mother gets over 34 years of age. Each year, there are approximately 6,000 children born here in the U.S. with Down syndrome, so that means there are about 250,000 families who are living with a loved one who has Down syndrome. We've got great news to report with regard to overall health and wellness for the population. In recent decades, the life expectancy for individuals with Downs has increased dramatically, which is such good news. Most individuals with Down syndrome who are born today will live well into middle age or beyond, and that's just such a good news story, and probably a lot of that has to do with improved early detection of Downs syndrome, and especially of challenges, health challenges that would increase mortality, and the primary one there is cardiac issues.

So approximately 50% of infants with Down syndrome are born with some type of congenital heart defect. For some of them, the heart defect will resolve spontaneously in the first few months, so they just have to do watchful waiting. For some children, they may have had surgery while they were still unborn, while they're still a fetus. Others will require surgery after birth. There's been a lot of talk recently about the occurrence of dementia in the population. What's important to know is that the risk of dementia is the same as in the general population. What is different is the age of onset, so dementia will occur anywhere from 30 to 40 years earlier than in the general population, so we're really talking about someone in early middle age, they, in their 30s or 40s, being at a very high risk for dementia, which is very young, and so then that is of course going to impact their independence and what happens with them as they age. Many individuals with Down syndrome today can live independently or with some support, say in group homes or some kind of supportive living arrangement. I'm sure you're seeing many individuals with Down syndrome out in the community working in different kinds of jobs. Some are very independent. This will require a level of support, and we see lots of individuals participating in fulfilling personal relationships, and sometimes SLPs will be involved in that in terms of helping individuals understand about, you know, communicating about, say, personal safety, sexual issues that arise in relationships and things like that, especially if you're working with an older population. So, let's just start with an overview of communication development.

So these points I have gleaned from the current literature that's on Down syndrome. At the end of the presentation you'll see a reference page where I have the citations that I've used. As you'll see, the literature on Down syndrome specifically related to communication is limited, especially the more recent literature. I will suggest, however, if you are working with individuals with Down syndrome clinically, that you take a look at some of the earlier writings of Dr. Libby Kumin. Her references are not in my presentation, but she's got some great strategies for management of communication and the things that she's written in the last, say, 10, 15, maybe even 20 years, a lot of them are still relevant today, so she's a good person for you to take a look at.

So, what you'll see is that, as you work with individuals with Down syndrome, there's a lot of variation. There really is a continuum. For some of the children, oral speech and language will come more easily. For others, it will be very challenging and they may not be able to become functional users of verbal communication, so we would like to consider augmentative communication as early as possible. We can't really predict who's going to be an earlier talker, so AAC can really benefit by giving the child a way to communicate early, as well as helping them learn about symbols, so I would encourage you to think about AAC very early, and we'll talk later. So what are some characteristics? Skills are generally acquired later, so any kind of a skill related to communication, cooing, babbling, acquisition of first words, they're going to start much later than in typically developing children. As they move through the developmental stages, they're going to stay in these stages longer, so if a typical child might start talking at one and then begin to put two words together at 18 months, that means it'll take them about six months to acquire, say, a core vocabulary of 50 words.

It might take a child with Down syndrome 12 to 18 months to acquire first words through the first 50 words so that they're ready to move to combining words into utterances, so keep that in mind. There are particular phonemes and linguistic structures that are problematic, and we'll go through those, and then there are specific issues that we see that affect voice, speech sound acquisition, fluency and then intelligibility. So let's begin with voice. So, the cries of babies with Down syndrome have been demonstrated to differ from typical infants, and this is likely due to differences in their respiratory and laryngeal function. So, we've got possibly structural as well as functional issues. I'd like to add in here that there is usually a generalized hypotonia that affects the entire body, so a generalized hypotonia can affect respiratory control and then laryngeal function as well.

So dysphonia is a very common feature in Down syndrome. It's been documented that the fundamental frequency of children with Down syndrome is higher than age-matched controls. That's likely secondary to a smaller larynx, and their voices typically judged as breathy and rough. Resonance is often hyponasal, and we'll talk later a little bit about what's happening in the midface that will influence that. But generally, the nature of vocal problems are not well understood, and should require more research, but if we think about having a generalized hypotonia, then if the laryngeal muscles are hypotonic, then it would take a greater amount of energy to produce the phonation that is needed to support articulation and oral speech. So it's important to remember that there might be structural as well as functional issues that are occurring that can impact voice as well as other aspects of oral communication. So what I have here for you is we're gonna take a look at a short video of a little one-month-old born with Down syndrome. He's just now about two months old, so this is a fairly new video, and as we watch it, I'd like you to listen to his cry, it is high pitched, and his vocalizations, and then also take a look and see how highly responsive he is to his mom and, you know, we don't see her in the video, we just see him, but you can see that he's really making eye contact with her and very interested, so take a listen. So we'll go to the video now.

