SUSAN GILL: Okay, good morning. We are going to get started. My name is Susan Gill. Welcome. Our video conference today is “Facing the Challenges of Assistive Technology Access and Adaptive Seating,” and I really appreciate all of you being here. Today’s video conference is entitled “Facing the Challenges of Assistive Technology Access and Adaptive Seating.” Our speaker today is Karen Kangas, and we are delighted to have her. We have been working with Karen on a project, which she and I would both describe, for the last year and a half.

Today you will be seeing a lot of videotape that is the culminating work of some of this project. Karen is an Occupational Therapist. She is a Seating and Positioning Specialist, an Assistive Technology Consultant, and a clinical educator in private practice in Pennsylvania. She has been an active clinician for over 30 years, specializing in work with children with the most complex problems and issues, and in the last 20 years with assistive technology, especially creating systems for independence and powered mobility, access to augmentative and alternative communication systems and computers. Karen always focuses on human neurophysiology sensory processing, and creating environments for children to explore, learn and develop mastery. For the last year and half, Karen has been working with us in Pennsylvania, going from school to school visiting with students, and teens and families with some of those students facing some of these particular physical access challenges.

A lot of what you will see today are videotape from those students and those teens. We are really excited about this project and our ability to bring you this information so that you can apply what we have learned, what Karen has learned over her long career in working with these students, so that you can get access to this information at any time on our website to be able to apply some of what she has learned. I am going to welcome Karen. Thank you very much.

KAREN KANGAS: Good morning. Again, this is a little bit awkward always when you are dealing with a video conference, so I am trying to say hello to all of you people out there watching today, and I am going to try to stay still so it won’t make you nervous, or me either. I also want to make sure today, when we look at the videotapes that we are doing, that we remember, all of us, the challenges and struggles that we’re facing, we all face, and this is not criticism. The raw footage is there on purpose for us to see what some of these challenges are, because they remain. It doesn’t matter how experienced you are, and in the field of assistive technology, we still know that we are facing similar challenges because of the equipment, because of how complex a situation is, and because of how we are trying to work in the schools. I want us to remember that nothing I say today, even if it sounds critical, was meant to be. It is not, and that I am talking about all of us, including me. I am not pointing the finger at anybody, except that some of the things we do look crazy when we look at them on videotape. The other thing I want to do is thank all the people brave enough to have accepted the responsibility of being on that videotape and allowing all of you guys to see them, as we make these things. The third thing I want to say is I am not an expert, as old as I am, to give you answers. I hope that what you understand is that we are involved in a process and a journey with our students.

What I am hoping I will be able to give and lend to you in terms of my long experience is instead the processes we need to be paying attention to, to work. In this project, when we looked at so many different kinds of kids, we tried to identify right off the bat categories that we would be able to put them in instead of just a whole generalized seating and access issue, since it's a really big deal. So today, we are going to look at the first two. We have tried to look at Susan and Nan Rodgers, and Debby Holzapfel, and we all tried to sit down and figure out how we could categorize some of the groups we are seeing.

Today we are going to be looking at two different issues. The first one this morning is going to be looking at the challenge of integrating the use of assistive technology equipment for independent control and access of multiple systems. So, all of the students you are going to see here are using multiple systems, but their integration of them is still not great. So their level of independence is greatly compromised in very different ways, so you're going to see kids in different settings, but the thing that is true about all of them is they have multiple systems in place. Then, this afternoon, we are going to be dealing with the challenge of developing consistency of access. Those kids, also, are in very different settings and have very different diagnostic categories. So I hope we are all ready to begin. We will first start out with me talking in terms of my Power Point.

How do we assess the problems of integration? Now part of this seems simplistic, but I have found when I walked around to all these schools and consulted in many situations, including what worked with myself, this is something you must make yourself do, and most of us do not do this. We are so focused on what is not working; we do not do a great assessment that includes a history. And so I want you to understand when you start to deal with integration you must put this down on paper. When you are first starting to deal with what the problems are, you need to list what the current equipment is that you actually have. What is interesting is people will instead say to me, "Well we have this communication device." Well, which one of it? How long have you had it? What software are you manipulating with it? I need to know all those things. We need to know what the memory is like. We need to know what access hardware is being used, what software is being used now, and I don't care if you are struggling with it. You need to list exactly what you have.

The next thing is, you also need to list the exact device. You know, with the computer itself, whether it's a PC or Mac, we still need to know what operating system you have, and I want to know what brand it is. Again, so we can look at compatibility issues. When looking at integration, it is going to be really important. I particularly feel this myself since I have just changed to Vista. So I'm a new Vista user, and let me tell you, it's a challenge dealing with some new issues that come there. When we look at the communication device, the same thing. You need to know its brand name, you need to know the age of that exact device, and how much memory it has. What access hardware is being used, what software is being used, and I don't want the access hardware for somebody to tell me that I'm using a switch. I want to know what switch, and it can't be 'the red switch.' The red switch has a name, okay? It's made by a particular company, and different red switches behave in different ways, so I want us to do that. And I'll tell you, when I look at the written work most people have, this stuff is not written down, and this is what's going to help us be able to look at the journey we need to be on.

The next thing is probably the part that in school people know the least, and that is the kind of power chair being used. And a lot of times, because in the United States, power chairs, seating, wheel chairs do not come from the school systems, but in fact come through your individual medical funding sources.

Then in school, everybody doesn't always know the names and the parts, but you can read, right? So I expect you to. You need to know the brand, age, serial number and model number of the chair. It is on the chair. It is on the chair frame. Now, I will tell you, if you see more than one serial number on that chair frame that is because if there is a power tilt that has a serial number. If it has two motors, each of those motors has a serial number, so you need to make sure that you are not just finding some serial number, that you found the chair brand serial number. If you don't know how to do that, you can call that brand's manufacturer rep, and that can be found on their websites. And it's not like there are twenty brands. There are not twenty brands. There are four primary brands, and generally I see three in the schools, so it's not there's so many. There is Permobile; Invacare; Quantum Rehab; and Sunrise Medical, which is also Quickie. Again, access hardware being used, it's not helpful for me to just know the joystick.

That's why it's important that I need to know how old the chair is, because there is also software and the hardware directly related to that chair. They make a difference whether or not we are going to be able to utilize it in its compatibility with our communication devices and computer access.

The next thing we have to know is if there's an auxiliary control interface, and you need to know what that is. That interface is a box that comes from the manufacturer of the power chairs. It can be called an ECU interface, an auxiliary control interface, and auxiliary interface, or a communication interface. They are all the same, meaning it's the same kind of box. Essentially what it is, is it is a box that is going to allow a signal to come out of the chair to go to your communication device or computer, so that you could use your joystick, or your method of access for driving, as the same method of access as you are using for your device. That is really is important, and a lot of times it's on the chair and it's mounted below the seat, so you wouldn't know it was there unless you ask. A lot of times families don't know it's there, but families do know who they got the chair from, who the medical supplier was that supplied it, and they would be able to tell you on the list of equipment if it's there. If that is not there, you chair cannot just automatically be used to be able to work with a communication device. You have to have this interface. It costs almost twice as much purchased separately than when it's purchased at the same time as the chair.

