Health Benefits: Program Funding of Speech Generating Devices Lewis Golinker, Esq. Assistive Technology Law Center, Ithaca NY Audio Transcript

Slide 1: Health Benefits

I'd like to welcome you all to the latest in a series of web casts that's being sponsored by the Rehabilitation Engineering Research Center on communication enhancement, more easily known and more commonly known as the AAC-RERC. The topic today will be funding for augmentative communication devices, now more commonly known as speech-generating devices by health benefits programs. We're broadcasting today from the Center for Health Sciences at Ithaca College, and I'd like to thank Professor Elizabeth Baghely for making the facility and staff available to make this possible. In a few weeks, the materials that are here as slides, and an image of me, finally, for those who have suffered without that opportunity to this point will be available on the web site of the AAC-RERC, which is triple W dot AAC and then hyphen, RERC dot com (www.AAC-RERC.com). Today is December 8, 2005.

Slide 2: Scope of Presentation

I'd like to speak with you this morning about health benefits program funding for speech generating devices and I'd like to discuss with you the scope of the presentation first, and then go through it, and then sum up. So, we'll be talking about 5 questions about speech generating device funding, pretty much all the 'wh' questions with the 'how' thrown in. Who needs to know about funding, why it's important, how do funding programs operate, how do they decide what they will pay for, what's my role (meaning the clinician's role) in the funding process, and then where would I, as a clinician, go for help.

Slide 3: Who Needs to Know About Funding?

Who needs to know about funding? Those of you represented here in the room includes practicing speech-language pathologists and students in speech-language pathology in addition anyone who works in the public schools, teachers and school administrators, as well as family members and advocates really have an interest to know as much as they possibly can about funding.

Slide 4: Why Is Funding Important?

Why is it important? The answer is that you have a group of clients who are seeking or will be seeking, or you will be recommending, a type of treatment, and they will not be able to afford it on their own. So the only way they're going to be able to get this treatment is to be able to have some third-party program, and we'll be talking about programs in the health area, to pay for it. In order to turn the question of funding around a little bit, you need to know about funding for a second reason, that is you want to be able to know how to plan your assessment and plan your treatment recommendations. And let me digress with an example: a couple of weeks ago the New York Times magazine had a one-year follow-up of people who had survived the tsunami in Indonesia and one of the people that they followed had been a physician, is a physician. And the story that was reported about her was that immediately after the event the day after Christmas last year, she returned to her hospital where there was an endless line of people seeking her attention. There was no water, there was no electricity, and very quickly there were no supplies. And even though the needs of these people presented crossed a wide range of medical needs and her knowledge of what was appropriate for these individuals, certainly would have been able to treat most of them, if not all of them, but she didn't have any way to do it and she had to tailor her response to the circumstances at hand. If you don't know that or have a strong degree of confidence that a speech-generating device or any range of treatment is going to be available for funding, then it doesn't give you any confidence that recommending a speech generating device is a worthwhile activity, and the phrase that had worked its way into discussion was "Learned Helplessness." That it won't work so why try. And, the idea of learning about funding is to erase that, to give you a sense of predictability, to give you a sense of expectations, to be able to convey that sense of expectations to your clients and their families. So that when the time comes for them to have a treatment recommendation, that they will believe that this piece of paper will be able to be turned into a device, and that device will be able turn into a treatment.

Slide 5: Why Is Funding Important?

Another element of learning about funding is it tells you how to do your assessment and what is required in order to report about your assessment, your clinical findings. Here's the sort of official speech line which is: You have to know about it as well because you have ethical obligations as speech-language pathologists to follow. The guidelines say that you're responsible to use every resource, and every resource certainly includes pursuing funding options. In addition, right after using every resource,

there's a reference to using every referral when appropriate, and the bad news is that there is no one to refer funding to. There isn't anyone that's going to do this for you, just doesn't exist, there are no resources. There are people who can help you, and at a particular point in time, the speech-language pathologist can turn the funding question over to someone like myself, an advocate or an attorney to pursue appeals or if necessary going to court, but the primary responsibility for funding lies with the speech-language pathologist.

Slide 6: How Does Funding Work: What Do SLPS Need to Know?

