

Genia: Welcome to the Good Things In Life Podcast, the podcast that helps parents of kids with intellectual disabilities to build good lives in their community. I'm your host Genia Stephen. I'm an imperfect parent with a perfectly clear vision of where my son and other people with disabilities belong, right in the heart of community with everyone else. This week's podcast episode is a recording of a live event presented by Erin Sheldon titled Using AAC as a tool for self determination and supported decision making: how to stop guessing what people want. If you don't know, Erin Sheldon earned her graduate degrees studying the educational needs of students with Angelman Syndrome.

Genia: Erin conducts professional development workshops and webinars for educators and therapists on the assistive technology, communication and literacy needs of students with significant disabilities including Angelman. She has published journal articles, book chapters, and manuals for educators. Erin is the CEO of Integration Action for Inclusion: Ontario's parent association for school inclusion. She works for Assistiveware, which is a company that makes and distributes AAC software. And Erin is the mother to two girls - Maggie, a 16 year old with Angelman Syndrome and Ella. Now, the response to this live presentation was really positive. Speech language pathologists, educators and parents had been emailing in to tell me how very helpful it was. So, go to goodthingsinlife.org/031, download the slides and handouts, grab a coffee and a pen and enjoy.

Erin: The intention and being in this field until Maggie was born and it just seemed, it was just what I had to do in order to make sure that her her needs were met. So, this talk today, this topic about supporting autonomy with AAC, really I contacted Genia after she did that amazing series on supported decision making because my daughter is, she's just turning 16, she's going into grade 11 in high school and we've been thinking for several years about how we would support her to make her own decisions as she approaches adulthood. But what I kept finding in the literature, if you just read up on supported decision making was kind of if a person can communicate, then here's how we do it. And if they can't communicate, then we just do our best to interpret them.

Erin: And the people around them really end up making the decisions for them. And so, what I've been trying to figure out for the past year or two is where's that middle ground? How do we make sure that we are actually teaching students the skills they need to be able to make their own decisions? And how do we, regardless of how old someone is and whether they're still in school, how do we move past that point where we're trying to make the decisions we think that they would make, are there, what can we do to improve their autonomy as much as possible regardless what levels of skills they have with technology? So, just to get some common terminology going before we keep going, what is AAC? I imagine you already know what that is, if you've signed up for this, but if you haven't, it's anything that it's any technology or strategy that augments speech.

Erin: So, just the fact that I use my hands is I'm augmenting speech. I can't help it. But it's also anything that's an alternative to speech. And we all know what AAC is because we all use it. If you've used the chat window, you are using an alternative to speech. If you've ever sent a text message or posted a Facebook status update or sent an email, then you have used an alternative to speech and you abused AAC. And what I've heard from

many adults who use technology to communicate is that the way they think of it is that everyone uses AAC. AAC is completely universal. Every gesture we use is AAC. What's not universal is speech. Some people cannot rely on speech to meet their communication needs. And so, just think of it that way as AAC is a more universal way that we all communicate together.

Erin: And so, AAC might be something that has voice output. Like if you use an iPad with an app and when you press a button, you hear a voice then it, then that's for as output. AAC can be visual symbols. So, you press a symbol that represents where it's like I and you. And do and don't. It can be photographs and it can be selected and letters of the alphabet cause the alphabet is really just a symbol set, right? Each letter just stands for a different sound and we put those together to form words. It might have hardware like an iPad and it might be a printed book, like a Pod Book, a pod communication book. And so, you know, all AAC has something if someone says, you know, reuse an iPad for this student to communicate, that doesn't tell you very much.

Erin: That just tells you what the hardware is, but we don't really know what words they have access to. And it might be, is as simple as just using social media. So, robust AAC is different than just any form of AAC. If someone says, for example, my son has a pecc system that too, they see, then we would probably say back, that's great. So, he's got a way to request things but that's probably not robust AAC because we don't know from that that the person can say anything anytime, anywhere to anyone. And so, our goal with robust AAC is that you can generate just about any message. It's really only robust AAC. If there's a symbol system, there has to be some form of symbols. Photographs by themselves are not AAC all alone because have you ever seen a photograph of tomorrow or a photograph of yesterday or a photograph of even a photograph of I'm scared or a photograph of, I had a nightmare.

Erin: Have you ever seen a photograph of dead, right? What would that look like? Would we really want to use that? But, dead and death are words and concepts that we need to be able to communicate about. And so, it's not robust if there's not a symbol system. It's not robust if there's not a really broad range of words that we can say in order to meet a really broad range of communication needs. So, if I referred to robust AAC or anything we see really in today's session, we'll be assuming that you've got something more robust than a peck system or a photograph system. And really for in terms of supporting our sons and daughters or whoever else, we're supporting AAC as a second language. We can think of speech as a first language that most people can use and AAC as a second language.