The next part of this that I want you to pay attention to, that I'm leading to, I'm just going to bring it up now, is if you are engaged in helping recommend a new chair, because of those of us who are therapists in the schools very much involved with the recommendations of new systems. You need to really make sure that you have added this that you have dealt with an auxiliary control interface. The next thing you need to make sure is that you have a remote programmer, and every chair that has programmable electronics have remote programmers. They all look a little bit different. In the past, many people didn't provide it automatically. I have, for thirty years in Pennsylvania, no matter what the funding source is, always ordered it as a part of the chair and always gotten them, so that they are available. What that is letting you do, is that's what not only controls the parameters of how the chair drives, but it also is something that we are going to need when we deal with auxiliary interface when we are looking for that chairs power to do something else other than drive. The first thing you're going to do is make a nice list of the real equipment. And, it's not going to be a list that says "powered wheelchair, AAC device, PC computer." Okay? It can't be that simple. I want real specifics. The next thing is I want the students AT experience.

This is the biggest challenge for me as a consultant, is going around and trying to gather a history. Most of the time I'm called in when we've tried everything, and what works? Nothing. At that time, I could spend probably a day trying to dig up the history. I know that in school systems teens change, therapists change. But we really have to get this history somewhere. This history is what is the student's experience with the access methods and devices. First, I want you to really say, "What is their history?" Their history doesn't mean they were successful. I want to know what their experience has been. Even a high school student, I want to know how long they have been involved with assistive technology. And again, I want specifics. I don't want you to say "an enlarged keyboard." I don't want you to just say "an onscreen keyboard." I would like you to tell me it was an onscreen keyboard that was in a qwerty style, an onscreen keyboard that was alphabetic array, an onscreen that had efficiency of access array. I want you to tell me that it was an onscreen keyboard that did not have word prediction, an onscreen keyboard that did have word prediction. I want to know, when you are looking at access methods, what was the activity paired with that access method? You notice that I did not say just the device. I am saying the activity. That is really important too.

Most of the time I go around, or when I read reports, people will say "The child has had a lot of experience using their hands to increase their independence in the environment." Well, that doesn't help me understand anything. I don't know if you're saying "independence in the environment," some people think that is making a toy go. Other people think that may be opening a door. Some of it may be that you're turning on a blender while you're in a cooking activity. That's very different if the same thing would mean that I'm actually managing a communication device. I want to know all of it. All of it. This is not going to be done in 5 minutes, but when this is not done, it is one of the reasons we are having problems then when in fact we try and look at compatibility issues.

Once you have done this, you don't have to do it again; the history can pass on with the child, so that's one thing that is really important. I also want to know the software that's being used. I'm pretty surprised in many places that people will tell me, "Oh, I'm using a DynaVox." Well a DynaVox has had a lot of different kinds of software, and a lot of different kinds of software can fit into a DynaVox. I also think it's still really funny in the field that we talk about Minspeak but we talk about DynaVox. Now, Minspeak is software. It fits also into multiple different devices that are made by Prentke Romich. And DynaVox is hardware, so it has multiple different kinds of software. I need to know specifically what you have paired with what, and then in addition to that, what access method was used. And now, in terms of the student's history, I want to know how successful it was. And I'm not happy for you to say it was successful or wasn't successful. Again, I'm hoping that you can do specifics.

When we've listed the history, I want a level of independence identified with all of those activities. And although this sounds like a lot, it is. If you are brand new to a student, this, if you want integration to occur, must occur. This process must occur. We have to know where we came from before we can know where we are headed. Then, after we have done the history, we are going to look at current problems. And although I allow people to talk to me about those current problems, and in teams we meet and talk about the current problems, please make them a list. That list can be your love list and hate list if you want to. Sometimes I have to ask people, “Okay, tell me your problems” and they will say, “We can’t access a computer.” Well, that is still too generic. I hope then I can look back at the history and see what ways you have tried, as opposed to “What have you tried?” “We’ve tried everything and nothing works.” This real list could include equipment needs. Tell me what you want. If you’ve got to complain, this is the time. Let’s get it written down. What are the staff support needs? Again, we need to write down here quite honestly “We have a whole new team this year, we have an inexperienced AT person, we have inexperience speech therapist, we have an inexperienced teacher, our whole team is inexperienced, we don’t know the device, we wish we had more knowledge.” The real list could be that our student is experienced. We also could have software needs. We have some older software. We know that this other software exists but we don’t have it. And we could have some other things.

The current problems could be “We don’t have a mount for our chair. The seating itself, the chair is a problem. A mount won’t fit on the chair that we have.” So it could be any of those things, but let’s make a list instead of just having a discussion. All right, when we’ve made that list of what the current problems are, we are going to identify our goals. And this is not the big exciting part. So far I haven’t told you anything that you don’t know, however this isn’t written down. This is not stuff that’s written down. And it is really important because when we are looking at issues of seating and access, one of my biggest problems is the fact that we are utilizing a paradigm of assessment that was not developed for students in school. And that paradigm in assistive technology, and I know this one because I’m this old, and some of you are so young to the field you may not recall it, but this assessment process has unfortunately continued.

The paradigm of assessment that is utilized in the field is one that was developed for adults and there were not adults in school and they were not college students. They were adults who had progressive diseases or who had an acquired injury. So, they were primarily individuals who had ALS, muscular dystrophy, and some kind of other degenerative problem or had an upper level spinal cord injury. These adults were already readers, writers, and talkers, and most of them had also been walkers. So when we begin looking at the issue of Assistive Technology, we begin looking at assessment of their access method first and the reason we could look at the assessment of access first is because they already knew a lot. They had skills. They were fluent. They were experienced and we were then looking at an alternative way or an augmentative way for them to do what they already could and have done. The difference is when we are dealing with children who have never talked, who have never spoken, who have never walked, who have not yet read, who haven’t written, we can’t be looking at access first. You have to have an activity that the person is familiar with and then fluent with and interested in to then introduce access. So access is not the place you start first.

When we start looking at this, it’s one of the reasons why I want this history in terms of how we’re going to be integrating with students today. These first students I’m going to show you have a great deal of experience with different pieces of equipment but still aren’t independent. That’s what we’re really looking for. We are all here for the same reason and that is we are working in schools for children to be prepared for life. That's what we're hoping to do. That means we have to be looking at levels of independence. So, when we are identifying our goals, I actually want you to put away now those papers that are the history, the experience, and all your problems. I want you to take out a fresh paper and say this is what I wish for. This is my wish list. Some of you are going to know that something would work. Some of you are thinking that something could work, and some of you are hoping that something might work. And these again should be specific. I always hear when I ask people what are their goals for the child we want them to be independent. I want them to be able to communicate. Again, not helpful. Communicate with their family. Communicate within their school system. Communicate via writing. Communicate with unfamiliar people.

Those things need to be specific and I am here to tell you that strategies utilized are not the same cross environments. They're not the same for any of us. So, I want that wish list. What would work. What could work. What might work. What you wish might be able to work. I want you to then identify in terms of the goals, where you are planning to start. This is probably the most difficult thing to decide is where to start. Often, it is decided by who, who is willing to start. Who is willing to start this process of looking at integration? Let's discuss some of the common problems and they are going to be the ones that I show you when we start really looking at the students. We have incompatible equipment. That's why you have to give me the list. Not only do you have some equipment that is older, it may be incompatible. It's incompatibility may be the difference of a cable or it may be that it can't possibly work at all. Let me explain a little bit about power chairs. I'm not expecting all of you to know this but I do expect you dealing in the field of Assistive Technology to know these basic concepts. I do not expect AT, OT, PT, speech therapist all of them to know all of the power chairs and how to program all of them but you do need to understand these concepts, all of you, in terms of the field including the teachers too. And that is, when we deal with power chairs, we have what are called low-end electronics.