Going to the substance, or starting at the point of substance, we're talking about 5 programs primarily when we speak about the healthbased programs. These are the five. Medicare is not listed first but it happens to be the largest of the funding programs for AAC or speechgenerating device funding. It came into the list pretty much on January 1, 2001, which is when Medicare put into effect a set of guidance that supports communication device funding. Previously to that it had guidance that excluded them, so they reversed their position and in the four years that they've been in operation, Medicare has become the single largest funding source for communication devices. Medicaid, particularly New York Medicaid, is at the opposite ends in terms of time. New York Medicaid was one of the first funding programs to agree that communication devices were covered, that occurred shortly after communication devices themselves came into existence. The New York policy, initial policy, went into effect in 1980, so it's now 25 years of coverage and funding. And, New York Medicaid had been the largest single funding source for communication devices in the country for many, many years. And then in 2001 it assumed 2nd place as Medicare eclipsed it, but New York Medicaid is the largest of the Medicaid programs and the 2nd largest overall.

For each of these programs, and the reason why we can talk about all of them as a group, is that your role is the same and the way they approach the questions of what they will cover is the same, and we'll talk about that in a minute. But your responsibility is to conduct an assessment and to prepare a report. And the report will follow an outline that the programs themselves require and we'll talk about what those elements are and how you're able to insert vocabulary, sentences, findings in it that will support the funding question, the ultimate decision to support the person being able to get a device.

How do you communicate with funding programs? I've already mentioned that you communicate with them in writing. The other way is that there is an awful lot of back and forth that occurs on a telephone

with the funding program staff and your ability to recount the essential elements, the key points, the key principles that guide your work and that guide the funding process, will make your ability to persuade them that a yes decision to the funding question is the appropriate one and should be answered. The next slide I'll put up is to start off with what you shouldn't say, and then we'll go through all of what you should.

Slide 7: Remember: SGDs Are NOT "Assistive Technology

When I asked those of you in attendance, before we started whether anyone had a position in the schools, there weren't any hands, but clearly in a discussion like this, or those people who will be watching the web cast, will include speech-language pathologists, and others who are associated with the schools. The concept of assistive technology devices is a school, a special education or vocational rehabilitation concept. It is not a health-based concept. Health programs use the bottom two examples. They cover durable medical equipment and they cover prosthetic devices. So when you speak about a communication device, either call it a communication device, speech-generating device, an AAC device, or call it an item of durable medical equipment, or a prosthetic device, but don't call it an assistive technology device. Not that it is not an assistive technology device, it's just that the programs we are talking about and the people who work for those programs, and read the reports or hear you on the phone, don't recognize that phrase as something that they cover, and it will lead them in the wrong direction.

Slide 8: Will SGDs Be Provided?

Will speech-generating devices be provided? The answer is yes. Speech-generating devices will be provided under all of these programs because all five of them ask the same four questions in order to get to the question "What will I cover?" "What will I pay for?" So, the four-question test is not one that each question is equally important. So the first one is the least important in terms of controversial, the second two are the most important in terms of what you need to focus on, and the last one varies based on whether or not it applies at all, and we'll go through each one in order. Again, the key to be able to address these and to understand how it works, is to help you through the process of speaking with, or writing to, health program staff.

Slide 9: Eligibility

Eligibility, we need to think about it because we don't have a universal health benefit in the United States. So someone is going to have to be eligible for one of these programs, but it's not something you're going to have to help someone become eligible for. They'll come to you with a card and the card will say 'New York Medical Assistance,' 'Medicare,' it

will be a card that we may have from our insurer. It's very typical that the suppliers of equipment will ask you to make a photocopy of that card, front and back, to attach to your report when you submit it as part of your documentation. So again, it's not something that you'll have to establish, it simply is something that you'll have to ask about in the course of conducting the interview with your client or his/her family.

The programs themselves have different focuses in terms of population that they are intended to serve. Medicaid is a program that serves the poor and the disabled. Medicare was created at the same time in 1965, but it was designed to serve a different population, people who were elderly, people who were 65 or older, and the reason that Medicare focused on that group was that the expectation that at age 65 people would retire, the employment based health benefits that they received would cease upon their retirement, though some people had health benefits as part of a pension, but many didn't, so Medicare was created to extend the opportunity for health care coverage to that population. Medicaid, created at the same time was for people who didn't work, they were poor, they wouldn't have access to health care through employment, they were disabled, same problem, and then because of their poverty, they wouldn't be able to go out and buy insurance in the commercial market. Tricare is a special program for military personnel and their dependants, and people who have retired, they've worked 20 years as a soldier on active duty, and then they retire rather than become a veteran, by being discharged or becoming injured. They've worked through, the military has been their career, and they retire and health benefits are extended to them as well as to their dependents. It used to be called the Champus program, and now it's called Tricare. And then for insurance, people still get insurance primarily as an employment benefit. It also is possible to purchase insurance commercially just as an individual in the community, and there are two ways in which insurance is administered. One is through a policy and the other is through a health benefits plan. And, the legal issues related to them are different, but the scope of coverage and the way in which they operate tend to be the same.