Erin: And if we're trying to teach AAC to someone, we really do need to think of it as a second language. It's usually a visual language. So, if you can't generate words out of your mouth, then you need an alternative. And the most common alternative is a visual language. And we can think of AAC as the second language and as the shared language that that if our son or daughter can't speak with us, then we need to think about a shared way where we can both communicate. And that's really where we're thinking about AAC. If a person cannot rely on speech, then they need an alternative to speech or they can't meet their communication needs. If they're learning to use AAC. And especially if they have very early skills and they haven't yet learned different symbols for

different things, then they really need a second language environment with AAC where they're seeing other people communicating with an alternative to speech.

Erin: And I think most importantly, if you have a son or daughter or a student or a client who it's not clear that they understand speech, there's many reasons why they might be struggling to understand speech, then they really need AAC. And they really need us to use it with them because they might need a visual language and a visual language, which is much more stable. And as I put it here on the slide, less fleeting than speech. Speech moves very, very fast. Every word is fear and gone is as quickly as it's said. And so, if we believe that someone is really struggling to comprehend speech, then we need to provide a visual language systems. So, you can read more up on AAC. I'm not going to go into it more deeply than this. I will talk a little bit about AAC modeling. And when I talk about modeling, I mean it's us as speaking people using the AAC system in order to demonstrate how it's used and how we create that kind of second language environment. And so, then the other question that I just want us to think about as we go into this is what do I mean by autonomy? And go ahead and say something in the chat about what you think of when you think of autonomy.

Genia: Erin, just while you're waiting for people to respond there, you've got an apple colors toolbox there on the screen that's blocking part of your slides. I'm not sure if it's there intentionally or not.

Erin: Well, colors. Oh, hold on a second. I don't see it on mine. Does it, is it this thing?

Genia: It's gone now.

Erin: Alright. Sorry about that. I just give the answer. So, does anybody have any comments about what you think of when you think of autonomy? Having your own sense of agency? That's from Molly. Karen saying, say what I want, when I want to, whom I want. Those are all perfect. The things I would add to that are self-governance, right? Being in control of your own life, in control of your own self. Having choice and control over your own life. Being understood. And I think being understood, I'll get into that a little bit because it's not enough to just have the words to say what you want to say, but those words also have to be understood by other people. We know that for example, being able to say words by itself means nothing if other people aren't listening.

Erin: I think the Me Too movement has really shown us that, that you can have all of the words, you can be a completely verbal person with a very large vocabulary, but if you're not listened to and heard and understood and people aren't acting on what you're saying then they're limiting your autonomy. So, the old way, and this is just my interpretation as a parent, when I was introduced to AAC, it seemed that this is how the speech pathologist assumed autonomy develops. That we start by having the students select the correct objects. I say, where's The cup? And you hand me the cup. And then once they've figured out that, then we say, show me the picture of the cup or show me the picture of the cat or the dog and you get it for them. And then we say, show me the symbol of the dog or the cat.

Erin: And then I say, you know, you reach for something. And I say, you know, that kind of next step is, you know, say I want, you know, put it together. I want, I want [inaudible] or I want eat or drink. And I think our thinking was that if we just tell people what to say and how to say it, that they would eventually get to this point of graduating where they can now say anything to anyone. This is just my interpretation of what our field of assistive technology and AAC seemed to think was happening. The problem with this way of thinking is that we, what we're really doing is teaching compliance, right? Selecting the correct object structure, selecting the correct picture structure, selecting the correct symbol. But all of these are really about following somebody else's directions. And we're assuming that if, if you learn to comply was what I tell you to do, then that will get you to a point where you cannot say anything.

Erin: And it also presumed that we know what the correct answer is. If I say, use your words, say I want pizza on your device, I'm assuming that I know that you want pizza. And we might not always be correct with that, but this is, if you just look at how we've often done speech pathology, speech therapy, this is kind of what it's looked at. The issue being, we have no evidence that learning to comply teaches you to speak for yourself. And in fact, we actually have a lot of evidence to the contrary. We have ample evidence that learning compliance makes you more vulnerable. So, our goal is self-governance, right? Having choice and control and ownership of our own life so that we can be understood and we can go do what we want to do with whom we want to do and say what we want to say all of that.

Erin: But we have to figure out a way to do it that isn't based on, I'm going to teach you to have power over your life by making you comply with what I tell you to do. And the reason this is so important is that our sons and daughters and students and clients, because of their disabilities, they're already more vulnerable. The US Department of Justice estimates that just having a developmental disability for example is associated with a three times risk of being physically abused or assaulted and a five times risk of being sexually abused. Women with a developmental disability are even more vulnerable. Depending on the study that you look at, anywhere from 40 to 80% report that they've been assaulted by the time they become adults and half of them more than 10 times. So, we really have to question things.

Erin: That assumptions that learning to comply can somehow teach you autonomy. We know that within women with developmental disabilities, more than 40% of women with developmental disabilities who had been sexually assaulted were actually non-speaking. And the research showed that the more severe their speech problem, the greater their risk of abuse. And the issue was that they were seen as an easy target if they can't use speech. So, there's a number of things that heighten the risk factors for vulnerability for people with disabilities. And one of them is having reduced choice and control. One of them is social isolation. And both of these together are really common with our sons and daughters. One of the things that we often end up teaching people with developmental disabilities or range of disabilities is reduced choice and control, rewarding them for compliance and punishing them for speaking out.