It's not any different than the field of communication. That means they are the least flexible. Those low-end electronics, although they may have some programmability, most of them do not have the ability to use that axillary interface and to be used also with a communication device and/or computer. Okay? So a lot of times the first power chair that maybe what's decided. It's one of the reasons why I'm really hoping when you're being involved with these multiple systems and if you are looking at and know that a child is being considered for a power chair, that you become involved at that level even if it is simply to say, "Look, I think when they are getting the power chair they may need to use their method of access to also access their computer or they may need to access their communication device." If you know that much, then you need to say, "I need to know what parts. Are we ordering the parts that will allow that to occur?" Because those have to come from the wheelchair manufacturer.

The next thing you have to understand that those parts and the method by which you go to use your power chair to be able to access another piece are not equal. It's as if we would get a representative from DynaVox, a representative from Prentke Romich, a representative from Assistive Technology, and we would ask all of them can I spell on your system? They would all say yes. Can I use symbols on your systems. Yes. Can I do sequencing on your system? Yes. Can I do one-switch access, two-switch access, joystick access, mouse simulation on your system? Yes, yes, and yes. The thing is how you're going to do it is going to be different those systems. The what isn't different. The how is going to be different. Same thing is true of power chairs. So what happens is that if you do say, "I'm an AT person, I'm a speech therapist, I'm a teacher at the school, I want to make sure that child can use that power chair's method of access also to manage their communication device. Will it do it?" That is not a good enough question because the answer is going to be yes. You need to see how. You need to understand although we live in Pennsylvania, one thing about Missouri every person in the AT field should adopt is the Show-Me. Show-Me. All right? You need to have people show you how it's going to happen because it's not a matter of just driving up in front of a computer and pushing a button and all of a sudden the computer is going to work with your joystick. It doesn't happen that way. And so, when you have a signal coming out of the chair we need to have a method of being able to do that and we have to have a method of being able to tell the chair that's what we want to do. And, in my opinion, it needs to be a method that the person who is driving the chair can manage. Let me just give you an example in terms of two different types of ways this can occur. In one of the systems, all of the systems have multiple drives or profile arenas. Those are the same things as user areas. We are used to calling them user areas with communication devices. So, all power chairs have that. As I say, they may call them a drive or they may call them a profile but they are separate user areas. When you plug in the joystick into the chair, that joystick in some systems is the method of access in all those user areas. In some other power chairs, it can be in just a singular user area that you can identify. So in other words, it can be global or it can be isolated. Can you understand how that might be very different for some students? Yes. Okay. One of the things that is particularly for very young students and for those who are beginning to use their power chair, their method of access may change.

The next thing you have to understand is often when you need to tell the chair that you want to be able to do something other than drive, you're going to have an additional switch, and that switch is essentially a reset switch or select switch or mode change. All mean the same thing. And what you're going to be doing there is there is going to be an additional switch site. Don't let you think that your students aren't going to be able to do that. There is going to be another switch site but what that switch site leads you to is critical. Some times that hitting of the switch leads you to a menu that must be read. Well, I work with a lot of students who don't read. All right? So there is only one system that allows you to not have to read and that has auditory feedback but all the other systems will say we have auditory feedback. But their auditory feedback is of the same tone but just signals change. Only one of the systems has a different tone for different functions. So you can't just say there is auditory feedback. It has to be how does that auditory feedback work? So we want to know if in fact we are planning for students to be able to manage their communication device from their power chair with the same method of access, how they're going to do it we want to know how that will happen. So that is really important.

The next thing is that I am really pretty surprised that those of us in the field of system technology all of us have been able to opt out integration. Speech therapists get to say, "Ooh… I don't do power chairs." OT goes, "I don't do communication devices." PT says, "Oh, I don't do alternative access I do the power chairs." We don't get to opt out and I don't care if you're the teacher who says, "Oh, I don't do any of those. I have all these specialists." No. If that student shows up with you with this chair and a communication device or you're in the process of doing it, you have the responsibility to understand how it works. This is no different than if you had a student show up who was hard of hearing and they had hearing aids. You would know, if they fell out, what you had to do with them. You would be shown how to turn them on and off. If the batteries weren't working, it was going to be there. If the person also signed would you not learn some sign? Even the most basic stuff? Yes, you would. So, you need to understand that the communication device and the power chair are now attributes of this individual and just like you don't get to ignore that someone is left handed or they need to sit in the front of the room because they wear glasses, or they might need to use a calculator because they have mathematical problems or they may be motor apraxic so you have to make sure that they have an opportunity to have a structure to the way in which they are doing their handwriting, or in fact they have auditory processing problems so you are going to speak simply to them. All of those are things not a single one of us would not think was vital information we needed to embrace and understand and adapt our teaching strategies to support those things. Yet, somehow, when equipment arrives, still where is the AT person? Where's the speech therapist? Oh, she's brand new. She doesn't know how that works. That's why you need the history still but it is also I'm telling you this is the challenge I give all of us. When somebody new comes into your classroom, when someone new comes on your caseload and you don't know this, in my opinion, you have the ethical, professional responsibility to understand that it is a part of that student. You need to learn it. It is just as easy to crawl down on the floor and find the serial number and to find these pieces. They are not rocket science. Once you understand how these work, you and the student will benefit.

The next thing I want you to know…So there is that lack of knowledge of integration of what the parts are and then there is a lack of real practice. A real practice of integration. The other thing that happens is those of us in the field hopefully none of you have attempted to give a child a device you don't know how to program. I mean, I would assume you don't just go and say call PaTTAN. This is how it works because this is how it came. I got it from the loan program and it arrived like this. Wow! I guess everything is big. I guess I have to start with two-switch scanning because that is how it's set up. No. I think we all recognize in the most simplistic ways that when we get a system, we need to understand how it works and we need to program it. Although there may be some default programs or standard programs or a particular way it's configured to begin with, we need to understand how to alter that for an individual. It is absolutely no different when you are looking at other systems. A lot of people say to me well, I've never been in a power chair. You need to get a hold of one. You need to get a hold of one. Oh, no we can't get a hold of them. That's not possible. Yes it is possible. You can't get a hold of one for a year. You can definitely get a hold of one anybody for a day. Anybody for a day. You can't get it by calling on Monday and have it on Tuesday but every place in Pennsylvania there are medical suppliers and there are manufacturer reps who could get you a chair if you can actually tell them what you needed and a programmer for you to get in yourself. You need to get in these systems yourself and understand what the process is. Not just be shown it but learn it. This is no newer than how we began with communication devices, is it? Home at night. Programming until midnight. Where is the book? Look at the manual. How do they work this? If you don't understand on this stuff, it's like, good Lord, I knew how to do PowerPoint. Where is the view slide? Where's the view slide? You know, they've had to make it so