Let me digress for a second having mentioned the word legal in the course of the presentation. The purpose of this presentation, to talk about funding, is not to translate legal concepts for speech-language pathologists, it's the reverse. It's to have you understand speech-language pathology principles and how they apply in a legal context. So I'm not trying to teach you something that I know, I'm trying to reinforce something that you know and organize it in a way that will pass a screening that has a legal framework. All right, funding programs are

legally based, these Medicare, Medicaid, Tricare insurance, are governed by laws, either the federal or state level. But what you do is clinical based. Funding isn't requiring a SLP to become an attorney or a paralegal, it's requiring the SLP to understand that your words are going to be interpreted by people who have a legal framework that they have to work from.

Slide 10: Coverage

When we speak about coverage, which is the second of the four general questions, we don't have a set of universal benefits, and the way in which health programs list the things they are going to offer somebody is not by an encyclopedic list of procedures.

So, a number of the folks here around the table with us this morning are from the Cayuga Medical Center, our local hospital. Inpatient hospital care will be a typical benefit of all of the programs that we're talking about, all health-based programs, insurance and then the public ones, Tricare, Medicare, Medicaid. So when we have an inpatient hospital benefit, there isn't going to be some appendix that says "Here's a list of every single procedure that could occur in a hospital so you can check off to see whether what you're about to receive is going to be paid for." That's not the way it works.

What we have instead are general descriptions of benefits, they often have definitions, and the expectation is that anything that fits within the definition will be covered and paid for. To the extent that something won't be, they'll be an exclusion, that's the fourth of the general questions we'll be addressing. So if there's going to be reference to a specific procedure, it's more likely than not to be a procedure that won't be covered rather than one that will be covered. If it is covered, we need to look to fitting my word, to showing that the procedure that we are talking about, the type of treatment or piece of equipment that we're talking about, fits within a scope of a benefit category that's covered.

I said that for health benefits the key categories are durable medical equipment and prosthetic devices. These are benefits that you will expect to find in every one of the programs that we're talking about, they are common benefits. When we talk about Medicaid programs in particular, and a couple of you, and certainly people who will be watching the web cast later on, but some of you are interested in working out of state, Medicaid programs in other states often classify communication devices under other than the DME benefit. DME is the most common, but it's not the only one, and you'll find that that's true with many things Medicaid covers, they'll fit in a bunch of categories and

here's a list of them, this is just alphabet soup: EPSDT is the benefit that is available to Medicaid recipients who are younger than age 21, OT/PT/SLP are the therapy services, IC/FMR is a facility based service and stands for Intermediate Care Facility for people with mental retardation or developmental disabilities, NF is nursing facility services.

Slide 11: Coverage

Now, I had said that coverage and medical need are the two places where the questions may become controversial, where you may get pushed back, where denials may be issued. That may be the case but it's not always the case. Sometimes, coverage is established for SGDs generally and for most Medicaid programs, for Medicare, Tricare and a few insurers, they've pushed the coverage question off the table by establishing coverage criteria. There's an acknowledgement there that an SGD is covered and these are the criteria that Medicare and these other programs have adopted that outline for you the scope of what's covered and then the documentation and assessment requirements for the speech-language pathologist to show that they are needed and they meet the criteria for this particular individual.

So, to the extent that you are dealing with New York Medicaid or the Medicaid programs in more than 30 other states, we have a specific set of criteria that we would look to and try to satisfy in order to establish that the client that we are working for is entitled to the device that we're recommending. With regard to insurance, we'll have to look at this on a one-by-one basis, but what we're finding is that insurers are starting to adopt for their own use the Medicare coverage criteria.

