

# Supporting Communication of Individuals with Minimal Movement

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A webcast for the AAC-RERC

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DB: Hello, my name is David Beukelman from the University of Nebraska – Lincoln and medical center. And today I’m joined by Susan Fager, and Susan by way of introduction, tell me a little bit about your role in the AAC field.

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SF: Yes, certainly. I’m the assistant director of our communication center at the Institute for Rehabilitation Science and Engineering at Madonna.

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DB: And, you also have a research role...

SF: We do research at the institute; we focus on new and emerging assistive technologies with adults with severe impairments.

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DB: This webcast that we are going to present today, comes out of several years of work that we’ve been doing, trying to serve people with very minimal movement, and trying to support their communication. In this webcast we will be discussing several different types of people with different medical conditions.

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This was a presentation that we did at the RESNA or the Rehabilitation Engineering Society of North America in 2009, as well as on the World Congress for Disability. The webcast is sponsored by the Rehabilitation, Engineering and Research Center on Communication Enhancement, we call it the AAC-RERC for short and we would like

to thank them for their support and we would especially like to thank Olinda and Merle and John. You will meet them in videos of the film today and they're doing more than just demonstrating the equipment for us. They actually work with us closely and they give us their opinions about what they think about developing technology. They are very much a part of our effort. We also would like to thank Tom Jacobs of InvoTek who does a lot of our technical development work and of course contributes in a lot of other ways with his ideas as well. And then Laura Ball who used to be here in Nebraska and is now working at East Carolina University. Laura was very active in the ALS area and you'll be meeting more of her work later on. We'd also like to thank Amy Nordness who now works with us in the ALS area. Finally we'd like to thank Vicki Philippi from the Education Department at Madonna Rehabilitation Hospital who helped us prepare this webcast.

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The presentation rather will come in three different parts. The first one will be to talk about people who have minimal movement as a result of brain stem stroke and they present a unique challenge that we'd like to talk about. Our work here is part of a project called the New Interface Project, which is part of the AAC-RERC. The goal of this project is to develop new AAC interfaces for people who present interesting challenges. We'd like to comment at the beginning that we're going to talk about some technology today but truthfully there are many other types of technology that are quite similar to some of it that's produced by other companies. We'd like to refer you to Tech Connect, which is a website and a resource that is on this same AAC-RERC website, for extensive information about the technology in the AAC field. Let's begin today with people with four different etiologies. Susan, you do a lot of work with these individuals. You want to kind of talk about the challenges you face with them?

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SF: So let's talk about some of the challenges that a clinician faces with working with individuals with minimal movement capabilities.

First off, a lot of them are medically unstable and so it really changes your intervention in that you often have to limit the periods of time you work with them. You have to work around the medical care providers because they are so medically fragile. They are very fatigued, and their endurance is low. Because their movements are so limited, it's difficult to find technology that fits what movement abilities they have.

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Positioning is an issue.

A lot of them are in bed and can't tolerate sitting upright or aren't able to get up in a wheelchair yet. Also, the technology training and the ongoing support these individuals need because typically the recovery is a slow process or if their in a degenerative condition they might be in a wide range of settings and so training is quite extensive.

DB: Don't you also have a unique situation if someone has a medical issue like this that as you're trying to serve them you really have to maintain day-to-day communication because they need to communicate about their medical condition?

SF: Right. Also the change in staff and caregivers that they have in a day-to-day situation in a medical facility really requires that on-going communication.

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DB: Today as we talk about these different areas, we're going to be talking a certain amount about clinical decision-making.

We'd like to call your attention to a book that was recently published and it deals with a chapter in the areas of AAC and intensive care, brain stem impairment and spinal cord injury. As I page through it traumatic brain injury, ALS, degenerative diseases, Aphasia, and so on. What we did is we invited clinical experts in AAC across the nation to get together with colleagues who are also very expert in that area and present a chapter on the clinical decision-making process for these individuals and would encourage you to take a look at it if you're someone who currently serves people with chronic-acquired medical conditions or someone who plans to potentially be in the future. What we're going to do with this presentation is we're going to kind of talk about intervention phases since that's how the book is organized. Why don't you start with the initial assessment for these people?

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SF: Some of the initial things that a clinician needs to consider in working with an individual with brain stem impairment are first establishing a yes/no response mode. It's very important for these individuals to be able to communicate their basic needs and one of the earliest signals we often try to find is a way for the person to signal a yes/no response. Additionally a nurse-call system is essential for an individual because they are so medically unstable and the fact that they might have some emergent medical needs that they need to communicate to a nurse finding a way for them to work a call system is essential. Some of these individuals aren't able to access a traditional call system or even an adaptive call system. At our facility is an example in these situations where we have to establish a fifteen minute checking system where nursing is required to come in and check on that person every fifteen minutes to make sure that they're okay and that their needs are being met until they can have a reliable and consistent way to access a call system. So

your initial assessment really focuses on those basic areas. Early in recovery we find typically that individuals are communicating when they're able to communicate, they're doing it in a low-tech or no-tech means. Some examples of this are eye-gaze systems so early in recovery we'll see that a person has eye movement and that may be one of their earliest responses and so we're able to use that movement in an eye-gaze response to communicate their needs or eye-linking or partner dependent strategy.

DB: When you're doing the eye tracking or the eye-gaze, how much time do you spend reminding staff of the system and what are some of the barriers they face?

SF: Actually you work quite closely with staff in developing a system. Usually you want it to be simple so a lot of individuals can pick it up.

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New agency staff, float staff that are coming in it has to be a really simple, easy to use, concrete type of a system. Some of the barriers are the change of staff, the new people that you'll be working with. Education is probably one of the largest roles you play early in intervention so once you find a real easy, consistent method of communication then making sure all of the caregivers are trained, the family is trained, that there is information about it on the wall, that's just as easy as possible for any individual to use.