easy now I can’t do it. All right? As opposed to I knew where things were. Well, I don’t expect that when I look at a communication device because I know it’s so customized that I need to have a way to get into a toolbox. I need to understand how things link. I need to know what some of the underlying messages are in terms of how that symbol performs. How it is associated with another one. When a new communication device comes to you, hopefully you don’t just look at it. You actually have to make it work in terms of doing that. The same thing is we aren’t having very much real practice by staff. I know it’s hard. We can’t take a kid out of their chair and put our butts in their seating. Most of us wouldn’t fit. But also it’s so unique we wouldn’t be able to do that but we can have the like chair and a like communication device that we would be able to try this with. The reason we need to do that real practice is I think we have totally misunderstood what real time it takes to develop mastery. Yet, in the same token, I am tired of seeing the same IEP goal and the same switch and the same program of three choices for four years. If it doesn’t work quickly, you need to change. Now, when we start talking this morning I am going to show you some kids who really are quite adept at all their different systems but they don’t work together. That is not their fault. That falls on our shoulders. I will say that again I know all of us have time problems. There is not a doubt about that. All of us have large caseloads but you have to understand one thing. The way in which we manage ourselves and our caseloads and our professional responsibilities is our responsibility. We need to equally educate our supervisors. It is not the same ten kids who need assistance in handwriting is not the same as one child who is learning a system to write with an augmentative communication device. You cannot as easily support the same children who have to learn handwriting and understand should I be giving this kid a QWERTY key board? Should I be giving him efficiency of access? Should I be giving them alphabetical array? When I am doing word prediction, should it be under the word, should it be above the word, should it be to the left, should it be to the right?
These are very important decisions and they are not ones you can just show a kid and in five minutes decide. You have to live through this process and that is how you need to spend your treatment time in the beginning. And you need to understand that it is going to take some time to figure this out. Because we don’t do that, we’ve not been able to educate them, our supervisors and those responsible for giving us our caseloads as to what the time really should be expected in terms of what we’re needing to do. That is the only reason your caseload continues to grow. When we as professionals can identify it takes us about this time with the new user or if we’ve got someone who is already capable here, we may have to support them this way, we’re going to do the exact same thing we do with any kind of therapy. There are going to be times when we need to move in and work intensively and now we’re going to back out and watch. Well, guess what? In the field of AC, I think we’re lousy at both. We either stay too involved for too long and we don’t do any stepping back.

We just think I’m just going to stay involved and involved and involved as opposed to no, I need some critical time I am involved and then I need to step back and I need this to be working. I need to come back in and then I need to step back and see this working. The three students you’re going to meet today, Christopher, Kaitlynn, and Zach, one of the problems is they are actually all capable at separate situations but the idea of integration somebody, I don’t who, thought Santa Claus was coming to do it on Christmas Eve and it would work. We have all the parts. Why isn’t it working? When you get to the point of integration, you might as well be starting with a brand new kid and a brand new device. It’s all so complex and it’s in layers and you need to try things different ways to see if they’re going to work. You cannot just look at someone and say it’s going to be more efficient. And efficient itself has to be a different definition. What is efficiency mean? One of the things that is the most challenging to me is I am sick and tired of people saying how fast someone can do work. How fast someone can produce work. How fast somebody can talk. As soon as someone talks speed then I know they have never used a device because when you use a device you don’t care about fast. You care about accuracy. When you’re using a device you want it to say what you want it to say and exactly what you want it to say. You don’t actually care how long it takes to say it. You’re not interested in becoming speedy for it to do the wrong thing. But everybody watching you wants you faster and is in a belief of being efficient.

Why don’t we just use this very interesting separate example and one that we do all the time. I’m old enough that I had to take typing classes and not only am I old enough I was really good right away. In fact I was so good, I made money in college by typing people’s thesis papers because I could do 170 words a minute. Flying on an electric typewriter. Now, my bad days I was at 100. Still pretty good. I play the piano. It was something I could do. It was something very simple. It was super easy to do and in fact just came simply. However, the efficiency of me typing had nothing to do with word processing. I was copying and part of the reason I was fast was because I’m a fast reader. Not only that, I’m such a fast reader I don’t stay on the page with my eyes, I have an excellent memory so I actually read, remembered, typed. Read, remembered, typed and rarely did I make a mistake because I didn’t keep my eyes on the paper all the time. I wasn’t even just copying. I was actually reading, remembering, and then typing. Because I could do those three tasks quickly, it was only the amount of what I could do accurately that people could judge. Whenever I went to go get any kind of a summer job, people used to ask how quick you could type. What did they give you? Two sentences. That was really fast. Those two sentences had nothing to do with how you had to type and what you had to do. Did you have to do carbon copies? Thank God, you guys don’t have to do this anymore because you never could wear a white shirt because you were always dirty. The thing is that when we took typing classes we were also just taught to copy and our practice with our two hands was first just on simple rows. The words we use were just the words on a certain row and then we would add words that would let us extend our fingers and hands.

We used our strongest fingers first and then we reached to our weakest ones and many of us took typing for an entire year. At the end of that year, there were still people who did not pass typing. It got to be pass/fail and then it got to be a problem. Why? If this is how kids who read and write and all they are doing is copying and all they were doing was try to manage a typewriter with their two hands and become touch typists, there was a huge variation on skills there in terms of what they were able to do. How can we possibly expect access methods to come quickly? Practice is involved. But practice can’t happen. We didn’t take typing before we read. We were already readers. We already knew the vocabulary we were typing so that you could also look, read, and remember. Guess who were the kids in the my typing class who were struggling the most with typing? The kids who had the most difficulty reading. These skills in terms of when we’re dealing with a communication device, we need to understand we’re not giving somebody a voice. We are more giving them a typewriter than we are giving them a voice and I know that sounds alien because all of the things that we’re talking about in terms of speech emphasis but I’m telling you the part of your brain that allows you to immediately respond vocally has nothing to do with the part of your brain that causes you to write. We know that they are related. We know orthography and spoken language are related but we don't know how. We're still studying that in the brain, how it works, the central nervous system.

We know it happens in two separate areas or maybe even more. We're not exactly sure but we do know nobody, no scientists who are studying it, are studying in English. They are studying it in Spanish and German. So just think about that. We are already just because our kids are in America they already have a problem because their English doesn't make any sense in terms of what we're doing. What I'm trying to make the point of specifically there is that when we give someone a device, we're asking for them to manage the device so they've got to know how it works. They've got to know how the machine works and how the software maneuvers around in the machine, and then they have to put it into a familiar and unfamiliar setting. That's a huge, huge issue and I don't think we respect how complex it is. My challenge to you would be for you to appreciate its complexity, is that I would ask any of you on any workday, I don't care when it is, just a workday. You know that work day we bring our kids to school. I want you to have a workday where you do all the same work you usually do but you use a communication device and don't talk. One day. One day. And I'm not even going to ask you to do it with alternative access. I'm going to let both hands work and I will tell you by the end of the day what's going to happen to you. You will resort to spelling. You will resort to spelling and you find you also will in many situations wait until the next day when you don't have to use it. I'm not calling her today. Whoopee! It already took too long. I will wait until tomorrow. The reason I ask you to do that is because time, time, time is really stretched out when you're using a communication device. It is nothing like speaking off the top of your head. Nothing. It's not using the same brain area. You, in fact, are having to think of what you want to say, hold a thought in your mind, look at your communication device, and even if you don't look at it, you have to hear it. You have to hope that the symbols are there. They are arbitrary symbols whether they are in alphabet or not. You have to pull those arbitrary symbols together and then you have to put them together and then you have to produce them.