This is not the way it was when I started 23 years ago. We dealt with coverage every time. So in 1980 when NY came out with its policy it made it a little bit easier. But one of the things we also learned is that nothing with regard to funding is permanent. So, even though there are funding guidelines, even though there are coverage criteria, the possibility exists that someone's going to forget they are there or not know they are there. So, funding staff at health benefits programs roll over, turn over very quickly, and to the extent that you have someone new, this is a very low incidence benefit. Very few people are going to be asking for communication devices, certainly in relation to wheelchairs, or hospital beds, or other items of DME the review staff will see far more frequently, and as a result they may not know these coverage criteria exist.

It would be appropriate for you to tell them to the extent that there is any question about it, to the extent that there are coverage criteria. You may find that the health benefit program staff don't want to follow it, and

that's been a problem in NY Medicaid over the years, that they forget that it's there, or they forget what it says. And, it's necessary for you to understand the underlying principles of coverage in order to make sure that you get passed this conflict to the extent that it is a conflict with program staff.

Slide 12: Durable Medical Equipment

So, coverage is DME. Let's figure out, let's look at what DME is. DME is the most common benefit classification for communication devices across the board, but it doesn't have a uniform definition. Every program is allowed to have some variation of what an item of durable medical equipment is. However, even though the dictionary is a thick book, the definition of durable medical equipment, in fact the terms used in healthcare tend to be very narrow and are copied from program to program, or in insurance, from policy to policy. The most common definition is that four-part definition on this slide, and it comes from the Medicare program. So Medicare is the largest of the health programs in the United States and it tends to drive the standards and drives the policies and drives the vocabulary of other programs. So, other Medicaid programs copy this, are not required to, Medicare and Medicaid are independent, but they copy this definition, insurance programs copy this definition, and it's a very easy definition for us to work with because speech-generating devices satisfy all of these elements. So, with regard to durability, being able to stand repeated use, is the next slide.

Slide 13: SGDs are Durable

It's not a controversial question, no one really says a SGD isn't durable, but I said there are ways that you can add to your reports, phrases, statements that will allow you to establish various points relatively easily, and the three statements here are ways to do it. Durability is established because these devices have useful lives over a period of years, they're expected to be used daily, even the fact they have rechargeable batteries demonstrates durability, the opposite of a durable item is a medical supply, a bandage, a catheter, something you would expect to be used once and then discarded. The more important information and the more controversial things that you would have to go through more slowly and carefully is what follows, so let's start talking about medical purpose.

Slide 14: Medical Purpose: SGDs

The second of the criteria is that the item has to be primarily and customarily used to serve a medical purpose. What is a medical purpose? So we are talking about speech. The medical purpose of any item or any service or any treatment whatsoever, is that it treats a

condition, it treats an illness, it treats an injury, it treats a disability, and a speech generating device does that. It provides treatment; it serves as treatment for severe communication impairments.

So, when you have a person in a clinical setting for the purposes of an assessment, you're going to see them first as having a whole body neurological impairment. For communication devices, there are six or seven that are most common: ALS, cerebral palsy, multiple sclerosis, Parkinson's disease, brainstem stroke, and traumatic brain injury. Those are whole body impairments and they will affect multiple body systems for most people. Among the list are conditions that are developmental or acquired. Among the list are conditions that are stable and those that are progressive. But all of them create common impairments to speech in the form of expressive communication, and those five types of impairments have their own diagnostic labels and they are listed here on this slide, dysarthria, apraxia, aphasia, aphonia and then the last is a phrase that I've invented, I don't know that it's accepted generally by the speech and language pathology community, but for individuals with developmental disabilities and autism in particular, we're lacking an effective phrase to describe the communication impairment they experience, so this is just an example of something you can use for that.

Now, one of the mistakes that speech-language pathologists make in their reports is they'll say this person has, they'll remember that they're supposed to mention treatment, and they'll say this person presents cerebral palsy and the speech generating device is intended to treat Johnny's cerebral palsy. That's not correct. The person is going to have cerebral palsy or ALS at the same level of intensity with the speech generating device or not. It's going to treat Johnny's dysarthria, and it's going to materially improve the adverse communication impairment that the person's cerebral palsy is creating. But the cerebral palsy will remain.