- [Mother] Hello, what are you doing? Did you have a good sleep? Yes? You have a good day? Who's the cutest baby? Give kisses? Where's your kisses? Kiss. Thank you. Hi. Hi. Hi. Oh, we're talking? My big boy. Kicking my hand. Are you kicking me? Kick kick kick. Kick kick kick. Ready?

- [Theresa] So we'll go back to the slides now, so. I hope you enjoyed that little video and you could hear his little voice. He's two months old. Fortunately, this pregnancy was monitored very, very thoroughly, and this little baby's very, very healthy. He does have some minor cardiac issues, but they're gonna do watchful waiting. I think what you can see is how responsive he is, totally very social, doing what we'd expect in terms of looking at his mother, but the responses are a little bit delayed. So now let's think about speech. So speech is gonna be influenced by perceptual, motor, as well as linguistic issues. As I said earlier, the onset of milestones are gonna be delayed, so while we would expect typical infants to be babbling around six or seven months of age, the onset of babbling is going to occur likely much later. As consonants begin to emerge, they are going to emerge more slowly, and then the mastery of individual consonants is protracted. Very similar to what I said earlier about moving through linguistic stages. As children begin, as phonemes emerge, children are going to take longer to master those phonemes. And particularly challenging for this population are lingua-alveolar phonemes, and they are more likely to be distorted. So you could think, what are the lingua-alveolar phonemes? So you have the t and the d, you have the n, you have the l, and then what is very, very hard, especially challenging are the s and the z sounds, and fricatives tend to be hard because of the specific control that is needed with regard to tongue movement and tongue placement. So these issues are occurring also because of the challenges of structural as well as functional issues. So if we think abut structural issues, the midface in individuals with Down syndrome tends to be small, so that's going to be the maxilla, the upper jaw, as well as the nasal area and the nasal cavity. So this is going to affect resonance. It can result in more hyponasal resonance because less air is going to be able to get up into that nasal cavity, and then it's going to affect the tongue size relative to the face and then of course the tongue position.

So, people used to the think of the tongues of individuals with Down syndrome were enlarged. They actually are not. They are of a typical size, but the tongue is large relative to the size of the oral cavity, especially with regard to the maxilla. So the mandible, which is the lower jaw, the tongue can sit in that, but as the tongue has to raise up and produce vowel sounds and any lingual sound, there's not a lot of space for the tongue to move, so we have errors with lingua-alveolar phonemes as well as vowels. If you remember from an undergraduate phonetics course, you remember that the vowel quadrilateral, the tongue moves anteriorly to posteriorly to produce vowels and then up high and then down low, and it's the combination of those two movements that result in the different vowels that we use in English. And so, children with Down syndrome are going to be challenged to produce those vowels, especially the ones that are the high, say high anterior or high posterior, because they're just not going to be able to have that room to be able to negotiate the movement of the tongue up higher, so we do see vowel errors are very common. So the easier vowels, like a schwa, like an uh, that's gonna be easier, but like an e, the high front or high back vowels are gonna be more challenging. To continue thinking about the face, the palate is high and shelf-like, so that does not give the opportunity for that tongue to come up and rest up with, say, the tip of the tongue on the alveolar ridge and the bulk of the tongue somewhat retracted, so that's also often going to result in an open-mouthed posture and a more forward tongue, which could also impact swallowing, so you may see some mild functional swallowing issues. We often perceive the speech of individuals with Down syndrome to be fast, and it may be, but also something you should consider is that they're having trouble transitioning from one phoneme to another, so what may sound like fast speech is actually speech that's produced where a lot of sounds are dropped out, so what we tend to see is we see deletions of syllables and deletions of ends of words, so syllables are not closed, so what you end up having is you end up having transitions from syllable to syllable or word to word are challenging for them, so they tend to delete those sounds, so the appearance is that rate of speech is very fast. Speech is going to take more energy to produce, just like we we talked about voice, because of that generalized hypotonicity.