DB: Maybe you could talk a little bit about the medical course of these people, I guess I don't mean medical, I mean where are they receiving care because that also seems to fit in to this a little bit.

SF: A lot of these individuals you'll find are early in recovery in an acute rehab environment or in an acute hospital environment. It's primarily medical and medical staff that are around them. They may transition briefly into an acute rehab environment where they might get daily rehab if they're making recovery. In some cases as well these individuals will go from an acute care setting and briefly in rehab but then quickly into a long-term skilled nursing facility.

DB: So that also means they've changed environments two or three times and so they have new staff that have to be prepared. Especially when they get into long-term care depending on the respiratory status they may be at a place where people are very familiar or they may be in a place where the staff is not that familiar with people who are this severe.

SF: Right. One challenge that I confront a lot is everybody having their own technique, low-tech technique of communicating with the patient. It can be very confusing. So if everybody..

DB: Oh you mean different staff members. They come in and do different things. I'm getting the picture.

SF: So that can be challenging. You're role is definitely education and having a real presence with the patient and their care and making sure everybody is on the same page. It just results in actually the patient being more accurate in their communication.

DB: One of the things that we talk about sometimes is that a person is accurate in their communication for the first four or five turns and then after that things start to get a little difficult. You want to talk a little bit more about that and why that may happen and so on?

SF: Yes, we've seen that quite a bit in several of the individuals we work with. Especially I've seen that a lot in individuals who have had brain stem impairment. They're so fatigued and they have to work so hard just to stay alert and awake in order to respond to your questions and use the technique that you're training them to use that after about four or five minutes it starts to fall apart because they're really just losing their ability to concentrate and are just so incredibly fatigued. In these cases we've really worked hard to first educate the staff as to what's going on so they understand this person can communicate meaningfully but you need to keep your interactions brief with them and then that also has led us to alter their rehab schedule so instead of getting a half hour of treatment they might get ten or fifteen minutes at a shot and just get it more frequently throughout the day with more rest breaks.

DB: I think it really shows up when everyone comes together, family comes together, the staff comes together, the person is there, and they want to have a meeting to decide about the future. This person has five minutes or so of involvement and these conferences often go longer and you have to be really careful the person is communicating what they really want to communicate at a time like that.

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SF: So then you move on to the formal assessments and some of the key considerations.

When you're doing a formal AAC assessment, funding is a consideration with this population primarily due to the long-term placement decisions that get made. Since these individuals are so severely impaired as I mentioned earlier, they might just have a very brief stint in rehabilitation so they might actually even skip it altogether and go from an acute hospital to a long-term care setting. This dramatically impacts their access to funding for AAC systems and definitely needs to be considered as early as possible.

DB: Now I might slip in here and say and this is particularly true in the United States where Medicare does not fund these equipments in a long-term care facility although Medicaid might.

SF: Right

DB: Of course when you look internationally other countries handle this in a very different way, but go on.

SF: Also, technology is another consideration. We're fortunate that technology continues to advance and there is a wider range of options available for people with minimal movement. Some of the eye-gaze technologies, the head-tracking technologies make a high-tech recommendation definitely possible for this group. Some other things to consider when you formally assess somebody, the fact that there's really going to be, it's not just a one-time assessment. In this group it is kind of an on-going follow-up strategy if you're able to keep in touch with these individuals. If not then establishing a communication advocate for them is absolutely essential because over time they might change facilities that they live in or their living situations. They might go from a facility to home or from a home to a facility or two different facilities and within the facilities there are commonly changes with staff turnover, and just making sure they have an advocate in place so that on-going education can occur. If there are problems with the technology it can be troubleshooted. There is someone to go to, that's really an essential part and something you really need to consider when you're doing a formal assessment with this population.

DB: Once you've, that formal assessment is a big process so that takes some time and it takes some testing and feild trial and so finally you settle on a piece of equipment for someone or a strategy. In most cases it is a series of strategies isn't it in that you have at times when everything is set up in a certain way they may use their high-tech equipment but then other times when they're in different situations they may use low-tech. In fact routinely use low-tech as well so they are what we call multi-modal communicators. Anyway so you've gotten to that stage and then what's the last phase of intervention.

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SF: Well this phase is the on-going assessment piece where you're really customizing the technology, training the staff and caregivers, the communication advocates, but also you're preparing for modifications over time in keeping those in mind. In some cases individuals will increase some of their motor functions, but the recovery is typically very slow, but you want to make sure the communication advocates and the caregivers realize if there is a change in motor function then that might prompt additional assessment. That might make access to different

technologies or more efficient strategies possible for this person. Some individuals also have changes in speech so some might be recovering some of their natural speech capabilities and that might change the low-tech strategies that you use with them. Just establishing that long-term support system because there are changes over time not only in their living situation but also with their own physical state and making sure that long-term support system knows when additional assessments are triggered or additional treatments are required.

DB: There really are several different strategies in the long-term that people use for speech-generating devices for these individuals.

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One of them, and the one that was used initially was switch scanning and this was where the system scans through your options and you activate a switch to make your choice. This was, in an earlier time, much more widely used than it is now partly because we did not have any other options frankly. Now, while some still use it, it is used much less. It is cognitively demanding. The communication rate is quite slow compared to other types of access to AAC technology and so today we're shifting and we use more head-tracking and we'll be talking more about that for those who recover head movement and then in the last few years we've become much more active in the area of using eye-tracking for these individuals so that if they have eye control, they can use that to access AAC devices. We'll be talking about head-tracking next, and then eye-tracking we'll kind of combine in the ALS part of this talk.