Consider a wheelchair, if a person has quadriplegia, they're going to be just as quadriplegic with the wheelchair or not but they are going to be able to have their mobility needs met. So remember that the whole idea, all of the professional literature that we can rely on to be there in case someone pushes you up against the wall and says "Prove this" is going to support the use of a communication aid for these 5 communication impairments rather than for the broader neurological conditions. And there's no concern about a communication device not treating ALS. Nothing treats ALS. But nonetheless, people should be able to get a communication device for that, nothing is going to undo a spinal chord injury, right, that's the research that was Chris Reeves had been so animated about and so active in raising funds for. They don't have

anything that's going to effectively going to treat that yet, but nonetheless people who have spinal chord injury get wheelchairs, and we don't want to get tripped up by the fact that, well, you're not treating the primary impairments so therefore you cannot have what you need for that. That's an incorrect approach, and that would kind of be the push back you'd get from funding programs staff that had never heard of a speech-generating device. I mean we live with this, day in and day out, but the people who run health-based funding programs hear about AAC devices once a month maybe, or if it's an insurance program, maybe once a year, if ever before the time your client presents their need. There are a lot of programs now that still have never encountered a communication device funding request.

Slide 15: Medical Purpose: SGDs

Primarily and customarily is the beginning phrase in this criterion. But for communication devices, we're dealing not with primarily and customarily as if it does something else. It only treats a communication impairment, it only treats the severe impairment, and only treats those impairments when, as it says in the bottom, it interferes with meeting communication needs arising in daily activities. How do you show that? The next slide will identify some of the things that are likely to be found in your clinical examination.

Slide 16: Medical Purpose: SGDs

If necessary we could rely on medical literature, that's what the first bullet talks about. But, in the course of your assessment, you're likely to find a functional gap between receptive and expressive language. And, that has been recognized since the mid-1980s as a set of clinical indicators that make consideration of AAC interventions appropriate. So in the very first of the AAC text books that was published by ASHA in 1986, there's a reference specifically to this in one of the chapters, as the whole purpose of an AAC device is to level the playing field, level the functioning between receptive language and expressive language.

We also know that for people with developmental disabilities in particular, that people may communicate via expressive behavior rather than expressive language. And, a lot of that behavior is inappropriate, could even be injurious to self or others, and communication has the ability to replace that and to be far more appropriate. The next bullet uses a way of speaking or a way of thinking about the question of why does this person need a communication device, 'but for' is the legal phrasing of it 'solely because' is probably the more common English phrase of it.

And, the reason why this comes up is that funding programs particularly in the health area will love to say that, let's look at how, where, and with whom the device is used, and those indicators will replace the concept of medical need with every other conceivable type of need but medical. You use it in school, must be an educational need for it. If you use it out in the community it must be social, recreational, personal, non-medical. If you use it in the work setting, it must have a vocational need. If you look at it as, let's make it easier for you, 'solely because,' can you add any of those words to the phrase 'solely because' of the kid being in school, he or she needs a communication device, that is not a true statement, why is it not a true statement? Because, the kid will need the device after school, on weekends, and holidays. The only thing that appropriately answers that phrase is solely because the kid has severe dysarthria, or if you want to take it out of any form of jargon, solely because the kid can't speak well, we're considering them for a communication aid, for any form of speech-language pathology treatment.

Questions about need have nothing to do with use. When we go to a physician for our own medical care, the doctor doesn't decide whether or not he's going to bill our insurance based on how we're going to use our health, that's our business, that's our lives, that's just our daily lives. We move about, we go to school, we run families, we go to work, we talk to all sorts of people. What the physician or speech-language pathologist is trying to do is to make those activities possible. To eliminate to the extent possible that those conditions that cause functional impairment or physical illness or mental illness, that interfere with our functioning, but how we function is not the need for the treatment, it's the existence of the condition and the adverse functional effects that create the need for treatment. So the only reason why a SGD is ever needed is to serve the medical purpose of treating the severe communication impairment. The next slide answers the last bullet which is that speech generating devices serve the same functional role as wheelchairs, again something you can say in conversation.

Slide 17: Medical Purpose: SGDs

The normal process of producing speech has five steps, three of them start in the brain, and then there's the transmission of instructions and the production of speech by normal operation of the speech organs. If there is a malfunction either because the speech organs themselves don't work or there is some deterioration, or interference in the transmission of nerve signals to the speech organs. Or, let's make it easy just to move forward, that there is some problem in regard to coding the motor instructions speech in the brain. You can't produce speech through the speech organs, you have to go some other way, so the easiest way to describe

this is that there is a bypass, you go around the speech organs to another body part that will enable you to communicate, your hands, no device whatsoever, all you do is write on a piece of paper. If you want to make it expressive, if you want it to be speech, you need a SGD and then speech occurs.