Sound acquisition may not follow a developmental sequence, and this is specifically related to the phonemes that require lingua-alveolar production and then also lingual palatal. So in addition to the lingua-alveolar phonemes I've talked about, you'll see that the palatal phonemes like an sh, a ch, a guh and the juh sound, those are also going to be very hard and they emerge later. So the speech difficulties that we see in these individuals are likely to do with the confluence of these factors, multiple impacts from the anatomical issues, challenges in motor control secondary to hypotonicity, and we may have some motor planning. We'll talk about that in a second. And then of course the overriding cognitive linguistic challenges that are going to impact acquisition of phonological aspects of language. Fluency is often an issue in individuals with Down syndrome, and what we'll see is we'll see stuttering as well as cluttering. So stuttering is, the flow of speech is disrupted by repetitions, so repetitions, prolongations and/or stoppages of sounds or blocks, and those may be accompanied by secondary symptoms. Cluttering is a disorder that mimics stuttering, but has a little bit of some different characteristics, and that's where we have rapid and/or irregular speaking rate, as well as excessive disfluency, so the characteristic disruptions that we see in stuttering, and then as well accompanying linguistic chronological inattention problems. So cluttering is a disorder that will incorporate or accompany stuttering, but we'll see both of those occur more frequently in individuals with Down syndrome than in the general population. So the incidents of stuttering or fluency disorders in the general population is about one percent, and literature says fluency disorders occur anywhere between 10 and 45% of individuals.

That's based on different research, so that's a mean of 31%, so approximately one-third of your caseload of individuals with Down syndrome are going to have a fluency disorder, and these can be influenced by their motor control as well as some linguistic challenges. We often hear about incidents of childhood apraxia of speech, or CAS, in this population. Diagnosis of CAS in Down syndrome is going to be a diagnosis of exclusion, and that's because you have these other fundamental issues that affect structure and function that you have to rule out, because the impact of the hypotonicity and the structural issues on respiration, phonation, fluency, cognition and dysarthria can really mimic symptoms of childhood apraxia of speech, so I wouldn't rule it out, but I wouldn't jump on making a diagnosis until you have a large enough speech sample and you get to see a child speaking in action, because you've got to think about the specific articulatory errors, what is the influence of tone and are they presenting with fluency disorders.

The literature on Down syndrome is suggesting that there are generalized difficulties in praxis in individuals with Down syndrome, and this is going to be affecting their entire body, so you'll see apraxic-type movements affecting limbs as well as speech, and the challenge seems to be generating actions from memories, so you could have a central apraxic problem affecting all movements, including speech, so they may have symptoms that mimic childhood apraxia of speech, but it's not just apraxia of speech, it's secondary to a generalized praxis problem. So the best thing to do is to listen, learn, get to know the child, see how they are acquiring speech over time, and that will drive your treatment. Now language. As we said earlier, this is the most common genetic cause of intellectual disability, so we know that cognition is impaired at least to some level in this population, and cognitional language, especially in early periods, will develop in parallel, so the cognitive impairment is definitely going to be influencing the acquisition of language in the early developmental period. But two things to keep in mind is that imitation and gesture use are strengths in this population, so you can think about utilizing those and exploiting those as you begin to develop an intervention program for your clients.

So let's dig into some aspects of language and just cover what are some of the challenging areas. Vocabulary is definitely going to be substantially delayed. This is going to be influenced by cognition, 'cause knowledge about the world is going to influence how you know about words. So the acquisition of vocabulary is going to be delayed and then the understanding of the complexity of vocabulary is going to be impaired, so they're going to need more support and lots of examples and less complexity to fast map. So fast mapping is how you learn concepts, and that's how many exemplars or examples of a concept you need to be able to understand that word and what it symbolizes, so individuals with Down syndrome are going to need lots of examples and varied examples.

But the literature is telling us that repeated practice can help advance at least concrete receptive vocabulary to exceed their nonverbal mental age, so that means there's great potential for learning in the population. They are just going to need repeated practice. And this is very different, a different way to think than when I was starting out as a young clinician many years ago, when people were talking about individuals with Down syndrome having a ceiling in terms of their cognition as well as their language, and people were talking about not, there wouldn't be a value of continuing to work on speech and language acquisition, say, past puberty in the population, because they would ceiling, and we no longer see that. It is good teaching that really is going to help these individuals advance to their capacity. A huge issue in the population is phonological memory, and so that's your short-term memory of speech sound information, and that's going to help drive your phonological development, so how you acquire sounds and syllable shapes, and it's also going to help you with developing phonological processing awareness so that you can begin to decode and read. So phonological memory's a real issue in the population and can impact their spoken as well as their written language acquisition. With regard to syntax or grammatical structure, the complex structures are going to be the really challenging ones, especially receptively, so testing a child and asking them to understand passives or specific pronouns is going to be really, really hard. You'll see that as they acquire syntax, they're usually pretty good with nouns and verbs, but as they get past an MLU of 3.0 and they have to start using those Brown's Morphemes, those complex structures to connect thoughts, to code different tenses, you're going to see big challenges.