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We've been working on a project for a number of years in order to get very precise head-tracking access so that a person can utilize a laser system that is eye safe so that we don't have a problem with them pointing it toward staff or a child running up and looking into the laser that kind of thing. It has several components so why don't you kind of introduce people to that and then we can get on to the videos where we show that in operation.

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SF: Well the safe laser access system consists of a laser pointer that an individual can mount to a headband, their glasses, any moving body part and then also a laser sensing module and as David mentioned this is a safe laser system and what we mean by eye safety is that the system goes to low power, a low pulsing beam that is eye safe until it's directed at the laser sensing surface so that's what makes it eye safe.

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DB: And on this slide, they can see the latest prototype of that particular system and you see the different components of it. It's also very lightweight and relatively small footprint so that it can be used in medical settings, long-term care settings, it can be easily carried with the person if they go to a family kind of activity or if they leave the facility for some reason or something like that or go to a different room in the facility. However, we'll get into this discussion by talking first about some of the really early prototypes that we developed.

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SF: So on your slide you'll see the picture of our initial prototype that was used, our phase one prototype and it kind of points out what the laser pointer is and the sensing surface. In the first picture you'll see this gentleman. His name is Merle.

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Merle was our first case study with the safe laser access system and in the early stages of using this we had three areas of exploration. We looked at it as a primary communication system, also as a head movement-training system and as a transitional system, so a system in which you can use to transition into different types of head tracking.

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As I mentioned Merle was our primary or early case study. Merle had sustained a brain stem stroke and when he came to our facility he was locked in, he had locked in syndrome. The characteristics of locked in syndrome is that your essentially paralyzed and maybe the only movement that you have is vertical eye movement and that was indeed what Merle had when he first came to us. We were able to introduce the safe laser access system with him after he'd been with us about two and a half months. He started to show a little bit of head movement. Prior to that he used low-tech primarily or no-tech to facilitate as a communication method.

DB: And I remember really clearly when we introduced Merle to this brand new prototype that we had. His medical condition was pretty fragile at this point so we went in and explained it to him and said are you interested? He flashed his eyes up to the ceiling, which is the way he communicated yes to us. We set it up and kind of introduced the staff to it and introduced his family to it and so on. He had it then in his room. The thing that impressed is that he was very insistent that when he was in bed that that was turned on so he had access to it. Didn't he?

SF: Right



DB: In the evenings when he had down time, he wasn't in treatment and after his family had left and so on, he would then work with this system. Interestingly enough when we watched him we couldn't really see any movement. He was so locked in at that point. Then the breakthrough came.

SF: I think it was really powerful for him to see that he actually had some control over something and so that really motivated him to continue to practice that movement.

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On your next slide again, you'll see the picture of him using it in vertical alignment so one of Merle's earliest head movements was actually vertical so we had to arrange the messages he was going to communicate vertically on the display. He used those to communicate basic needs to staff but then he also used that to practice his head movement training.

DB: So in other words he didn't have horizontal side-to-side head movement. He was just up and down in the beginning.

SF: Just vertical head movement initially. After extensive practice on Merle's part, he was able to move over into an alphabet overlay. He started to gain some horizontal head movement.

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As you'll see in the next slide, there's a picture of Merle using this display, and he used it primarily as a low-tech method so the communication partner would call out each letter as he landed on it, and he would spell out his messages that way. He participated in care plan meetings that way. He had conversations with his wife. He communicated and directed his cares with that method.

DB: We have a video of him, and that video will illustrate his use of the system during those early phases. It also kind of shows the increasing, but somewhat motor instability later on as he continued to practice and develop that really stabilized. So why don't we take a look at the video.

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##### VIDEO TRANSCRIPT

SF: If you were having a headache, pain in your head, where would you put the pointer?

Narrator: Once Merle began to gain some control over head his movement he started using the safe laser system to point to messages he wished to communicate.

SF: What if you were having a pain in your stomach or chest area, somewhere kind of in your torso? ...Yes, good

Caregiver: Wow, right on!

SF: Try to hold it here for the count of 5.

Narrator: He uses safe laser throughout the day to practice head control as well as to communicate.

SF: 1, 2, 3, 4, 5. That's good. Let's go up here to the one at the very top, "I feel pain." Hold it for 5 seconds. 1, 2, 3, 4, 5. That's hard to do isn't it, hard to hold it still. It's hard to leave it on one, isn't it? It's kind of bouncing back and forth. Can you get the dot closer to the words? And try to hold it in this area for the count of 3. Very good, there you go! Nice job. Now you can relax.

SF: Tell me what did Karen, I know Karen has been having you do food trials. What did you and Karen try yesterday for food?

Narrator: As Merle's head control increased he quickly progressed to spelling out all of his messages using the safe laser.

SF (for Merle): N, O, T, T, no, New word, Ok, so Not, T, O New word, so Not to... M, U, C, H. Not too much, huh?

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DB: So in the video you saw him using the first prototype and in this particular slide you see the latest prototype that is nearing field-testing right now.

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This picture here shows him using the device in a somewhat different way. You were there. I see you standing next to him. Why don't you talk about how he is using it now?

SF: Merle used this device connected to a laptop computer so he would spell out his messages on the board and the actual keystrokes would be sent to a text document on the laptop computer. He was in a skilled nursing environment at this point so this allowed him to spell out longer messages without the care staff having to stand there and look over his shoulder as he was communicating.

DB: So now he really has two systems doesn't he? He has the low-tech kind of version where he can point to the letter and the care staff can call out the letter he is pointing to and kind of co-construct the message that he is working on and then he also has the ability to prepare longer messages that can be spoken through the computer. Since he doesn't travel a great deal, the idea of having the one device act as an access to a laptop computer seemed to be a pretty good solution for him. Didn't it?