Erin: And in fact, there's actually a lot of research that when people who are nonspeaking try to express a negative opinion, it's very likely to be interpreted as a challenging behavior

and as a problem that needs to be extinguished as opposed to an opinion that needs to be, that has the right to be expressed and that we need to support that expression. And we know that if you're nonspeaking it's very difficult for you to give testimony to what happened. You're off, you're usually considered an incompetent witness. And so, if you don't have a symbolic way of talking about what's happened to you, then you're just at heightened risk. So, all of that to say that if our goal is to teach people to be autonomous, then they need to experience choice and control from as young an age as possible. They need to experience that when they express a negative opinion that's valued, that that's actually what we want to hear.

Erin: That there's no correct answer of how you feel about something. The only correct answer is really only what you know as the person experiencing it. And so we can think of kind of a new framework for thinking about how we expand autonomy. And this is just my working model based on the literature and supported decision making. And supported decision making is just a structure that supports a framework that supports people to have more autonomy. And it seems to start, from what I can tell, reading the research and trying to apply this myself is it starts with a foundation of supporting people to express preferences. We want to know what they like and what they don't like. And we need to hear that. We need to hear their opinions and support them to be as clear as possible and support other people to hear that when they do.

Erin: We need to then kind of that next more sophisticated step is we understand that they're saying they don't like this or that they're saying that they'd like this. Can they affirm it, somehow? Can they show us their agreement? Can we make sure that we are correctly understanding them? And build in some safeguards to make sure that we are putting tools in place for them to tell us if we're getting that right. And then one of the next steps is, okay, so we understand what you like and we know what we don't like, but we need more details. We need to be able to elaborate on our preferences and describe them. Or they, they're really in danger of having them be oversimplified, right? If I, for example, can tell you that my daughter really loves swimming, I know that she really likes swimming. But if I can't elaborate and describe that, then we could build in a structure where she go swimming at the YMCA twice a week without understanding that chlorine pools are actually much more challenging.

Erin: An indoor pools are actually much more challenging and much more difficult and can be really overstimulating because of the acoustics and the smells and that there's certain people we like to swim with and activities we like to do when swimming. Right. And we need to figure out how to elaborate on those and describe them or we risk saying because we know the person likes this, we're going to put this into place, but they're not really going to have as much choice and control over it as they could. Ideally, we support people to be able to compare their options and begin to rank their preferences because comparing things is actually a really important step of decision making. You know, if we ask someone what do you want to be when you grow up, what kind of job do you want to have? How do you want to contribute? There might be a hundred things that we want to do. We need to find out what they really want to do, what they most wants to do. And really a decision making is being able to compare different options and then select one. And so, I'm going to show you strategies for all of these including strategies for how we can expand someone's authority.

Erin: So, from what I can tell, my best guess is that autonomy starts with supporting people to express their preferences and their opinions. And the more clearly that they can express their preferences and opinions, the more that we can rank their preferences, understand what they'd really like, understand what's absolutely non-negotiable to them, understand what they really don't like and what is nonnegotiable that cannot happen to them as opposed to what sort of myth. That's fine. We can take these preferences and opinions and help us understand what's really working for them and what's not working for them. What do we need to problem solve? What do we need to change? And we can ask more about what's really important to this person to make sure that we're building this into their life. So, you saw my little stair step of how I think we tend to think of autonomy is something that we kind of earn our way to.

Erin: And what I want us to think about is how can we actually support a person's autonomy no matter how they communicate, no matter how early they are in their communication abilities. That you might be extremely emergent, that's just a term we use in AAC field, extremely emergent where the way you communicate is entirely with your body and with kind of spontaneous reactions to things. We can support your autonomy at that stage. You might get to a point where you can select symbols on an AAC system, right? Most of our folks do. They can get to that point. We can support your autonomy there, that as you move across and kind of move through these different stages of getting into more and more specific ways of communicating, we can support your autonomy at each stage. The trick is that the earlier you are in your communication skills, the more you have to be interpreted by other people.

Erin: And so, it's really the structures we put in place for how you're interpreted, that is the most likely to move you through these different stages because getting to the point where you can just use symbols and the alphabet to type a message, you don't need it. You need very little interpretation after that point. Right. So, that's really what we're trying to do is get people to a point where we don't have to guess as much. And what we can do is become a lot more strategic, you know, how we can guess. So, stage one, if we kind of think of different stages that sort of move us through here, I think stage one is supporting the person to express their likes, their dislikes, their opinions. That's the person. It's also supporting everyone else. We can call all of us their communication partners, their community, their family, how to be consistent in how we understand that person when they're expressing preferences and how we act upon the person's preferences. And the most useful tool to help us do this as a communication chart.

Erin: Now, I used to think that a communication chart like this, any of you guys for speech pathologists have already seen this before. A lot of you have seen this if you've done person centered planning. A communication chart says kind of at this time when this happens, when the person does this, we think it means this and we need to do that. And so, a classic example with my own daughter is when everyone's been quiet and seated like in class, or she's actually here with me and we're in Maryland at a course, everyone's quite and seated. When everyone stands up, she alerts and looks around and often starts doing this or she starts doing this. And when this happens, we think when she's doing this, we think it means that she's trying to figure out what's happening next. We think it expresses some confusion, but also some curiosity.