The acquisition of morphemes is delayed and this can persist well into adolescence, so you'll see adolescents with Down syndrome who actually are very, very conversational. You'll see Jordan later. She's 19 years old and it's been really hard for her to consistently learn to use irregular past tense. She can use it pretty consistently now in her spoken language, but her written language, she continues to make errors, so that's an example of challenges in morphological development. Pragmatics continue to be a strength for the population right from birth. They can convey same basic functions as typical children, so they're going to be requesting, protesting, commenting just like typically developing children. However, nuances of messages can be missed because their messages are often incomplete and that's impacted by cognition, and they're going to be challenged to make corrections or clarifications, so if their message to you is incomplete and you ask for clarification, they're going to have trouble figuring out what part of the message they need to give you, and vice-versa. If your message is incomplete, they're gonna have a lot of difficulties with asking you for clarification. Literacy. We see lots of individuals acquiring reading and writing skills, but their skills are definitely going to be impacted by some of those issues that I spoke of earlier, especially phonological memory.

So, now let's move into talking about intervention, and there's a real need for evidence-based interventions for persons with Down syndrome. The literature is very limited, but we can use evidence-based practices that we can glean from literature regarding other populations who have similar challenges. So, for example, we can use techniques that are used in children who have childhood apraxia of speech, we can use techniques to advance logical thinking in children who have cognitive deficits, we can use techniques that we might use with children with autism to establish, to improve emotional interaction and regulation.

So we can go to that other literature to help us develop evidence-based practices for this population. What has been reported is that many families feel that service provision is inadequate, and this is very distressing to read about, that families have reported that expectations of teachers and therapists may be low, so they may be going on that older literature that says there's a ceiling, and so families are feeling that expectations, and then ceilings, are set low, and so I think that we need to do our best, certainly we need to do work that is showing benefit. We always have to demonstrate that our services are effective, but trying to go in with a more open mind and thinking about possibilities, I think, can help the population very much. So here are some basic principles as you approach the individuals you work with who have Down syndrome. Begin with thinking about hearing. We know this is fundamental to learning spoken language, and babies and children with Downs have a very high incidence of otitis media, which impacts hearing. Be vigilant, that after they have an episode of otitis media that the fluid does not remain in the middle ear space after an ear infection has resolved and that it is cleared, so work closely with your families, make sure that they're following up with the pediatrician or their primary care provider to make sure that that middle ear space is clear. As the midface is slower to develop, the eustachian tube that's in the back of the oral cavity is going to be more parallel longer than in typical children, so that's a structural impact that can increase the incidents of otitis media. Also that, because the oral cavity tends to be smaller, if you have the oral cavity taken up with a lot space by tonsils or adenoids, the eustachian tube may not be able to be open and it may close more, which then can result in a imbalance of pressure in the middle ear and result in middle ear fluid, so we want to be really vigilant about that. Breathing should be a primary concern when we look at tongue position. If the child is presenting with an open mouth posture and the tongue is low and forward, we need to think about why, so work closely with your otolaryngologist or ENT to make sure that tonsils and adenoids are not an issue, because if the tongue is low and forward and they can't maintain a closed mouth posture, then that's going to, of course, impact all aspects of articulation as well as resonance.

Provide lots of multimodal stimulation. Think about visual, auditory, tactile, because they are very visual, and repetition. The literature is showing that concepts can be learned, but they require lots of exemplars, so keep that in mind. And a general principle is that early use of AAC can really help acquisition of verbal speech, and we have to convey that message to other providers and to families so they know it's not going to limit the acquisition of verbal speech and it's also, it can help them learn, and that also we're not giving up on verbal speech, which is something that I hear families share their concerns about. So don't delay AAC. It can always be faded or discontinued as verbal language is acquired and the child develops a functional vocabulary. So you know we have aided versus unaided AAC. For unaided, we use gestures or sign. Lots of individuals with Down syndrome start out signing. This is because imitation is a strength, gesture use is a strength, so we can capitalize on those by going to sign. They're very visual, they establish joint attention. You saw that with the little infant. They can establish joint attention very early, so lots of families are really open to using sign. My experience is that most of the individuals I've worked with who've learned sign will not acquire more than 20 or 30 signs before that is faded and they go to verbal language. For the other individuals for whom verbal language has really been a struggle, we'll introduce aided AAC then before further expanding the sign vocabulary, because so many individuals in the community are not signing and so the audience they can communicate is limited. So you may start with sign early on and then see how the child is learning and you may move to aided AAC if needed, so you can use a non-electronic communication board.

Some people use PECS, but be careful about using PECS, because you have to consider the motor skills. I've seen some children with Down syndrome who've been very challenged to pull those symbols off the, you know, the velcro strip and hand it to their communication partner and so adding that motor requirement has really been a barrier for them. Lots of children are using simple apps, AAC apps on iPads. Those are fairly low cost. And if dedicated AAC devices are considered, usually, they're considered on a more permanent basis for someone who may not be a talker because of the financial requirement, but that's just some guidelines. You definitely want to evaluate each child individually, have them seen by an AAC expert and work together on what might be the best system for the child and their family.