SF: Yes

DB: We followed up on this. As a result of Merle's experience and our experience with a couple of others we began to realize that there were people out there that might be able to develop greater head control if they were given a very precise tracking system like the safe laser system.

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What we did is we started a study. We had collaborators from quite a number of sites across the United States, and in the end we settled on seven people. These were people who had brain stem stroke, had very minimal movement or were locked in. They ranged in age from thirty to sixty six years, and they ranged in time post onset of their stroke from four weeks. One man who had had the stroke in his late teens or early twenties I believe had actually been locked in or essentially locked in for eighteen years. One lived at home; six lived in a long-term care facility. What we did is we evaluated them and once again you were kind of the lead on this project so why don't you go from here?

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SF: So what we did is we constructed a series of interface displays, kind of targeting the head movement training piece and they consisted of cells of two so we had two locations on an overlay. Then we had four, eight, and thirty-two.

DB: So some people started at two and then they went to greater as they could handle it. Okay.

SF: Right. So the idea is they would be assessed initially by the therapist, working with them as to what overlay they could handle. They would work and progressively work up to thirty-two cells. We collected data on the following: we looked at their age and accuracy across the different interfaces, their consistency with laser movement, also estimates of their laser use for communication. So some of the individuals used it to support their communication. Also, we monitored sort of their health status throughout the evaluation report because as we mentioned earlier this is a population that is typically medically unstable and frequent hospitalizations occur. That's a common occurrence for these individuals so it was

important to gather that information as it might explain some of the results that we were able to get.

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So this next slide sort of summarizes the results of the study from the seven individuals. You see that we have at the top there their pre-laser AAC strategies. So what did these individuals use to support their communication primarily before they started using the safe laser? As you see all of them used no technology to support their communication. It was primarily eye gaze. Some of it was eye movement to communicate yes and no. Some of it was eye movement and partner dependent scanning and facial expressions. Those were their primary communication modes. The length of training for these individuals occurred from one month up to six months and then you can see what their movement outcomes were. It looks like everybody pretty much started out with two cells. So these are individuals that were really pretty severely impaired in that they had pretty limited movement ability. Some of them were able to increase their movements to control a thirty-two-cell display. A couple individuals transitioned from using the system to using commercially available technology at the time, a head mouse and a Dynavox. You can see there was a number of individuals as well who had numerous medical setbacks and were hospitalized numerous times, which as I mentioned earlier is just a common occurrence with this population.

DB: What we found with that is that if they did have, and it was mostly pneumonia was that the problem? When they did have pneumonia and were hospitalized they would come back so fatigued that it would take us sometimes weeks to get back to where they were and so the health of these individuals really determines. I think from an everyday clinical perspective that means that when things are going well they may be able to use one kind of an option but you have to have some fallback options in case the health problems occur. Of course the other you have to have a communication system that will support them when they're in the middle of a health crisis so that they can communicate with their caregivers and their health-care givers when they are hospitalized or when they're in their long-term care facility. We were encouraged with these results. You have to remember that these were individuals who were only eye tracking or eye gazing and eye linking when they started, and there was a subset of them when the circumstances were right were able to move toward a head tracking strategy and at a deeper level it intrigued us and them that even though they had been limited for a period of time that when they were given the appropriate feedback, very precise feedback about the minimum movements they were making, a number of them really increased their ability to move. That's something to think about and it's something that encouraged the funding for the next phase.

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DB: What we had done also is we realize that with these individuals with very minimal movement, some of the commercially available equipment at the time was what we call relative head-tracking equipment where people had to do quite a bit of head movement to calibrate it and recalibrate it. It required quite a bit of head movement to in fact interface with the access system and so we began to work on a second project in head tracking that was really based on what we call absolute head tracking, a two camera system for head tracking that we've called the AccuPoint system. Why don't you go on, you did a lot of field-testing on this one so?

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SF: Yes, well I'll talk about our preliminary case study with the absolute head tracking or the AccuPoint system. The individual I'm going to introduce to you is John. He is a sixty-year old male who has what you would call chronic Guillain Barre. He initially came to our facility with Guillain Barre. Over time he was able to recover some head movement but that's essentially where it left him. He is not able to move below his neck so his condition is a bit more chronic.

DB: Now, many people with Guillain Barre have a complete recovery don't they?

SF: Yes

DB: In fact three quarters do.

SF: Right but there is a subset that have these chronic long-term conditions and that's the situation that John was in.

DB: Right

SF: At about four months post onset he started to regain a little bit of head movement. Initially he presented as locked-in and he had actually horizontal eye movement. It was his first movement capabilities. After about four months he was able to move his head a little bit. He started to use a light-touch switch with a communication device that was very slow and very frustrating for him. At about six months post onset we noticed he was able to tolerate longer activities so he wasn't quite as fatigued and his head movement was such that we could begin to trial some head tracking technologies.

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There were quite a few challenges though that we had to address with John. First off even though he had some head movement, it was still pretty minimal and it was so minimal that he couldn't use a lot of the relative head trackers that were available. He was also in a variety of positions throughout the day. Because he was

so medically fragile he was laying down in bed quite a bit. He had to be turned to his side for pressure relief. He was in a chair, but would have to be tilted back in his wheelchair. So we had to have some sort of access method that could accommodate all of these various positions and it also needed to be a relatively simple setup. He was in a skilled nursing environment by the time we were looking at this technology. Lots of different staff providers and so the simpler the technology the more likely it would be used in the setting.

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At that time we had the AccuPoint prototype, the initial prototype available and we thought John would be a great potential candidate for it. To describe this prototype system, it's a two infrared camera system and it utilizes three reflective dots that the individual places on the forehead and it also just uses a conventional computer monitor and a conventional computer with software that would compute your head location and align it with the computer cursor.