Erin: This seems to be more about confusion and this seems to be more about anxiety that she's trying. She doesn't understand what's going to be expected of her. And so what we need to do is use her AAC and explain what's going to happen next. So, it's called the communication chart. There's a lot of examples. And I used to think that these were only for people who couldn't communicate in another way, but when I did a series of interviews with adults who can type any word they want to communicate any message, they just don't rely on speech, what I heard was even though they can type any message, they feel frequently misunderstood. And when I talked with some of them about communication charts, their reactions were kind of like, "Where has this been all my life?" But some of them even started writing up their own communication charts to hand them out to friends and coworkers and colleagues because there were often things that they were doing that were being misunderstood and that were kind of difficult to explain.

Erin: And so, regardless where someone's at, they might really benefit from [inaudible] chart. If any of you have intimate partners or parents or anybody like that, you might find that there's times when you kind of wish there was a communication chart that said, you know, when mom enters the kitchen and sighs because all of the recycling is still on the counters and nobody's managed to put it in the bins, we think it means that she's frustrated that we haven't been sorting our own recycling and that what we all need to do is make sure that after we empty a milk carton that we put it in the recycling bin. That kind of thing. Right? So, all of us can use a little bit of support with making sure we're understood. When my own daughter Maggie was very little, we, I had a very detailed communication chart for her because of the number of times and ways that she was misunderstood.

Erin: So for example, when she was two, I went into her day care center and she had been barricaded in the corner. And when I asked, "Why? What's going on?" They said she had bit someone and she was frantically biting anything she could get. And we didn't figure out what had happened until I opened up her lunch box and she had never been fed. So, someone had left sick that day. Someone else had taken over and in the mix of people coming and going, she had never been fed. And I realized it actually needs to be written down that if she bites someone she might be very hungry and you need to feed her. So, this is kind of what her very earliest communication chart look like. And at this point when she had these very early ones, she was experiencing medical issues like epilepsy and pain from reflux and migraines that were very easy to misunderstand.

Erin: And so, it was a very long and detailed communication chart. But there's a of examples out there. These are, I think most of these examples are from Helen Sanderson Associates, which is that person center planning organization. And you can be completely verbal but still really benefit from having communication charts that just help make sure that everyone is interpreting you in a consistent way. And the reason that I focus on consistent interpretation is that our folks, for them to go from communicating more spontaneously to communicating in a much, in a more consistent way, they need all of us to be consistently interpreting them. If sometimes we get it and sometimes we don't, then they're not experiencing a lot of success. And it's really hard to stay motivated and key trying to make all the rest of y'all understand what it is that I'm trying to say.

Erin: And so, the more that we build in consistent structures for how we hear and understand the person, the more experience that they have with being successfully understood and it just make, it just provides the foundation for them to communicate more. So, you know, Maggie's communication chart at this age now that she's a teenager and is just so much more [inaudible] in a lot of her communication sets this up. So, really what I think about in communication charts is wherever someone is being misunderstood, we need to build a communication chart for them and we can support them to express their preferences in a lot of ways. I really discourage all of us from asking questions, "Are you frustrated?", "Are you angry?", "Are you, do you want this?" That life to a non-speaking person can feel like a constant interrogation. And so, we can just invite the expression of preferences using declarative statements rather than questions.

Erin: So, a declarative statement is, "I think you like that." I'm stating the obvious, I'm just stating what I see and I'm also mapping language onto what you're doing. So, if you're someone at an early language level, I'm going to give you the words that explain what's happening and that will help you develop more of the internal language and then be able to express the language. And we'll use strategies like verbal referencing. So, "You're laughing, I think you like that." I'm referencing with my words and what it is you're doing. And I'm going to use strategies like AAC modeling, right? So, where it says in all capitals LIKE then I might model the word "like" on their communication system or in a pod book more to say I like that and go into that. So, you know, follow that through to be able to show the person, here's how I'm understanding you.

Erin: And here's how you could actually say it more symbolically if I'm getting it wrong. And what that's also doing is teaching the person to understand why we think that they're communicating what they're communicating. And we're teaching them how we're interpreting them. "If I get it wrong, maybe you're laughing because you think this is really boring and stupid", and you're laughing. And if I say, "Oh, you're laughing. I think you like that", then I'm actually giving you information and you can use that information over time to go, "I better not laugh at this because everybody misunderstands me when I do." And so, we're helping them to self-govern we're helping them to change their own behavior in response to how we interpret them. But if we don't use verbal referencing, then they don't understand why when they're laughing and discomfort and we did black with them and don't do anything about it, what it is that's happening.