Well that is far more like writing than it is talking. We don't expect kids to be extremely good writers until what age? Anybody know? Fifth grade. Fifth grade. And is the fifth grade writing the same writing we're expecting when you're a sophomore in high school? Is it the same kind of writing we're expecting when you're in college? No. So there are huge leaps and bounds after that too but it is not at all the same kind of writing we're expecting when you're a kindergartner. I will tell you that I think it is very interesting for our kids who are using Assisted Technology, almost always falls apart at fifth grade. We start to see it around third grade but fifth grade is when it really gets to be a problem. One of the reasons is that we have not done a really good job at recognizing the time it takes to complete the work even if you're fluent. Even if you're fluent. If you're fluent with your device, fluent with your access. I didn't say familiar. Fluent. If you are fluent, it still will take you a much longer time and for then us to understand that and support that in the situations we are in. The other reason I really want people to start using devices is that I become tremendously distressed at our lack of role modeling.

Although everybody understands role modeling and they think we actually model language, we actually know we don't model language by the way because there aren't too many of us going around saying to our babies, “Me. Mine, Now. Mommy.” We don't usually say that. Usually those are children taking subject, object, pronouns. Reversing them and putting them in different places. They didn't hear that language said that way. They heard the language. They recognized the possessiveness of it. They recognized that there might have been a noun but they misplaced it in terms of where is. I always love when the kids say he wented there. You notice they've gotten the past test has an ED but they put it on a wented. He wented. He drinkeded. He really drinkeded it. That was more than just drink or drank. If its really in the past, you can get a couple ED, ED. He wanteded it. That meant he really wanteded it.

So when we are understanding that we don't even role model language and I think that is one of the things to put in the field we think we need to role model, it isn't that. Instead, what we need to see in an environment is that we need to understand that we see techniques and strategies of communication and independence that are powerful. That's what a child embraces is the power. The power of my voice is one of the reasons why I want to speak because I have an opportunity through that speaking to get what I want and the way I recognize that it is powerful is by how I see that power being utilized throughout the environment. I see when mom wants money she has to ask dad or she has to rob the piggy bank or she has to go an ATM and if she is like most moms, we talk to the ATM. Now, I know men generally don't talk to the ATM. Women, we do. We still want that to be a person and we act like it is a person. What can I tell you. That's how it is.

We talk to the dogs but any rate, we have to manipulate something to get something out. Well, I think one of the reasons why it is very hard to see communication devices really embraced is because they are not being used any place so they are not seen as very powerful tools. When you give something to somebody that no one else has, the only time someone else is going to want it is if you gave them an iPOD. If you gave them an iPHONE, everybody would want it but when you give them this big thing that has these arbitrary symbols on it that don't look like anything, it's kind of hard for people to embrace it. The same thing is happening when we start really looking at real experience. I think it's really interesting that for those of you who know me, I really am a strong student in physiology and the processing it requires for us as human beings to complete things. In one of our latest OT clinical journals in last November, it's very funny that we finally in the real world are beginning to understand some motor learning theory. Now this motor learning theory I would still call in terms of physiology a sensory processing process, but it really started in the field of professional athletes and their coaches. These are people that are quite dependent on their bodies to make a living. Not only that, they do it in front of a lot of people and they want to improve and they can be really well driven to do that. It is from that setting because again it was so vital to somebody's true monetary experience, they want to learn quickly and they want to learn to most efficiently.

There are three things we now know based on these studies of athletes that have been applied to human beings and we are now beginning to understand as a process by which we learn. If we want to manage a motor task, there are three things that have to occur. The first one is while we are learning no one can talk to us. While we are learning, no one can talk to us. That means while we are doing our practice, while we are learning. Can't talk to us. The second thing is that we need to have a mental rehearsal. That means we must be able to visualize our self doing the task. For example. An easy example there is when you are helping a child learn to ride their bike, they don't envision themselves learning to ride a bike. They see themselves riding a bike because they've seen people ride bikes so they envision themselves riding a bike. When you are teaching a child to drive a car, they are not envisioning themselves learning to drive a car, they see themselves in that car. They may see themselves in another car that they wish you had but they can see themselves. So one of the reasons they can do a mental rehearsal is because there are many examples of competency in mastery demonstrated in their environment. We need to have a mental rehearsal in order to be able to practice a motor test. That means we need to see it for us to be able to do a mental rehearsal. The third thing we have to do is when we have completed our practice, we absolutely cannot be told good job. Instead, what we need to be told is specifically what worked and what might work, or how something might change. So the example could be if it was going to be on the bicycle, "Oh honey, you seemed to balance yourself okay but it looked like you were having trouble getting those pedals to move smoothly. Maybe next time you could concentrate on moving the pedals smoothly." It could be when a child was using a communication devise. You could say, "Wow. It looked like you were having trouble using your switch quickly enough to make the selection you wanted or it looked like you had trouble identifying between this row and that row."

What happens is it cannot be a judgment, it needs to be a very specific observation. Not one which you say do next time but instead a very specific observation that you make saying, This is where I saw you had trouble or this is where I saw you looked like you were accomplishing things. "You sure do hear all those words quickly. I saw it register on your face but then when you went to go after them, it seemed you got lost after the first two choices." So, it's very different. That's how human beings learn motor tasks. Those are the three now foundational rules and I will tell you to a one we talked the whole time we worked with our kids, the entire time we are working we're talking to them. We asked them something and don't wait and then we talk with them about how they are supposed to be going after what they are getting and maybe they should and then we throw in a lots of "Oh that's so good, Oh good job, good job. Oh, not so good. Try again." You start to recognize even the software that we utilize that we think is practice. For instance, stitch access is utilizing some of the same stuff. It should not be saying good boy. Good choice. It should say something like try again. There are some other choices. I am not the choice you want. This one doesn't match. It needs to be more specific.

The next thing is this. The next common problem is this one. I have already mentioned it slightly but it really is true. Whose job is this? That is the common problem. Whose job is it? To make things work, whose job is it? It's got to be Daisy. Nope. I'll tell what it is, it's whoever is not there. Whoever is there it's not their job. There are some missing people wondering around drinking a lot of coffee some place and we are waiting for them to arrive on the day we expected. I will say that any of these people could be that person. Could be a primary person and all people who are involved with these situations cannot be equal. I will tell you that whoever doesn't do it, one of these people will. The will part that they may do is that if there is no help is that they will decide that this is not worth doing. That will be the ultimate decision. How things work need to be the responsibility of everybody but even on everybody on your team still try to identify a few key people who are going to do it. How to know about power chairs and the compatibility of equipment? Again, there are fewer power chairs and how they are programmed are so simple they are simpler than the simplest device you've ever had to deal with. The only trouble is that you're just unfamiliar with them. We have not done a very good job in our country between our medical community talking to our school community. That does not matter whether its just with our kids. That's anywhere. We have trouble with having our medical community talk with the patient so we are certainly going to have trouble with it being able to speak to the schools. What I want to say is more and more and more I understand school therapists because that's what I'm doing. Even though I am in private practice it is still the way in which I function. I'm still there too. It doesn't matter if I have access to anything more than anybody there. It means we still have to understand what's coming through the door. Why it's there. What it looks like, and how its supposed to work. Now we're to the fun part. What I want to do is I am going to share with you three different cases here and this is the part I am going to try very hard not to butt in. Meaning I am going to try and not talk over the cases. And you're going to see these are situations where I worked with all these students for a long period of time with their teams. I tried to pull out some key areas to look at.