DB: I think one of the really unique situations was in the calibration and that is that the system is calibrated by looking at a bulls-eye in the middle of the screen and all you have to do is get yourself in what you think will be a comfortable position for the center of the screen and sit there.

SF: Right. So whatever your center is the computer decides, calibrates that center.

DB: Then what you do is you move once that is, kind of you get a signal, then you just move down to a button below it and that says I accept this calibration. I think the thing that was interesting with John getting back to your multiple settings and situations he was in is that he could be laying in bed and he could look at it and he could calibrate it. Then they'd move the head of his bed up a little bit and he'd just look at it recalibrate it. He'd go on his side, he'd look at it recalibrate it. You know and so it didn't require moving across the whole interface like many of them do to recalibrate. I think for John that was a really important feature of this.

SF: Right, and also another interesting feature of this system is that it could be scaled up or down based on the individual's movement capabilities.

DB: So sensitivity changes: little movement, lots of movement. Ok.

SF: Right. So to give you an example in John's case, because he had minimal head movement we changed the scaling to ten to one so a little bit of movement would allow him to move the cursor completely across the screen.

DB: And I could never use ten to one because I couldn't be that stable.

SF: It is very sensitive. Right and to just give you an idea of how minimal his movement was, when we measured it from the tip of his nose his head excursion it was a quarter inch left and right and an eighth of an inch up or down. That's really minimal movement almost probably if you were to look at it him you would probably say this guy is not moving his head, but it was enough with the scaling settings that he was able then to completely control the computer cursor.

DB: I think one of the other issues that relates to this especially in the calibration is that when you're in a care facility and you have multiple staff many of them not necessarily computer savvy some of them are, but the idea that calibration is essentially independent. That he can do it really helps because it means that you don't have to bring staff in to help you recalibrate and even when they're helping you maybe change your position. You can take care of all the rest of it with the computer. I think the staff really appreciates that.

SF: Right that's a very good point. They do, yes definitely.

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Some of the results: the positioning we found that John was successful regardless of whether he was in his wheelchair, bed, laying down, on his side, and we also examined how his communication functions were served by using the system. He used it for written communication throughout the day when he was able to tolerate his talking valve with his one-way valve. He also used it extensively to email and get on the Internet, but at night he used it to support face-to-face communication. He wasn't able to tolerate his valve over night so evening and night time when he had pretty extensive care and communication with nursing staff he was able to use the AccuPoint system to facilitate that communication in those situations.

DB: And this is one of the other shifts that we're beginning to see. People are using this equipment for more than just face-to-face. As you mentioned on the Internet, email even supporting some of his medical care you know communicating with people that are some of his providers through email and that kind of thing. So we're really beginning to see a shift in the use patterns of AAC.

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SF: Right. As Dave alluded to early, the setup and training for staff was surprising for us, a surprising result in that in John's case we had one intensive training session with the patient's staff present on how to set it up and beyond that point John was able to train all other staff. It was simple enough and he primarily controlled it that he could tell them to open up an icon, hit a button, and he was good to go. Duration of use also, he used it quite a bit. Email/Internet was approximately 2 hours a day. Face-to-face communication was 8-10 hours in the evening and overnight. So an extensive period of time each day using the AccuPoint system.

DB: And how long has he used it now? A year or a couple years?

SF: John has used it now probably 3 years, 3 or 4 years now.

DB: Yes

SF: We have a video of John that kind of illustrates his use of the AccuPoint system that you can view at this time.

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Slide 36

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VIDEO TRANSCRIPT

SF: Why don't you show how you communicate yes, Merle? Yes, so real clear looking up and you kind of hold it there to make sure people know that. Right and down is no.

Narrator: Merle is a gentleman who sustained a brain stem stroke with locked in syndrome. Initially he was only able to communicate by eye movement. He moved his eyes up for yes and down for no.

SF: Ok, so we have D so far for your wife's name. And I can tell real clearly that you are looking at row three.

Narrator: He was able to spell messages by using an eye linking technique.

SF: You are looking at row one and letter O, good. So you are looking at row 2, Merle?

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Slide 37

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DB: Ok in the video you've seen John use the AccuPoint. He's very accurate with it and effective with it.

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Slide 38

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In fact we have him participate in the development or changes of that technology and he also uses some of the other related developments that we have. The AccuClick for controlling other software, managing the mouse functions and so on for other software and then AccuKeys which allows him to spell and to interface with other software. He's been a very active participant.

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Next we're going to be going on to eye tracking technology and we're going to discuss this in light of people that we saw earlier with ALS. You see our colleagues listed there, Laura Ball, Amy Nordness and the two of us. Our strategy is that, research strategy through the years is that we follow a large number of people with ALS-Amyotrophic Lateral Sclerosis or Lou Gehrig's disease. It's a degenerative disease as you probably know and we follow them from diagnosis frankly until death at about three month intervals and during that time we collect a number of, several pieces, a large number of pieces of information that helps us make clinical decisions. Once again I refer you to the green book *Augmentative Communication Strategies for Adults with Acute and Chronic Medical Conditions* and there's an entire chapter in there that lays out the phases of intervention that we'll be talking about today. We'd like to introduce you to Olinda. Actually she has been someone that you've worked with so why don't you; you know her well, why don't you introduce her.

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#### Slide 40

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SF: Well Olinda, she's a sixty-year old woman. She resides at a skilled nursing facility here. She's had ALS for a number of years. One of her very early first systems was a scanning AAC system. About the time that I saw her she had just received a new eye tracking AAC system and she had gone a number of years without the ability to access a computer system just due to her difficulty and being able to access a scanning device with a switch. She's currently has been using her eye tracking system for about two years.

DB: How long has she been unable to speak?

SF: Quite a number of years, at least over five maybe almost up to ten years.