Things to remember about AAC, that we have to include training on how to use it for meaningful communication. It's not just about touching icons or signing, it's about interaction, so utilize multiple modalities, we all do, and consider adding communication partner instruction to enhance your interactions. Data is showing us that AAC programs that include partner instruction are very effective, especially for children with developmental delays, and a meta analysis that was done in 2015 had identified skills that were most frequently targeted in successful communication partner programs and that would be aided modeling, like aided language stimulation, expectant delays, so providing lots of wait time, letting the child know a response is expected, and that can really especially help with somebody who has a praxis problem or motor planning difficulties, and then offering open-ended questioning so the child has lots of different possibilities for their response. Speech. I would say the data is showing us there's no ceiling on improvements. Skills can continue to improve over the lifetime, and as your clients get older, they will demonstrate better self-monitoring and then they can work on their speech. You'll see that with Jordan. We have a little phrase that she said, she has to speak slow, clear and loud, and she's memorized that and she uses that little reminder to try to become more intelligible. So, you can use techniques that we see in the apraxia speech literature. Begin with single syllable or syllable approximations and then move to rote phrases, phrases that can repeated in multiple contexts and using carrier phrases like I want or I see or go plus noun, common verbs and then adding a noun on. If we want to improve motor learning, we need repeated practice, so drills are critical.

We can do that in play context with young children and then move to more structured practice as they get older. Pacing boards, which we've seen lots of populations with motor impairments use, work really well. You can begin with a visual like I have on the screen and then you can move to something that's unaided. With Jordan, we started with a board like we see there and then we moved to have her tapping and counting on her fingers so it was more private and she didn't need an aid. So techniques that provide tactile input may really be helpful, so think about the PROMPT program.

As I said earlier, interventions that are targeted for apraxia of speech may really help with motor learning. Integral stimulation is one. The data is showing that if we start with high intensity practice, and you can even begin with non-sense targets, so say consonant vowel syllables or vowel consonant syllables that approximate real world reference. So you start with the expectation of bah for ball or guh for go and that may result in improvement of speech control. So with regard to language, we say the same thing about language that we say about speech. Vocabulary and syntax can improve over time. For early language stimulation, you might wanna think about programs that we see for children with specific language impairment or developmental language delay or even autism, so Milieu communication training, the Hanen programs and functional communication training all can be very helpful for individuals with Down syndrome. As I said earlier, those syntactic aspects are going to be hard. Think about your Brown's Morphemes, using tense, using plurals, and then, as they get into an MLU of over three, approximating four, they're going to have to use connectors like and, because or so, use multiple examples and do explicit teaching using repetition. That's going to help, especially, because of the cognitive challenges that these children will have. And use reading and writing as a tool to improve your verbal language.

Think about pre-literacy strategies that we introduce to children with specific language impairment to help try to mediate some of those later reading problems they might have. Let's do the same thing with this population. Introduce print early, especially since they are so visual. Remember we said that phonological memory is a challenge, so address that early on and very directly. With a young child, you can get into things like songs, early vocalizations, imitation of sounds, getting them used to paying attention to that phonological material and doing repetition, so you can begin with drills and then increase complexity over time.

Cognition is going to be a challenge. Their ideas can be very literal, and we know that in early language development and play language develop hand-in-hand, and the play of children with Down syndrome may be simplified and it may be harder to get them to those higher levels on symbolic play. So you can use programs to advance logical abstract thinking and one of the programs I've used very successfully is floor time, which is part of the DIR program, Developmental Individualized Relationship-Based therapy that has come out of Stanley Greenspan and Serena Wieder's work with individuals, with lots of individuals with autism, other populations as well, but this is a relationship-based therapy that's based on emotional engagement and relationships and really can help advance that logical, more complex thinking that we really need to help these individuals move as far towards that they can. So now I'd like to talk about Jordan. Jordan is someone that I said I've known since she was 12 months old. I've worked with her on and off over her lifetime. We began by using sign language with her and her family exposed her to lots of videos for word learning, alphabet, signs and songs. She was very visual. We transitioned her away from signs, so we started with sign, always paired with verbal speech, and as she began to form two to three word utterances, her sign was faded and that was completely gone by about age five, and all through her life so far we've had a continual focus on improving her word knowledge, her comprehension and the clarity of complexity of her spoken language. So her goals that we're working on right now are to continue to improve her speech intelligibility, to improve her ability to communicate in conversation, work on grammar, vocabulary and how to answer complex questions.