Erin: And number of people with disabilities have said, I can't see my own face. So, I don't know what my face is doing that makes you react the way you are. With verbal referencing we can tell them, "Here's what your body is doing, here's what your face is doing that's making me think what it is that I'm interpreting." And so, we're just providing a tool for them to be able to shape how they're being interpreted by them, by us. I hope that makes sense. The next stage is we're using verbal referencing. We're saying, we're telling them what I think you're communicating. We're creating a space for them to start to correct us. Right? So, this is kind of affirming and denying, creating a space for them to be able to say, "Yes. You're actually understanding me" or space to say, "No. When I'm laughing like that, I'm actually trying to tell you something else."

Erin: We're using the strategies and now creating an invitation for them to let us know if we got it right. And we can use this in a lot of ways, right? So, if we're supporting a person

to, with personal care, if we're supporting a person to eat, we can say, we can invite them to tell us to affirm or deny whether we even did a good job, right? And we can teach them from the very beginning that your right to support is your right and your right to support on your own terms as your right. And I'm going to create space that invites you to let me know if I'm doing it well or not. And that's a strategy we can use through all of these. So, we're going to invite a response. So, if I say, "Oh, you like that, you know, you're laughing. I really think you'd like that."

Erin: And you look at me with that kind of a shared smile, I can say, "Oh, you're nodding and smiling. I think I got that right." And help teach them, "Here's how you can let me know whether I got it right or not." Well, one of our tricks, one of the things I see, the pitfalls that I see as falling into is we try to reduce things to limited choices or to false choices. And we set people up to think that rather than affirm or deny it's what we're doing is expecting that they can just make a choice and that because they made a choice that therefore they had autonomy. It's not really a choice if we haven't listed all of the options. So for example, if I say to you, "Hey, it's lunch time. Do you want a ham sandwich or a turkey sandwich?"

Erin: It's not a real choice if you choose a ham sandwich, that's a selection you selected from a field of two. But it's not a real choice if what you really wanted was something else. It's definitely not a choice if you're a vegetarian and the only things you're being offered are to meet options. If you refuse to make a choice, it's really easy for all the speaking people to go, "She doesn't understand choice-making yet." When in fact, what you wanted was something that wasn't actually offered to you. So, we really have to be clear on what is an authentic choice. It's only a choice if you can ask for something that wasn't offered to you. If you're choosing between what's been offered to you, then that's a selection, right? If you go to a restaurant, you look at a menu, you select from the menu, but it's not a real choice unless you got to choose the restaurant.

Erin: If you got to choose the framework within which you would be making that choice, it's only a choice if you can choose to say, "No. None of these." It's only a choice if you can say, "Ah, something different." It's only choice if you can say, "Yeah, I think I want a ham sandwich, but tell me more about it." Or "Yeah, I want to have a sandwich, but I want it on a rye and with mustard and no tomato", right? If you've got more choice and control over how you want it. So, it's only a choice and it's only autonomy if it's on your own terms. So, if you've got someone, for example, who really only expresses a preference between things, if you hold up two options, then what we want to introduce is here's one option and here's something different. It might just be a single symbol.

Erin: It can actually be anything, but it just stands for the concept of different, and I can say, "Do you want a ham sandwich or do you want something different?" "No, you're not looking at the ham sandwich. I think you want something different." "So, here's a turkey sandwich. Do you want a turkey sandwich or do you want something different?" "You're not looking at the turkey sandwich. I think maybe you want something different. What else do we have? We've got a pasta salad. Do you want the pasta salad or do you want something different?" And then maybe that's it and we can say, "I'm sorry. That's all we have. I don't have anything else different. These are the three options we have." That's one way that we can build real choice and control into choice making is make sure that

every time we ask someone to make a choice, we're giving them the option of something different.

Erin: If the person can choose from a bigger field, then maybe we've got the ham sandwich and the turkey sandwich and something different. And tell me more. So, let me tell you more about each of these. I don't see you making a choice between them. So, let me tell you more about them. The ham sandwich is like this, the turkey sandwich is like this. Or I can tell you what would the other options are. We might use the same framework for thinking about what classes we want to enroll in the fall, or which friends we want to invite over for an activity, or which movie we want to go see. But what we, the real key is making sure that we're not creating this false choice of "Do you want to watch Spiderman or Black Panther" without providing the option of something different. And I created this as, this was just a laminated, like a table mat.

Erin: That we were using with one girl just to prompt the people around her to make sure that they were always offering authentic choices. And she wanted the word "but" because she was being put in a position of making choices, like, "Do you want to go swimming with your mother or do you want to go to Nana's?" And she wanted to be able to say, "I want to go swimming but only if my sister's also coming or if my sister's not coming." Or "I want to go to Nana's, but only mom's coming too." And she was really struggling and just demonstrating a lot of behaviors cause she wasn't being understood, that she wanted to put conditions on the choice. And so, we introduced the symbol for "but". And that was just a prompt now for her team to get her family to get out of her communication system and try to figure out what were the conditions that she was trying to put on the choice in order to have more choice and control over it.