DB: Ok so she obviously is someone who had spinal ALS to begin with that was her presenting symptoms and then in time it reached up into her brainstem and affected her speech and that's why she probably has lived as long as she has with ALS. We have a video of Olinda that we're going to show, we're going to change it a little bit. We're going to show you the video first so you get a little feeling of what it's like to see someone who uses eye gaze to communicate. So why don't we go ahead and roll that video now.

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#### Slide 41

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#### VIDEO TRANSCRIPT

Olinda via AAC system: This is an eye gaze computer. I use it to communicate with family and friends. I also use it to read books and my bible.

SF: So there you turned on your call light, right?

Olinda: I love the eye gaze. It allows me to keep in contact with my children.

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DB: As you can see from this video she uses eye gaze, she uses it accurately, uses it effectively, and she uses it to support what communication functions?

SF: She does use it to support some face-to-face communication with her staff, but she's primarily using it to support written communication. Care providers and family at a distance via email.

DB: Ok

SF: She uses it extensively. In fact when she is having some difficulties with her system I get an email from her. She also supports medical needs that she might have with it. So it's been a real efficient method for her and really opened up a lot of opportunities that she didn't have before.

DB: So she lives in a long-term care facility and then she manages her medical, she manages you, she connects with her family.

SF: Right

DB: This is a pattern, we'll show some data that we did on follow-up, and what you'll see is that this is a pattern that we're seeing. That communication has become more than face-to-face.

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Slide 43

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Let's talk a little bit about AAC decision-making in ALS and the chapter in the green book here was written by Laura Ball, myself, and then Lisa Bardach. In phase one there are really several, three distinct phases that we think about here. In phase one the people are generally just have learned that they are diagnosed with ALS. They are still speaking and our task is to help them monitor their speech performance and to do what we need to do to help make their natural speech effective for the time that they can still speak. Of course we need to work with them to educate them and the key decision makers in their families about the timing of making decisions about communication as well as other areas of their lives obviously. So what we do here, we worry about energy conservation. In other words if you're going to go to a big party tonight why don't you take it a little easy for the rest of the day in terms of your talking. The other is we kind of teach them how to manage environmental issues too so that their speech is more effective. I remember a woman who really her, would go to church, her religious family was really important to her but had great deal of trouble talking out in the area where everyone else was talking before and after services and so she managed to reserve a bit of a room off to the side where she would kind of go in there and people would come and visit her in a quiet

place. We use voice amplification for some people. Just a part of a voice amplifier, you mount the mike beside their mouth, maybe put the speaker in their pocket and that helps manage groups or manage communication in a noisy situation. Then we go on and we monitor very regularly their speaking rate. We find that speaking rate is simple to measure and it also is a very effective predictor of when they're going to experience decreases in speech intelligibility that is going to make their communication with others difficult.

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#### Slide 44

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DB: This is a bit of a complicated slide here but what we have on the vertical, on the left side is their percentage of speech intelligibility represented. In the bottom we have speaking rate. We used the sentence intelligibility from the speech intelligibility software, and the reference for that will be provided later on, to measure speaking rate and what we find there is that the average speaking rate on that task for the typical adult speaker when you're reading those sentences is about 190-200 words a minute. What we do is we simply, when they come in for their medical visit at the ALS clinic, we have them read those items and then what happens is we can measure the speaking rate right as their doing it so we can say ok today you're speaking rate was 180. Things look good I think that you're going to be doing fine for a while. Then the next time they come in or a time or two later we may measure it and say you know you're down to 160 now, yet you're still doing well although we're beginning to see. What we're doing is getting them ready to make some decisions. A lot of times we make medical decisions after we have severe symptoms you know. We have the fever and then we go to the doctor. This is common for all of us and in these people they have to make the decision well in advance of losing their speech intelligibility so they have enough time to complete an assessment, do a trial, and then receive the equipment, have it purchased, and finally learn how to operate it. Getting back to the slide, what you'll see is that when people are speaking on the right hand side of the graph at about 190-200 words a minute their speech intelligibility is over 90%. Then as they slow down to 180, 160, 150 their speaking rate stays at over 90%. Then once they get in the neighborhood of about 130 words a minute we see the first people kind of start to fall below the 90% intelligibility. Once they get past 120 words a minute then we start to see a number of people falling out. What we do is we kind of have a rule of thumb when people, we tell people when you get down to 125 or 120 words per minute we're going to recommend an AAC assessment, and we find that prepares them for it. If they have questions along the way we introduce them to equipment if they ask that. If they don't we say when that time comes we come, and we find that way of preparing them is quite effective. Speaking rate can be measured over the phone when you live in the northern part of the country where you have winter storms and when you have ALS and travel is difficult and you can't make it to the clinic, we can have them read the sentences to us over the phone and we can measure the speaking rate. So we can monitor it and say ok when you are feeling better or when the weather is better you need to come in and have an assessment.

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Slide 45

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DB: This is another bit of a complicated slide but it contains an important kind of message and that is that on the previous slide you saw that the red squares were for spinal ALS, the blue were for bulbar or brainstem ALS, and then the black were for those that were mixed in symptoms. What we see here is what is quite typical and that is on the vertical you have intelligibility of speech and on the horizontal on the bottom there you have months post diagnosis. What we see is that the people with bulbar ALS or brainstem ALS lose their ability to produce intelligible speech much earlier in the course of the disease than the people in red who are the people with spinal ALS. So we see that the bulbar individuals are showing a decrease in intelligibility within the first year or even earlier than that where you see the spinal people will go on for quite a number of months maybe up to two years or past that before we see them intelligibility. So what we find however is that speaking rate going back to that particular slide, speaking rate is a good predictor no matter what and that's really effective. So that's why we make that decision. And that ends phase one. So during phase one, we help them maintain optimal natural speech. We don't do speech intervention in the typical way because we tend not to give them exercises or things like that for speech just like the rest of their body so that isn't recommended rather we prepare them.