Jordan is now taking more responsibility for her goals, so for example, if she's trying to write and she's unsure about how to spell a word, she's asking Siri on her iPhone, and that's also an oral speech challenge for her, because Siri has to understand her in order to be able to come up with the right word, and it's interesting to watch her. She'll say, hey Siri, how do you spell, maybe say, reason, and if she says reason unclearly, Siri's going to give her the wrong word. I mean, Siri makes a lot of mistakes, we all know that. But Jordan will say oh no and then she'll try again, and you'll see how she'll say her words more clearly, so she's got good self-monitoring strategies and she uses a slow, loud, clear phrase that we've worked on. We've been really challenged to try to work on her problem solving skills to get her to have more complex conversations about new topics and express a higher range of ideas and emotions. So what I'm gonna show you here is, this is a video clip of a session where I was trying to get Jordan to engage in a conversation with me about a trip that I had taken. So her goal was to prepare a list of questions and we were supposed to have a dialogue about the trip. So you can listen to her asking the questions, but also think in the back of your mind about how conversational is this and is she really trying to share new and more complex ideas. So now let's go to the video. Yes, okay.

- Did you go fishing?

- Did I go fishing? When?

- In Europe.

- When I was in Europe?

- Yes.

- No, I didn't.

- Did you swim in the pool?

- Did I swim in the pool? There was no pool in our hotel.

- Did you go to eat?

- I did. But wait, how about, don't you want to find out about where I went to eat?

- Yes.

- Okay.

- So where did you eat?

- So guess what we did. Every night, we ate at all these great restaurants.

- Next question.

- Nope, Jordan, don't you want to talk about it? Okay. So every night we ate at all these great restaurants.

- Okay.

- So I had really good food.

- What kind of food?

- Oh, okay, I had lots of fish, I had halibut. I had clams, I had mussels.

- Shrimp?

- I did, I had shrimp. Yeah, I wanna know what you think about shrimp.

- What?

- I wanna know what you think. What do you think about it?

- Tastes very fishy.

- Tastes very fishy, but.

- But good.

- Yeah, especially if you put it in a sauce or a cream.

- Put it in ketchup.

- Ketchup? Or you know what, I like cocktail sauce.

- I like it in ketchup better.

- You like ketchup. You like shrimp and ketchup? Uh huh. And we had lots of cheese and bread. And it was great.

- Next question.

- [Theresa] Okay, so now we'll go back to the slides. So, as you saw there, I hope you saw there that she's very interactive. I'm sure you saw her articulation there, she has lateral sh, lateralized ch and you'll see that she's not doing a lot of monitoring in that conversation. She's prepared these questions on her own, but you'll see that she was having difficulty with maintaining a back and forth flow. It was hard for her to, after I gave her an answer, come up with a new idea, so that's something that we're trying to continue to work on. So one of the things that I had added to her intervention was to add DIR, because I wanted her to be able to advance her thinking so she could come up with her own, more complex ideas. So using this kind of a model, you work with a child in play and you help push them through to advance their thinking using certain techniques. So, there's a lot more about DIR and floor time, but these are some basic strategies. To pull back and wait, so give lots more wait time. Say less, try to give her time and space to develop the complexity of the play and the situation, and then really think about the affect of the situation, so this is something that as SLPs we're not always thinking about, but I found that taking courses in DIR really expanded how I thought about emotional engagement and how important it is for communication, and also how it can help advance logical and complex thinking. So I was really working, I've been working to try to expand her emotional range and introduce conflict, because Jordan would typically have a very low level of play, so if we were playing with dolls, everything would just be fine and dandy and not like real life at all, so I tried to introduce conflict, and so in this particular scene, and Jordan is actually the one who did the bullying. Her doll, my doll's been bullied by Jordan's doll and my doll is very sad. Now, and Jordan just wants the dolls to move on and my doll not to be angry and not to try to push through and understand why, so instead of just going with her, I stuck there and you'll see in the next video that I protested and really stayed there and Jordan finally gets it and you'll see how she handles this. So let's go to the video. She put paper on my head!

- Sage, why did you put paper on Josephina's head? Um, I felt like it. Then don't felt like it. Sage, go please apologize to Josephina so she'll be friends again with you. I'm sorry Josephina about what I did.

- I don't feel like you're my friend.

- Wanna be partners on our project?

- Yeah, but now I feel like I can't trust you.

- Well then I'll get a different partner.

- You're gonna pick a different partner?

- Yep.

- Oh, you're even worse than I thought. Now you're just going to be with somebody else?

- Yep.

- Oh, you're not a nice person.

- Now you walk over and push Sage.

- No, you're not a nice person because now you don't even really want to be my friend.

- Yeah. Let's go to our lockers and both have friends.

- Yeah, I still don't even know if I trust you.

- You know you trust me, will you sit next to me on the bus?

- What?

- Will you sit next to me on the bus?

- I sat next to you on the bus, but now I'm afraid you're gonna be mean to me again.

- I'll never be mean to you again.

- Why were you mean to me?

- Because I wanted to be very mean to you.

- But why?

- I felt like it.

- Why did you feel like it?