Erin: So, when we get people to, when we're trying to get them to affirm or deny, one of our real tricks is we have to avoid interrogation. We don't want to keep making them repeat themselves. It's like, "So, do you want to go swimming or do something different? Oh, you want to go swimming? Say, yes you want to go swimming. You want to go to swimming?" We can just focus on making declarative statements at that point. "You've chosen swimming and you want to go swimming? Oh, you're looking at me. Okay, I think you want to go." It doesn't have to be incredibly formal, but we need to teach them that I'm interpreting you and you are in a position to give me feedback on whether I'm doing a good job on that and whether or not you actually feel understood. And some ways that we can better support that is use their communication system, make sure they have ways in their system to say things like, "I don't understand" or "You don't understand or that isn't what I meant."

Erin: That they need these messages in their system and they need us to use them for us to say, "I don't understand. I can tell something's wrong, but I don't understand what it is. Maybe it's this. You're not looking at me. Maybe it's this. I heard your voice. You used your voice. Okay. So, maybe this is what's wrong. It's too noisy. Do you understand that? Did I get that right? You're looking at me, you're looking at, I think I got that right. That something's wrong is too noisy. Right?" And we're modeling ways that they can help us understand whether we're understanding them or not, whether they're being correctly interpreted. The next stage is, so I'm not suggesting that we start all this right away with someone who's very early in language, but just be thinking of kind of a roadmap to

move people along to more autonomy is teaching folks to provide a response, really inviting them to respond in a way that expands with a why.

Erin: "So, I hear your voice, I see you're upset. Something's wrong. You're turning away. You're covering your ears. I think it's too noisy, right? So, I'm helping you understand how you can communicate that something's wrong, you don't like this and it's too noisy." Or "I see you smiling and reaching. Wow, I really think you liked this a lot." And I'm providing some of the language that helps you expand, but it's not just that you like sandwiches or cookies or Spiderman that you like it a lot. And how mean this language, being able to be more specific and to expand on your message helps you go from being someone who likes swimming to a swimmer or someone who likes course spec writing to being a writer or someone who likes Spiderman to being a fan, a marvel fan. Right? It's the more that people can expand on their message and start to explain what they like a lot versus just a little helps us understand what is it about them uniquely that really makes them a whole person, right?

Erin: A person with their own interests and opinions and roles. You know, such as the role of being a marvel comic fan, like half of us have become with all the latest movies out there. And one of the tools that can help us do this is think about a receptive communication chart. I often see teams where they've developed different strategies for expressive, right? That's that first communication chart I showed you, when Maggie does this, we think it means this and what we should do is this. A receptive communication chart makes sure that we are planning, that we're putting enough energy into making sure that the person understands us and we're not just putting the burden of understanding on them. So, when we want to tell the person something, how do we do this and what are the technologies or tools we use to make sure that they understand us?

Erin: And this is particularly important with anyone who we think is struggling with comprehending speech. There's a number of reasons of sensory processing reasons, auditory processing reasons, intellectual disability, all kinds of things can make it harder to understand speech, particularly because speech is so, just so fleeting, right? It comes and goes so quick. If you didn't catch the word the moment it was spoken, then you missed it. And so, we can make sure that we've got consistent structures in place so that everyone knows how to communicate in a way that helps the person understand us. So, this is just an example of a communication chart, a receptive communication chart from Helen Sanderson Associates. When we want to let Kyle know that it's time to get up, here's how we do it. We knock on his bedroom door and then we open it. That kind of thing.

Erin: So, just take the time with your school team, with your support team, with your family to make sure that we all have a consistent way of making sure that the world makes more sense to this person and that we're building in structures for them to understand more abstract things that happen. So for example, with my own daughter was all of her sensory processing issues, I think it's very difficult for her to be a body emotion on her way to do something and then have to process language while already walking and thinking about something else. We had, you know, just one incident we had, she was riding the bus everyday to school, the regular city bus, and I was riding the bus with her.

And there'd been construction on our street and our bus stop had moved and I hadn't warned her about it.

Erin: And so, we're trying to walk down to the bus stop and I realize the bus stop has moved. I hadn't warned her. She was so bound and determined. She knew exactly where she was going. She knew how to get there and all she could comprehend at that moment was that I was trying to stop her from getting to the bus. I was trying to explain, "No, the bus stop has been moved and we need to go." But in that moment it was just really difficult for her to process language. And the bus ended up coming and missed us went on because we weren't in either stop. She burst into tears. I burst into tears. I hadn't been able to explain this fairly abstract idea. And so, what we know is that to make sure that Maggie really understand something that abstract, we need to tell her ahead of time whenever possible.

Erin: Tell her ahead of time. Ideally tell her when she seated and she's not trying to organize her body to go do something else. Use her AAC, use her high-tech AAC so that she has visuals, right? She can see the symbols moving across that "I'm telling you something, it's happening right now. There's been a change or something different, right? I need you to listen to me and see this." And then use partner assisted scanning to make sure that she understands, which is like, "Okay, did you understand that? So, we're going to go somewhere else. Are you ready to go? Are you ready to go or go somewhere different?" That kind of thing. When it's things like she needs to make an important choice, like what courses she's going to take in high school in the fall, it's a false choice. If we just sit her down and say, "Do you want to take drama or do want to take music or you want to take social studies?" That is a false choice because she needs weeks to think about that kind of thing.