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Slide 46

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DB: In phase two it's a formal assessment now you do a lot of formal assessments for our group. You want to talk a little about what a formal assessment looks like?

SF: Yes, a formal assessment and usually they come to you an individual with ALS will come to you prepared for what they're going to see in terms of the formal assessment. Occasionally if they're a late referral and whoever they were working with wasn't aware of kind of the rate guidelines, they come to you a little bit late in the game it's a bit surprising, but they come to you prepared and you start showing them some different kinds of technologies. Typically the assessments that I do we work with trialing a variety of different technologies and really understanding the individual's communication needs and what types of communication that we need to be able support with technology that we're going to have them trial.

DB: Now obviously physical issues are important. Yet there are some other issues that figure into this. For example what about cognitive, is cognitive an issue with these people or is it all motor?

SF: Well there is a subset of individuals that do have what's called a frontotemporal dementia, and sometimes those individuals can be difficult to point out early. Sometimes we see it first starting to manifest itself in terms of their decision making so sometimes this is a subset of individuals to delay some of the crucial decisions

such as whether they're going to do ventilation, the feeding tube. Sometimes other things such as whether they want to have a wheelchair assessment. Things just really seem to be delayed and also somewhat almost seem kind of apathetic to what's going on around them and their declining condition don't seem to be able make a decision one way or the other in terms of the type of technology or route they want to go to support their communication.

DB: You mentioned a couple of other things. You mentioned feeding tubes. That's kind of a different discussion probably makes the, what I've seen you do is you get a feeding tube and it makes feeding much easier, much less risky, and much faster. A good friend of mine Tom had ALS and the feeding tube allowed him to receive his nutrition quickly so he could go out with the rest to a ballgame. Where he would have had to spend an hour and a half eating every meal that would have taken up a lot of his time. Interestingly enough it had an effect on communication because if he went out to the ballgame he would have to talk to people.

SF: Right

DB: We found that while it didn't necessarily extend his life it made it a lot easier and he communicated more. What about ventilation?

SF: Ventilation is something that at first assessment I usually talk to individuals about and see what kind of decisions they made with regards to that.

DB: And maybe we should point out right away that there are kind of two kinds of ventilation here. There's the kind of ventilation, the CPAP type ventilation that they maybe where a mask like this that delivers concentrated oxygen to them and that's pretty common.

SF: And that's often in the overnight.

DB: And that's often in the overnight, maybe in time during the day. While it makes their life easier and so on it isn't the big life extender that invasive ventilation. What's invasive ventilation?

SF: In invasive ventilation these individuals typically have a trach and they are actually connected to a ventilator and that supplies the breath for them so they can live for an extended period of time on a ventilator. Some individuals that I've worked with here have lived up to fifteen years potentially with a ventilator. It's important to know this, what decision they've made right up front, because it does influence the kinds of technology that you look at. Individuals who choose to go the route of the invasive ventilation might live to a point to where they're essentially locked into their bodies. So you want to make sure the technologies that you're looking at are adaptable. They accommodate the person's declining physical condition over time.

DB: Ok and once again I point out fifteen years, yes we do have that happen but we do also see it even an extension of two years, four years, five years, seven years is really important.

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Slide 47

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DB: Going on with the formal assessment, another part of the formal assessment while we're making decisions about the high-tech AAC device. Once again these are multi-modal communicators and so they will need low-tech options for times when they're in bed if their systems are set up for bed, when they're in the restroom these kinds of things. So once again part of the formal assessment is to provide them with a range of communication options to meet their needs that is acceptable and valuable to their family members and caregivers. The third phase is to finalize AAC assessments do equipment trials, prepare paperwork, make funding requests, get the prescriptions that are necessary depending on your funding requirements, Medicare, Medicaid, insurance funding requirement and so on. Then finalize the AAC options that are used, the range of AAC options that are used.

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DB: Kind of switching now a little bit what we did is we followed the first fifteen people that our group had done with eye tracking. Once again there are a variety of eye tracking systems out there we acknowledge that this is only with the one which is the ERICA system from Eye Response and it was their first generation in the sense that it was the single camera system and now most of the companies have the dual camera system. We'd like to be sure that people are aware the time, which this occurred.

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The eye gaze was at this time was just beginning to be regularly used in ALS because the new technology was there, and we were impressed with the possibilities that it had for some of these people with limited movement or essentially no movement or people who were losing movement. We wanted to be careful about it. This isn't going to, we're not going to spend a lot of time talking about this but the eye gaze tracks the eye movement by monitoring the reflection in the eye and using cameras and computers then to convert this information to mouse tracking. Choices are made using dwell meaning if the cursor, mouse cursor stays on a location for a set period of time, which can be adjusted, then it will accept that letter or that word or that phrase or whatever.

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Slide 50

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DB: If you look at the literature and the presentations on eye tracking, there are a variety of concerns that were initially presented. One of them was physical ability, head movement, ventilators, dry eyes, and so on. Those were issues of concern. Another one was the environment, the lighting in the environment, the home, the nursing facility, wherever the individual was being outside and so on. Another issue that was put forward was positioning. In other words were you always at a table when you communicated, could you communicate at a table and in bed, all these kinds of things. Another issue was glasses. The reflection that came from glasses or contact lens or all these issues was there and then of course the general lighting in the area. There were a group of issues that we wanted to pursue to try to understand with these fifteen people.