I want you to meet Zach who also was out from the Erie area. I am going to give you a little clue about the beginning. What is really funny is we are in a setting where because we are dealing with high school students, it was too hard to actually be in the classrooms in terms of internet and they didn't really have a homeroom. We are in a separate room and we were like that with Christopher. Not only was his key team there but there were other team members and AT people interested that were in that region that came. So there were quite a few people around that weren't in the picture. The same thing is true with Zach. The difference is is that when I got to Zach, Christopher actually flew in the room before I even had an opportunity to pull up my computer and wondered over to say hello, so you did not see me introduce myself with use of the computer. With Zach on the other hand, you are going to see me using a computer to introduce myself and talk to him. I apologize that the speaker isn't working well for you to hear. That part is just real, that is the way it is. What is interesting is I am trying to talk to the group who are settling down. Zach is coming in with his parents and I am saying something like, I can't' actually recall exactly, because the hearing—the sound is so good. I usually say something like "good morning. Do you all know why you are here? Is someone going to introduce me to the student that I am going to work with today?"

I am actually saying that with my computer and it is speaking and I am looking around, like I am supposed to. Right? Don't we teach kids that. Say your thing and then look. No one—everyone is ignoring me. Everyone is ignoring me except Zach. I am actually, when I look, I look I am at his same height but it is kind of a camera view. I felt like I was almost at his knees, he is really tall and I was sitting on a little chair and then on a mat table. Out of the blue, he answers me. Everyone else is ignoring me. I am looking, I am typing, I am looking, and everybody is ignoring me. Then Zach answers, which I just thought was amazing. Again, what I want you to do is to see Zach in some real time and we will talk about some of the integration of issues after we have seen it. Here's Zach. (VIDEO)

Let me just pause here for a minute. I thought I edited that a little bit better for you to be able to see. Everybody told me later that they thought I was just ignoring him. What I wanted to say I was really writing out my sentence. Hello. Did someone say to you why I was coming today? Blah blah blah.

I do hope that what you heard him say is "power chair and Vantage." I asked him did he know why he was coming to see me today. That was his answer, "power chair and Vantage." He is already looking that he would like the two of them to be able to work together. So now we can just go back. (VIDEO)

Again, just for interpretation. His mother knows him well. I asked him would he mind me showing me how he was driving. He had to answer yes on that device. Wasn't that interesting. So she had to leave the switch there for him to answer before she can now show him that he is gonna drive. Pretty amazing. (VIDEO)

Well, I see my editing got a bit reversed. Now, see this was the introduction, actually should have happened before. I apologize for that. Just still live through. But that is when I was looking around for people. I thought I had that in the beginning. I apologize for that. I will change that for the next time. (VIDEO)

Now what I am doing here is I am looking behind his chair to see if he has all the components we were talking about. He has those originally there. He has a tilt function on his chair which he cannot manage himself. You can see that he is driving with head array and those are proximity switches, electronic switches within that headrest. For him to be able to go in reverse, his mother has to hit a switch that is the select mode change switch in the back. She hits it. Then he is in reverse. Reverse could be like that, you choose reverse or you could have a separate switch for reverse. You are seeing that he is managing his communication device with a mechanical switch that is being dropped over on top of the electronic switch that is available to him. I am looking behind to see if in fact he has got the interface. Sure enough he does. Okay, so let's see what he decided to do here. (VIDEO)

Oh, I just want to turn the sound back up. (VIDEO)

All I have done is I have already changed it. (VIDEO)

Now what happened is I immediately could set up an electronic switch to manage his communication device. You can see him tapping it and trying to use the same motor pattern he had to hit the mechanical switch. One of the problems was that head array is really huge. It is really a large one that I have never used with anybody. It was one of the first ones that was around. I am putting a smaller head array on his system. He already totally understands what was going on and then I was explaining to him how once we have it plugged in there are a couple of different ways that we can manage it. I will just explain that to you while you are seeing me make those adjustments and adding a smaller switch, I mean a smaller head array. You can either have a drive be each of these drives with his chair be separate so we can have a communication device in one drive and I can teach him to change drives. So he can be driving, change drives, talking, go back to driving. Or we can put it in a menu format and that within a drive he is driving forward, then driving reverse, then talking, then back to driving, then driving reverse, then talking. The way that he would do that is he would toggle his switch in between each of those to manage the menu. We actually, it is a personal preference how you like this.

In the beginning I like to have the communication device just in one drive so guess what, everybody else can just flip to that when they don't have to worry about him driving. Everybody gets used to that he is using an electronic switch. He can choose to manage the drives or he can use another switch. The other thing I want to remark is Zach appears to have dystonia, his mother was told he just had spastic quadriparesis. One of the ways that I can talk about that and I don't have a lot of time to talk about that but it makes a big difference. One of the ways you can see that he does is by how much he is able to open that hand but you see it just rhythmically involuntarily happening at the edge of his tray. If he will attempt to grasp but he cannot necessarily stay on and do that. That is a sign of dystonia. You don't have that with apoptosis. You have that with spasticity. You have that with dystonia. Generally, people with dystonia as a type of cerebral palsy have completely intact systems in terms of knowledge of where their bodies are in space. They also have intact processing systems. In terms of being able to make some of these changes, although there still may be a practice in terms of what he is going to do, it still should happen pretty quickly for Zach. (VIDEO)

I thought I edited it out. (VIDEO)

What I am wanting him to do is not use this necessarily first with a communication device but first feel it and it feels like a drive. Again, it is going to be a little bit unusual. I wanted you to see it is not hard to necessarily do this but it does not mean he will be able to do it right away. He would actually when I am changing anything is with anybody else just as I would change the position you were doing something in and gave you a new computer, gave you a new lap top, it would still require a little bit of getting used to. What I wanted to show you was that this could happen and he actually had all the parts on his chair to be able to manage these things but again from a lack of information including his parents who are right there, very willing. They had no idea these things could go together. That they would have the cables to do or if they had the parts that would work it. (VIDEO)

Okay. What I wanted to say is, I just got a note from the team Zach, how wonderful that we can do this on line. I am going to just read this to you as they sent it to me. In January of 2009 Zach began using a stealth head array on a new echo. He switches between driving in the echo independently and is startling learn how to, they are saying joystick in parenthesis, I think they mean mouse immolation, on the echo along with keeping his switch scanning method. He was recently in the school musical Grease as an extra. A learning support teacher helped him to move around the stage during the dance numbers. Again, just from the time that we saw him but just because we are doing it now, I am glad to hear that he was doing that. We still have to go to class. The rest of you. So we gotta still go back and talk a little bit about what are some of the problems and what we would change. I just wanted to go over here. Ooops. With Zach, he actually had all of the equipment. But again, it was the lack of knowledge of knowing how it was going to go together and when it went together how it might change. He had been driving pretty well but it was still the slow speed. That is what I found out when he turned. One of the things I was wondering when I changed that small head array is he had to come forward with his head to be able to get a switch in that really large one and now it requires more subtle movement. I was worried at first that when he turned he was touching the back pad and the side pad together, those two make a slow big turn on purpose. If you want a fast turn you touch, you come out a little bit and touch only one of the switches at a time. I thought that was happening because that often happens when somebody has had a bigger one and then we have made it smaller. There is a little more subtle control. It turned out that his turns were really really slow.