Erin: She might need to visit the different classrooms. We probably need to record some kind of video of what each of those abstracts choices look like and we need to review them frequently over several weeks so that maybe a month after we started the process of course selection, she's really had all the information that she needs to understand what her options are, understand where her choices are for us to do things like use verbal referencing and modeling when she's watching the videos of her different options to say, "Oh, I think you really liked drama. You know, I think we know from your past experience of drama you really liked drama. I'm looking at you, you're watching the history lesson. You don't seem interested. I don't think you like that. I don't think that's the class you want to take. Let's see what our other class options are." That kind of stuff.

Erin: So, it's just making sure we have a consistent and thoughtful and strategic way of making sure that the other person understands the options that we're putting in front of them rather than creating these false choice things where we're just like, "Oh no!" We asked her what question she want to take, she touched that picture, therefore we're all going to assume that that was really her decision. One of the next stages, the second to the last is introducing the concept of ranking. That all of us have things we really, really like. Things that are completely non negotiable. They're just very important to us. For me, waking up in the morning and having espresso. To help wake me up that I actually started with black tea, a cup of black tea, and then I move on to espresso that's really important to me that it's not a good life if I don't get to have that.

Erin: I also, I mean I like tea, tea's good, that's not as important to me, but that's actually a really important routine. When we have access to language, like most and least or worst and best or favorite or love versus like and meh and okay, then we can start to communicate so much more nuance about what's really important to us, what we really like and don't like. And so, we need to use that language and introduced structures to help people use that language as they're thinking about what's working for them. And so, you know, it can be as simple as teaching, "What do you think, what did you think of that movie? Was that a thumbs up? Was that okay or was that a thumbs down? What did you think of how I supported you at meal time? Do I get a thumbs up or was I just okay?"

Erin: We can, if we introduce this, if we introduce these kinds of structures where we're asking folks to respond and rank and critique, then we are creating a situation where they expect to give their opinion on they're being supported. And we can get to a point where maybe we started out in kindergarten where we were talking about "Did you really like dinner or was it just okay?" To as an adult, "Do you really like the support person or are they just okay?" And be able to take that information to understand who should be supporting them and when and which activities are the most important to them. And there's a lot of ways that we can do it, but what's, the structure that's, you'll see me talk about talking maps in a minute where I'm kind of stealing this from, the structure that seems to make sense is choose a topic like classes in school.

Erin: And now choose what it is we're ranking, what are the classes we really like in the classes we don't like in the classes that are okay. Or what are the classes or activities that are really working for me and what's not working for me and what's just sort of okay. And always provided in the same structure that this sort of the positive, the like is always on the same side and then not like as over here. The working is here and the negative is here. Always providing that same structure so that we have a routine for how we choose a topic. And then we think about how to rank and we can use photographs. We can use symbols to say, you know, "So, what do you think of this class? Do you like this class? Is it just okay? Do you not like this class?"

Erin: We can use verbal referencing. "I think you really like drama because I see how you smile and run into the classroom. I don't think you like gym as much because you stand at the doorway, right?" So, we can move these away around and show them why we're interpreting that this is something they really like and this is something they don't like. And we're creating, even if we're only modeling this and they're not participating in it, we're creating a structure for them to go, "Oh, the fact that I hesitate at the door going into gym is making them think that I don't like gym when in fact I'm really just trying to organize my body because I'm excited about gym." And it just gives them some information and it starts to give them a way to be able to correct us and be like, "No, I actually like gym. I'm just being misunderstood when I express it."

Erin: So it's just thinking about structures and thinking about language that allows people to really express nuance in the things that they like. And I'm not going to, I have a video here but I'm not going to show it right now. If you just Google talking, that's on YouTube, you can see it just a very formal process. It assumes people are symbolic that they can use visual symbols, it assumes that they're at a point where they can use the

paths up to ranking. It's a very evidence-based process for involving people in decision making. And what I think we can do for our folks who are more emergent than that is take that structure and teach it rather than waiting for people to get to that point before we use it.

Erin: And what you'll see with the talking maps approach is just what I talked about a slight ago, that there's always a topic that we introduced this very familiar routine, develop a routine of when we're choosing, when we're talking about something and whether you like it or not and whether it's working for you or not, we always use this same routine. So, here's our topic, here's our ranking system. Whether you know, "Yes, I like this", "No I don't" or "Sometimes I like it" and we're going to move images around to be able to indicate what we thought about them. So, last stage that we can think about is how we're really expanding somebody's authority and their right to make more decisions that were really protecting their right to make more decisions. And one of the tools that can help us do this is a decision making profile.

Erin: And what a decision making profile is, is just a consistent structure for how we support the person to express decisions. And again, this is a tool from Helen Sanderson Associates. So, we think about, it can be what we know about the person that inviting them to respond as much as possible. How do, oh, I don't know what just happen. Hold on, I think I just lost my shared screen. It appears that my keynote suddenly crashed. So, hold on. I now reload it. No idea what happened there. But it's just a structure to be thinking about what is this person showing us that they need in order to really participate in decisions so that we put that structure into place every time we ask them to be involved in a decision. Now hopefully this is working and your now seeing my screen again. Sorry about that. So, it's just, if the person is very emergent and they're not yet using symbols and words to help us understand this, then this is us using our best guests. Here's what we think so far. And I don't know why, I'm sorry, but my keynote is crushing and it just crushed again.