- Because I always felt like it.

- But why? That's so mean and that's not good. I don't think you're my friend.

- Well, I'll pick a different friend.

- Well, then you really aren't my friend and I don't want to be your friend ever. I want a new friend. I'm gonna have a different friend.

- Jessica, do you want to be my friend?

- No, she wants to be my friend. Nobody wants to be your friend because you are mean. You throw things on people and then you don't even really feel sorry. She's gonna be my friend instead.

- Well, I feel sad and start to cry now. I want to be your friend. Hi.

- Hi.

- Well, I was just crying because I want to be your friend.

- Yeah, I saw that. You really did feel very sad.

- Yeah. Josephina, how come you have a new friend?

- Well, I thought I would be her friend because Sage, we didn't know that we could trust Sage, but you looked so sad over there, Sage, 'cause you were by yourself.

- Yeah.

- So.

- So. Josephina.

- What?

- I was thinking to apologize and we would be friends again.

- [Theresa] So now let's go back to the slides. So what you saw is that, as we stuck through it, and I have to tell ya, I wasn't really comfortable, kept saying, you're so mean and all that, but I think what was able to happen here is that Jordan was able to work through the appropriate emotion for her doll to feel remorse and to try then to do the appropriate action, which would have been apologizing instead of just saying oh, let's go to our locker. So, I think by adding a relationship-based type of intervention where you work on emotion, it can really help advance logical thinking. So I had taken the training for DIR originally because of my work with children with autism, but I've really found it very applicable to advancing cognition and language in individuals like Jordan. So now Jordan, here's a picture of her sorting mail. She's 19 years old. She's staying in high school for at least one more year. She's doing job sampling and her therapy goes to continue to work on expanding her vocabulary, so we try to figure out what other vocabulary items that she needs for the different environments that she finds herself, working on reading comprehension because we're thinking about job skills. What does she need and how can I support those needs with regard to her communication? We're really working on writing narratives and editing her work and then of course clarity of speech. So here's a little clip of Jordan that she just took recently. She and I are now dong teletherapy, because we're in different states, and so she writes stories, she writes her stories, shares them with me on Google Drive. She does that on her own, and then we share the screen together and edit them. So if we can go to the video.

- We can do some shopping at a surf shop. There is a restaurant called Burning Duck. I always get the black and blue burger with lettuce and tomato and onions, and it's delicious. I get my orange juice too.

- [Theresa] Okay, we'll go back to the slides. So that was just a little short story that she wrote for me about her recent vacation. She writes that all on her own without her mother editing it and you can see her grammatical structure's pretty good. We still have a little bit of intelligibility issues, but she's really made great progress and we continue to work together. So in summary, for individuals with Down syndrome, intervention should begin early and continue well into adolescence and young adulthood. There is no given ceiling. Introduce AAC early. Remember about drill and practice, those are key fundamental principles of intervention, and teamwork is critical. We should know about whatever the vocabulary, oral vocabulary, reading vocabulary and other skills that can assist schoolwork and performance to help our individuals with Down syndrome thrive. And then here are the references I was talking about earlier and I want to thank you very much for your attention.

- [Amy] Wonderful. Thank you so much, Theresa. I'm gonna open up our community pod here.

- [Theresa] I did see one question. The first question, I did see, was asking for clarification about phonemes, and so I do want to go back and just clarify that vowels, as well as lingua-alveolar phonemes are going to be very challenging and it has to do with the structure, so the size of the midface, that it's smaller, a lot of individuals will have a small maxilla, now many will get orthodonture. Jordan actually did have a palatal expander, and as a young teenager, probably about 12, 13, and she wore that for a long time, and that definitely helped open up her midface and give her tongue more opportunity to kind of sit higher in her mouth, so that always could be an option, so I wanted to clarify that one.

- [Amy] Thank you so much. And kind of as a follow-up, one of our participants is asking if you see initial consonant deletion very often. She said she has a child with Down syndrome who is doing that while the final consonants are usually present.

- [Theresa] Right, and I would say no. So that, initial consonant deletion, as you know, is a non-developmental phrenological process, and that is not something that we would, say, see typically in a child with Down syndrome who would have that delayed acquisition of phrenology. An initial consonant deletion is hard to work on, it certainly is, initiating a syllable with a phoneme for a child who cannot begin their syllables with a consonant, so that would probably be something that you would wanna target pretty early because of the significant impact on intelligibility because it is a non-developmental process.

- [Amy] Very good, thank you. There's a question here, that kind of comes along with a comment which is that oftentimes when you're dealing with special populations, the standardized testing is not standardized for them or is not appropriate, and so she is asking, she's stating that she often uses the developmental scale for children with Down syndrome by Layton to help track progress and do you have any other assessments, checklists, inventories that you feel are appropriate and useful for this population?