The next thing I find pretty ironic, I am really a strong advocate of the use of electronic switches when you are using communication devices when you are driving power chairs when you have accessed the computer. That is because they require no pressure. That means that the switch automatically becomes not the activity. Most of the time we are spending too much time at having a kid hit the switch, find the switch, use the switch. That is not the activity. The activity is producing the voice, is producing the sentences, is writing something in terms of getting at the activity. When you have a zero pressure switch it means that location of the switch is its activation. Then you have to release. This is particularly helpful for any of our students who have cerebral palsy. One of the simple facts about having cerebral palsy is that you don't have an opportunity to have graded movement. When you are dealing with a mechanical switch you actually have five things you have to do. You have to first locate it. That location is often visual. Then you have to touch it. Then you have to press it. Then you have to hold it. Then you have to release it. Because many individuals who have cerebral palsy don't have graded movement as an opportunity of control in their repertoire. They do—they know they don't have graded movement. They do one big windup and go right to hold. Then what do they have problems with? Release. Okay.

When using an electronic switch, your location is its activation. You only have location release. Because you only have two activities there is no graded movement involved. Quickly the switch can become automatic or transparent to the task. The switch is no longer the task. That is one of the reasons why I also think when we start looking at our kids who have the most complicated bodies, why we somehow fell in love with single switch scanning in a way we never should have. That is the only reason we fell in love with single switch scanning was because a kid could not hit a switch repeatedly. Two switch scanning, just for reminder those of you who may have forgotten what it does, two switch scanning is I do not have any timing involved. I have complete control. One switch is managing the array. The other switch is a select switch. That array could be as simple as a single line or it could be a group, and I select that group. Then it could manage the lines in that group, I select the line. Then it manages each item and I could select the item. The reason we did not do this with mechanical switches is because kids were doing big wind ups. There is no possible way with a big wind up that they could hit, hit, hit. We decided we would do a single switch, simply. We could not deal with how much effort it was requiring them to get through an array.

When we went to a single switch the part that we ignored was single switch scanning requires rhythm. Because they also did not have rhythm because rhythm is a graded movement, we made the scanning array short, like 3 choices, 4 choices. Well, it is hard to get rhythm with 3 choices. You can't play chopsticks—ey—ey—ey—ey—ey—ey—ey—ey—ey —ey—ey—ey—ey—ey—ey—ey. It is not going to be like the song. For you to develop rhythm you have to have a song and you have enough keys to play the song but you also have to know the song. Then by knowing the song go find the song. That is really how you become a scanner. We have actually asked someone, we have taken a technique just simply because repetitive switches were impossible when mechanical switches. They require too much effort. We then went to a category of single switch but it required rhythm. And because there was not a rhythm we then insisted upon a weight. Then you have a limited window of how quickly to hit the switch. We then extended the window.

Now this is our array. Lets just choose for selections like A, B, C, D. They are like this A—B—C—D, whoops I missed it. A—B—C. You can see what happened is that we have taken it out. When we have kids learning, learning, learning. I want them to be able to explore their software independently. In order for them to be able to do that they need to be two switch scanners. They could also be three switch mouse simulators we could do that too. They need to move out of the range of timing. If in fact, we then want to go with that timing and you do have some single switch users who are already pretty good at that, you can also try an electronic switch and you will be pretty amazed how quickly they do not have to use as much effort. It may not look like they use much effort. We will see some students this afternoon that makes a big difference. For Zach, I had to really show him because I cannot tell you how many students I see all over the United States that have an electronic switch embedded in a head array and someone is Velcro-ing on the mechanical switch that has to be flipped over for them to breach, for them to be able to talk. I just find it hysterical. Most people don't even know that the possibility of that electronic switch in the head array could be theirs. Again, how we teach somebody else to do that, we can be able to and we also need to move to electronic switches. Last but not least, Kaitlyn. Yes? (Audience member asks question)

I guess I am not sure what they mean by integration with a manual chair. The only thing you could be—if you have switches in the manual chair what are you integrating. Integration generally presumes you are dealing with a power chair. Now if you are looking at that you would be able to use a communication device and a computer that sort of is integration but even then you would still be using your method of access that still depends upon how that communication device works with a computer. Whether you would use that communication device as a keyboard immolator so that you can use that to just speak to the computer to use whatever is on the communication device to print it, or whether or not . So that really actually not integration, so whoever that person is that wrote an email maybe needs to have my email address and tell me what it is you really wanted. Integration really means that we take power chair and we are being able to put an output out. They may have been asking about electronic use with a manual chair. You can use electronic switches with a manual chair by having a battery pack. Then you can, you can have in a head array, you can have a head array on a manual chair to use electronic switches to activate your communicational device or electronic switches to manages your computer, software programs so you can do that. That just requires a battery pack. Hopefully one of those two was maybe what they were asking. All right lets meet Kaitlyn. (VIDEO)

Although that was a long one to look after. What I wanted to show you is the therapist all had legitimate concerns. The thing is when you actually take her out and go through all the examination of what is going on; again this is a student who is in high school. It is one thing for us to say what we wish how her body would change and it is another thing to look at how we have to accommodate what is going on. Another thing is we need to look at what the choices of some our equipment has been. This chair is one of the few portable power chairs that exists and that is what they needed for her home. When you make a decision about something it always impacts everything else. The fact of the matter is was she functionally independent in that chair. Yes, she was. Clearly she can drive it. Was she functionally independent with her communication device. Yes. Yes, she was. She could speak all the time. She talks to her mother and her mother understands her. That often is often true and they are not making that up. She has that little high pitched voice and what I would be carefully listening to her you could catch a lot of stuff too. What are we are going to do when she has an overly rotated pelvis. What that means is that she has a scoliosis. Scoliosis is an active disease state. It is not something that is fixed. It changes. It has exacerbations and remission. It can be a direct relationship to how the shoulder girdle and pelvic girdle work together. The fact of the matter is she is overly rotated. How she is getting stable on that pelvis is unbelievable. But she has figured it out. If she figured out if she would move slightly forward, let her legs go out and her ankles cross. She had complete control of her arm and her head. But everybody kept correcting it. As we made her right and she is a teenager. It is a very different thing when you start talking about—we look at alignment of bodies when we are looking at bodies that are long and are fluid and are maturing. It is very different when you are looking at mature bodies. When you are looking at mature bodies you have to understand what they are now. What they are doing now. What they are able to do. You could see that when I got her on my lap, what I was looking for is does she have postural control? Is her head control under her control. It is. The only thing is that she could be upright, I could not—there is no chair that would allow us to place her that far upright and have her legs underneath her because of the pelvic rotation her knee, her hip joint had to be open to almost standing. You would have to have her propped on what almost looks like a stool in a chair. No possible way you could do that. It would be totally inaccessible. You could kind of build something onto the base of a chair but it would not make sense in terms of any environment. I did that to see does she have those equilibrium reactions intact. Does she understand where her body is in space. Yes. Yes. Yes. And yes. Then when I put her back into her chair and I was creating—trying to make that anterior tilt situation so I could see if I could get what I thought she had best. Same thing. I figured out pretty quickly with the amount of rotation she had she needed to be where she was. And that’s probably the hardest thing to realize is that when your wish list…you think everything is wrong, then you go to discover that everything is pretty right. Only, the thing is that she doesn’t know, and that’s what I talked to her at the very end, if I had a choice of what are the things that I would wish for her, I would wish that I could teach her to tell people she slid. Because, what happens is, her sliding an inch at her pelvis doesn’t look like anything to us; she looks in the same position, you can’t see that, especially with a rotated pelvis. How do you check? The thing that everybody was worried about! Her arm gets caught on the trunk lateral and the elbow hits the joy stick box. So, everybody is trying to change position when all they need to do is slightly move her pelvis back, and she would be fine. So, if she had a way of being able to tell that.