Erin: I am going to wrap this up and move us onto questions. I'll just talk through what that last slide was because I don't understand what my computer is doing. But the last tool I was going to show you is called a decision making agreement. And what a decision making agreement does is we built this profile of what we understand the person needs, they need a lot of time, right? That's usually one of the most essential thing. They need a lot of time to be able to consider their options. They need visuals. They might need to go personally experience something. They might need video. They might need, they might be best at making decisions in the morning, right? Or they might be best at making decisions on the evening. They might just depending on their biology and their own kind of cycles, you know. Just, you can imagine how any of us would feel at 6:00 AM and we've just woken up.

Erin: If somebody asked us to make a really big decision, we'd probably say, "Come back to me after I've had my coffee." And that's really what a decision making profile is meant to be. And then our next goal is to put a decision making agreement into place. I'm going to try to not actually put play on my keynote. I'm just going to try to show it to you this way and see if that helps. A decision making agreement means we have taken an inventory of all of the decisions that we're making for this person and that they're

making. We've kind of listed what are these important decisions. For some people it's really important to their quality of life to be able to choose what they eat today or whether they take a bath and when they take a bath or whether they take a bath or a shower and what they wear. And other people, we all know people who could care less what they were on any given day, right?

Erin: So, we're trying to figure out what are the decisions that this person has shown us are important to them. And we're going to be structured about how we agree that they must be involved. And we're going to be really clear about who has the final decision making authority. And what we're thinking about is that as the person grows older and becomes an adult, we're gonna keep trying to shift that final decision making authority to them as much as possible. So, here's just a really simple version of the decision making agreement. This is for my own daughter Maggie. One of the things that we realized was really important to her all the way back by late elementary school was having the right to decide whether to enter a room or whether to leave a room, that she was experiencing a lot of anxiety if she felt she was trapped in a space and didn't have the right to leave.

Erin: And so, we agreed that she had the right at school to stay in a room or to leave a room. And we put this in place in part because we felt it was important for her safety that she needed to learn from a very young age. That she always had the right to say, "I'm leaving. This isn't working for me and I'm going." And so, how does she decide that she's going to enter a room or leave everything? She votes with her feet. She would just get up and go. How are we going to respond? We're going to invite her to stay and encourage her to stay cause we really want her to be part of it. And then we're going to offer choices of where she can go because she has the right to leave the room, but that doesn't mean has a right to go anywhere she wants to.

Erin: And so, it's just having a formal structure for how we deal with these things. As she's gotten older, she's weighed in on things like her placement. She found a class at school that moved at a slower pace and that had other students who were non-speaking who were using technology to communicate. It wasn't an inclusive classroom, but she made it very clear that she wanted to spend at least part of her day in that classroom, that she wanted to be with other non-speaking people. And so, we had to take that input. Now I don't allow her to decide what her placement at school is. I'm her mother and I actually get to make that decision. But here's how she gives input and here's how we hear from her about whether her placements were working and here's how we negotiate that. So, decision making agreements can be about anything from what we were or where we're going to go or how we spend our money, but it's just putting a more formal structure into place and it's about constantly asking is there a way that we can move more choice in control to the person themselves.

Erin: So, I'm going to leave it there cause we are up for time. I'm just going to show you three, the ideas that we talked about here are actually written up as articles that you can read and share. If you go to this AssistiveWare website, I, like I said, I worked for a AssistiveWare and I create materials for families and educators and speech pathologists. If you go to the Learn AAC section of the AssistiveWare website and you look under the

section called AAC for everyone. There's a list of articles that are around the themes of autonomy, advocacy and safety and so you can see a lot of these there.

Genia: I hope that you found this helpful. All of the resources that Erin mentioned are included in the show notes at goodthingsinlife.org/031. If you're interested in learning more from Erin, then sign up for her upcoming live free online presentation titled Creating a positive student experience for Maggie using role theory. Focusing on the role of student has allowed Erin to understand her daughter Maggie in more complex ways. It's changed your priorities and made her a more effective advocate. Understanding the rule of students has meant that as her mother, Erin can work with school teams and in their home to maximize Maggie being accepted for who she is as an individual and also as a student. This is created authentic opportunities for friendship for Maggie and a more meaningful education. In this presentation, Erin will explain what and how she implemented role theory and supporting Maggie to be a successful student in their community school.

Genia: This presentation promises to offer actionable, practical insights into how you can do the same. Interested? Go to goodthingsinlife.org/august7. That's goodthingsinlife.org/august7. Can't attend live? No worries. I'll send you the replay if you register. Now, next week's episode is a little bit different. I'm speaking with Andrea Askowitz, author and writing instructor about the power of storytelling in advocacy. Andrea and I get pretty honest and raw. It includes some adult language and content so have your ear buds handy next week. Until then, have an excellent week. And I hope to see you on August 7th at Erin's presentation. Take care.