- [Theresa] Oh, that's a really good question, and thank you for suggesting that for all the other participants because assessing skills in this population, just like with other special populations, is very problematic. Many of us have to use a certain standardized test and we know that those tests are sometimes needed for insurance purposes for documentation in schools, but because of the co-occurring cognitive deficits that using these standardized tests, their performance is likely not reflective of their performance. I don't have any other suggestions for checklists that I use. I take a developmental perspective, so I use, for example, the Bloom and Lahey model for semantic relations, because I always want to make sure that I'm introducing vocabulary and content to help expand that thinking and using, you know, developmental information on grammatical structures, such as, you know, the list of Brown's Morphemes, going through that that way, because they're not, we're going to want them to acquire all of those structures, but again, they're going to need lots more practice. But thank you for that suggestion. Again, go look at Libby Kumin's work. She wrote a really nice paperback book on communication skills in individuals with Down syndrome. It's probably 20 years old, so there's some information that's outdated, but she's got lots of strategies and also information for parents.

- [Amy] Very good. Someone wanted you to clarify the rates of stuttering and cluttering. I believe this is on one of the slides.

- [Theresa] Right.

- [Amy] Page seven of the handouts, but could you just review that for us?

- [Theresa] Sure. So do you want me to go back to that slide?

- [Amy] No, I don't think you need to. I think you can just go over it.

- [Theresa] Okay, so I don't have rates specifically for stuttering and rates for cluttering. The literature that I've reviewed has said that fluency disorders occur in about one-third of individuals with Down syndrome, so it means the risk for a fluency disorder is going to be very high in that population, so if you see a child with Down syndrome whose fluency is disrupted, you cannot rule out that it's a developmental, that it's developmental, because as we know, lots of children have fluency disruptors as they're advancing their syntax, and they do not turn out to be true stutterers, but because the risk is high, you want to pay special attention and you may want to intervene in a very gentle developmental way with the family early, but be mindful that they may have a stuttering disorder or a cluttering, that both of these are known to occur in the population, but we don't have good incidents data on those specifically, but fluency disorders are common in the population and they are hard to address because of some of the challenges with regards to self-monitoring and awareness and some of the cognitive impairment. Okay, so I hope that clarifies.

- [Amy] Very good. Let's see. We have lots of questions. I don't think we're gonna have time to get to them all, but I wanna get to just maybe a couple more quickly. Someone's asking about, as with children with autism, do you have opinions about letting kids play with toys that perhaps don't match their age, so having a 10-year-old and an Elmo toy or.

- [Theresa] Right, right exactly, and, you know, I see that a lot also in my work with girls with Rett syndrome, because there's a lot of girls with Rett syndrome I work with who are in their 20s and all they want to do is watch Cinderella videos. So that, I think, I know we want to work with age appropriate, we always want to move a child towards more age appropriate materials, but I think for a child with a developmental disorder who especially has a high interest in something, we want to try to capitalize on that high interest as long as it doesn't get to the extent where they are obsessively interacting with it without regard for others. So, like with children with autism I, you know, I might be working with bubbles with a 12-year-old, but that won't be the only thing. I will try to also introduce print. If you have a child who maybe has, they love a particular topic like a superhero and they're 25, maybe you can look for books about that or make up stories about that so that you work to move them a little bit more developmentally, but I tend not to say oh, you can only play with things that are appropriate for your age level, because that can be very hurtful and limiting for some children.

- [Amy] Definitely, thank you. I think we're gonna wrap it up here. I did want to throw out one comment from a participant that's talking about play scale from Carol Westby.

- [Theresa] Oh yes, right.

- [Amy] Which is a free online tool. You can just Google Wetsby play scale and that should help you find the checklist and that can help you determine where the child is, at least as far as stages of play and where perhaps to go next.

- [Theresa] Perfect. Yeah, I see Maria's comment on that. Thank you very much Maria, that's a great suggestion. I use that, I didn't think of it. And yes, you can go online, and I believe there's a modified Wetsby, like an updated one, I think you can find that on Google, 'cause I've given that to my students, just this summer, so that can be really helpful too, and the DIR folks use that as well as they try to advance play and language, and so I think it's great.

- [Amy] Great, thank you so much. Theresa, fantastic presentation as always. I found it to be so informative, and we have lots of nice comments from our audience too, so thanks to our participants for being here and for lots of great questions.

- [Theresa] Thank you, Amy. Thanks for that feedback. I always love doing this and I really appreciate the questions and the suggestions from the participants. We all learn together, so thank you. It's really been fun to do.

- [Amy] Very good. I hope everybody has a great day, and we see you back in a webinar before too long. I'm gonna wrap up the class from here. Have a good one, everyone.

- [Theresa] Okay, buh bye.