The next thing that I wish that I had talked to her about is that I wish there was docking station for her pencil. And, if she is all the way back, she can reach completely across. Everybody has presumed, because she is right-handed, again, the right thing to do is place it where the joystick, but then it would be in the way of the joy stick, wouldn’t it? So why are we hung up on what the right thing is to do when instead we need to look at function. This is a mature, young woman. We need to stop worrying about what we think we need to do to fix and instead the fixing part we need to be worried about is that she is more independent. If she can reach, it would be an opportunity for us to look at, could we built a docking station that she could get a hold of the pencil? Can she get a hold of it? Well, she could really open her hand to take it from somebody, but she took it like this from back here; she didn’t reach it this way. That is the other thing that is really a problem in terms of a docking station. She may need to have it higher in a place where she can reach open and get it. Now, we tend to think of a docking station as almost a little holder that the pencil lies in. That is because that's the way we would approach it; so we would approach it by rotating our arm, coming at it with the wrist and grabbing this way. That's not what she has. She has a rotated pelvis and with a rotated pelvis, the arm that she has is already in external rotation at the shoulder, so she has got to be able to come at a grip to reach it this way and pull it. What happened is from those patterns of movement, that would be something that I would wish she could have. If we couldn't do that, if we can't find a docking stations for her, what other way might we be able to help her be more independent at looking at integrating those systems? I have to tell you, the electronics she that she has on that chair, the joy stick could not be what manages the communication device. It wouldn't be my choice anyway. She does such a great job at direct selecting that I wouldn't have her go to a joy stick.

Well, the other thing might be, is that we have an augmentative communication device to our augmentative device. This would classically be like a little MAC. I could say, could you put the pencil in my hand so I can talk to you? I could have two messages; the other message was, I slid slightly, can you move me back in my chair. If she had those two messages that could be located in a position that she could actually touch with her elbow, she has a lot of movement. That could be something that can be controlled at her head. It could be switch that would be easily located there. It could be with her other arm that she just had to touch it with an elbow. Do you know what I mean? You would have to look at some place that would be easy for her to get but not dependent on her communication device. Is it not more independent if you can request someone to set you up than it is if you just have to wait? Yes, it is more independent. In this case, sometimes more independence is that we actually augment the augmentative communication device by something we used to call an attention.

We used to have attention buzzers all the time. It just was a call, and that meant come over to me. Well, I am happy to say that now we have small enough devices that could actually just give you those two messages. Does that make sense? So in terms of looking at it, the other thing I love is I love how Kaitlyn knew she was right.

We worked together for 3 hours. Whenever I go see somebody, I think this is one of the things you need to remember to do, is you want to look at them within the system, take them out and look at them, look at the system separately, and you may want to stimulate some change, but make sure you still go back to the system the way it was because that is what she has to live with, and see if there are any changes you can make there. I am happy to say that, really, by the time of just examining all that, I hope that I brought a better understanding of how she used her body; what choices she had made so that we as therapists didn't have to be so worried. The other thing that I would hope is that she needs some time out of that chair. That's the other issue. But that is true of anybody in a chair needs some time out of their chair. That should help alleviate you looking at anything. If, in fact, we try and move her into what we think is a more right position, she gets really tight, and that is also when she can't control her self. Kaitlyn is a great study that things weren't nearly as wrong as they thought, but we weren't understanding why she was doing what she was doing. Now that we understand why it is, we can also look as a cue to what part actually slid, and what got in terms of being in the way?

Any others from the group here? First of all, she is worried about, are we looking at some little, unique position that this person is totally functional in? No, because remained functional through school. She didn't care if she banged her elbow, and she had trouble reaching some of the far areas, the far corners, which by the way, the far corners you don't use very much. In terms of looking at how adequate, when you have somebody who has a rotated pelvis, I don't know if you understand how critical the pelvis is to the support of your body and your control of movement. But when it has already begun to rotate, you don't have very much room to control yourself. The relationship between the pelvis and the shoulder girdle is really, really critical. What is going to happen is that people are touching her all day long, but they are not touching her in a way that is helping. That is one of things I am trying to get at. If, in fact, you have the opportunity to figure out that this is a position in which you can identify and function, and that individual can identify that they need to be there, when you get back there, the more you are there, the more control of your body you will get as opposed to losing control.

You need, all of us have a very tiny space that we actually have control over to use our hands, use our body in a long-term engaged task like using a communication device. As much as you may move and shift, you don't move and shift a whole lot. We all move from a center area. Her center had been majorly altered, so she has that centered area, which by the way, for the rest of us is between sacral level 2 and our ischial tuberosity, this small pyramid which is about this size, and we are going to be moving that until all of us would move it slightly a little bit over here and then we move from that. As much as it looks like we had a lot of movement, we don't; not to be able to use our hands in a fixed position in a way. Hers has been altered, and when hers has been altered for her to gain control, she needs to spend more time where she has control, and right now, no one, in fact, knew that was the position she had control in. Instead, they only saw her slipping out of it. The more you can identify where that position is, there is a potential that you can offer her enough support in a different way that she can maintain it longer. Does that make sense?

The trouble is, she is in a power chair. The way we would do that is that she would have a power tilt, and that doesn't go on that chair. So power tilt would allow her to move the chair back and then she could drop in. She could drop herself back, she could push against her foot rest and push herself back in, and she could reposition herself. What I want to know is, is during the day has she already so tolerated change of positions and just succumbed to them that it would just be like you and I have styles of driving that we do when we are tired, which is not the best way to drive, but we have them. One of the classics are your hands at the bottom of the steering wheel. You shouldn't be like that. How should you be driving? Ten and two! How often when you are driving do you drive 10 and 2. Now, only if you are an experienced driver, you only do that when you are nervous. So you actually only do that now in a dangerous situation you are not used to. So you actually move to a position you have less control, is not safe, but you have just accommodated to it. There is nothing about it that's right, but you have done it anyway. That is the same mechanism she has done when she slides out and it is still okay with her. I want to bring her back to a bit more conscious knowledge of where she is. And then if she is there longer she actually gains more control of it. That is why you need to find the key spot to begin with given it is a key spot in that seating system. That is why there is such a limitation. I hope that answered some of your questions. Any other questions?

Well, everybody gets to lunch a little bit early. Thank you very much and I will see you at 1:00PM.