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#### Slide 51

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DB: We selected fifteen people who chose eye tracking after their assessment and so in other words they made the decision that they wanted to go with eye tracking and we then asked them if they would be willing to participate in this follow along study of ours. These were fifteen consecutive people who had selected eye tracking. We weren't going and picking different people at different times or different facilities rather these were fifteen consecutive individuals. You see there on the slide ten men five women, the age 52 years although it went from 39 to 71 years so we had quite an age range in that bunch. Forty percent of them were on invasive ventilation and so following up on our previous discussion there and so we found that there were people with different kinds of muscle capabilities or strength capabilities. Fifty three percent of them having a significant spastic component to their movement patterns and forty seven percent were flaccid or weak.

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#### Slide 52

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DB: Each received instruction until they could operate the device to communicate. Once they received it, they received trouble-shooting support as necessary. You did some of this, what was the nature of that? That we contact you saying we're having a little bit of trouble?

SF: It typically resulted in lighting types of issues that we had to trouble-shoot. They were interfering with the calibration or the effective use of the system. In some cases it was an individual who wore glasses and we kept getting glare on the glasses and just doing those kinds of adjustments. Those were sort of the environmental and the positioning and the lighting were the typical trouble-shooting sessions.

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#### Slide 53

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DB: And the research strategy was really a survey strategy in which we interviewed the people who used the technology, family members, whoever was there and could give us insight about it.

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DB: At the result of this fourteen of them became successful eye gaze users. One discontinued because they had trouble controlling their eyelids and that sometimes happen where the weakness that a person experiences means that they have trouble keeping their eyelids open and this individual as I recall the eyelids would kind of droop and they would obscure the eye and then the tracking would be interrupted. It just got to be a little too much of a hassle so they discontinued use. For those fourteen that were successful we were able to manage different lighting conditions. Excuse me here just a second. Ten of them used dimmed lights to some extent and four of the switched to fluorescent bulbs at home. That worked better than the typical floor lamp in the background that seemed to get in the way.

SF: Right

DB: I remember one person would call you and you would say why don't you move the floor lamp over the phone and that often solved the problem. Three only used overhead lighting and got rid of the floor lamps that were at eye level around the room.

SF: Right

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DB: However fifty three percent of these individuals were wearing prescription glasses. Three of them had reflective type lenses and with work we were able to work around those wouldn't you say?

SF: Yes

DB: I don't think there was anyone that we said no you can't. Well fourteen out of the fifteen were successful and the one who wasn't was a different reason.

SF: Yes, right.

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DB: It was kind of interesting when we went to them and said why did you choose this technology over other kinds of technology. Fifty eight percent of them said they didn't have much choice because I only had eye gaze movement available to me so



that's why I did that. Twenty seven percent or a full quarter of them said I want to be set up so that if in fact I deteriorate further which you expect to do, and if in fact maybe I decide to go on ventilation, I've got a system that I can manage and so they were wanting the flexibility, the multiple access options. Thirteen percent chose it because they were unable to scan. They just couldn't learn how to scan efficiently and so they did. Seven just said this is what I want and didn't provide much more of an explanation. There you see a little bit of the funding pattern that was available for these individuals.

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DB: This I think is quite interesting. The question always comes up how much instruction do we need to do and what we found across all people was an average of five and a half hours, but it ranged from two hours. In fact most of them the largest group, five of them, managed it with two hours of instruction .

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DB: Really the one that really raised these numbers was the person who had twenty hours of instruction and that was a unique individual and you were involved with that person.

SF: It was the individual with eye apraxia.

DB: Yes, we called it eye apraxia and the symptom of it was that when we evaluated the person they were able to pretty accurately point their eyes to things. When we pointed to the "a" they could look at the "a" and all that but when they started to communicate what happened?

SF: They were unable to spell. We were troubled by that so they would be stuck in a pattern near a couple of letters.

DB: An eye pattern, yes.

SF: Going back and forth between letters, we would start to cue them more and they would get to the right letter and through the low-tech means we saw that they could spell. The individual could but it seemed like when we had them generate communication themselves using spelling and eye gaze, that's where the breakdown was occurring.

DB: So the problem wasn't in spelling, the problem was when they had a message and they tried to do the motor-planning necessary to communicate that message things kind of fell apart.

SF: Yes

DB: We did have the opportunity to put them in an on-going instructional program and it resolved, but it took quite a number of hours of instruction.

SF: Early on with this individual, we relied a bit more on full messages so this individual could still support their communication while they're continuing to work through the problems they were having with the eye apraxia and spelling.

DB: So anyway, actually I was surprised that this group that they didn't require more instruction than what they did actually.

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#### Slide 59

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DB: We see on this next slide troubleshooting issues. I think we kind of alluded to that already so I won't spend more time on that right now. One thing we really wanted to talk about was use patterns.

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#### Slide 60

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DB: What it does is it really reveals I think a change in pattern how people communicate when they have complex communication needs. They are required to meet these needs with AAC. What you find there is well over 90% use it for face-to-face and there is one who is kind of using it yet for the internet kind of email and so on still speaking to some extent face-to-face. You see there that 40% were actually using it to speak in groups. This is quite encouraging but the electronic communication, the phone, the email and the Internet, what you see there is over 70% of the people on email, over 80% of the people on the Internet. What we see is that people were really in significant numbers given the age span we were dealing with said no this is an important way for me to communicate, and many of them communicated regularly with family at a distance. Getting the benefits of the Internet because my daughter or granddaughter can type pretty quickly and get messages to me and then I can return the message even though it does take me two or three or four times as long as it does them. We certainly saw that emerging.

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#### Slide 61

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DB: We'd like to just close this webcast out with a few acknowledgments. Once again Merle, John, and Olinda played such an important on-going role in our program. They are really AAC experts for us and we appreciate them. Then we have colleagues in a variety of different settings that you see listed there who operate ALS clinics and who collaborate with us on the on-going data collection that we have.

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#### Slides 62 & 63

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We also have a group of references on the next slides that refer to the content that we have presented. Thank you for watching.

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