This is not unique to speech, substitute coding motor instructions can be for the speech organs, but it can also be coding motor instructions to enable you to walk from point A to point B. There could be a problem with that, there could be a problem with the transmission, a spinal chord injury, as a result substitute speech organs for those body parts that necessary to walk, it won't happen. Your functional intent of from point A to point B can't occur normally, so there's a bypass, you redirect again using the hands and a manual wheelchair substitutes for the speech generating device, the original functional intent is accomplished. And if you look through the legal literature, a number of hearing decisions recognize that there is a functional equivalence between a wheelchair and a speech-generating device, though they are physically very different in appearance and they do very different things for the individual, if you back away from the very specific, to the next level of generality, they do the same thing.

Slide 18: Medical Purpose: SGDs

One of the things that is available to us too when we're talking particularly to program staff that may be hesitant to agree with you is that any one program can be used to help prove the point for any other. And, this wouldn't be something you're expected to write in a report, but it is certainly something you could say in a discussion. So we know that if we're dealing with let's say an insurance company where this question would probably arise most frequently, you could point out that Medicare and Medicaid all recognize the medical purpose of communication aids. The FDA classifies communication devices as a prosthetic device, but they use the phrase, these are devices used for medical purpose, they call them electronic communication aids. Insurers, if it's not one of these, but it's another, you can point out that a group of insurers now have specific SGD coverage criteria that recognize they have a medical purpose.

What does it mean to you as you write a funding report or if you're talking to a funding staff person? It's not binding precedent, it's not if you pay before therefore you must pay again for insurers, but because the vocabulary from policy to policy is so similar, it creates something for the insurer to look at. Can you tell me United Healthcare when you are giving me a hard time for my current client that the 350 prior decisions that were yes are based on a scope of coverage in a policy or plan that is so

different that it warrants all the hassle you are giving me now, and they're not going to look, they're going to say yes. I mean, that's going to end it. Because they aren't going to be able to go back and to tell you that in fact the vocabulary is so distinct for this particular policy that your client now deserves the trouble that you're giving him. But this is something I would recommend you write into all of your reports. It takes 2 minutes to check, add it in one sentence, your insurer has paid for these devices in the past, and it would be something that you're putting them on notice, that you know and you're putting them on notice that they should check before they say no to this case.

Slide 19: AAC Devices are not useful in the absence of illness or injury After we get past coverage, we move to into the third of the DME questions, which is devices of durable medical equipment aren't useful in the absence of illness or injury. This is not something that you would need to write about in your report but these are a set of facts that you could add to your discussion. Nobody is going to use a speech generating deivce if they can talk. Now one of the things that does come up is this concept of generally not useful in the absence of illness or injury, what about a computer based device. They tend to be useful, even the dedicated devices have the ability to control a remote control, they serve as a remote control for a TV. Dynavox products, are now PRC products, store digital speech as a MP3 file. But what you won't have as a realistic, serious discussion is that anybody is going to seek a \$7000 or \$8000 TV remote control, you can buy them in the local electronic store for about 20. No one is going to say that a PRC device or a Dynavox product is the world's most expensive iPod, unless you are looking for a laugh. Nobody is going to buy a device that costs multiple thousands of dollars when the item that does the same thing better, since that's it's primary function, costs a few hundred or let's look at it a different way, thousands of dollars less.

So, the concept of not useful, is that it's not practical, so the cost of the item itself, is a reason why it's not generally useful that nobody would want it, and that to me is sufficient rebuttal for that. For computer based devices, nobody really bothers with them. Everyone recognizes that computers can form the basis or form the electronic foundation for augmentative communication devices, or speech-generating devices. Medicare made a fuss about them in 2001. Rather than fight about it, the manufacturers simply adapted their models to create dedicated computer based devices, and after the funding process is completed, the devices can be unlocked and they wouldn't be dedicated anymore. A couple of years ago, New York Medicaid started to raise its own questions about dedicated devices, I'll talk about that in a minute, but they've

abandoned that issue. So if you need to use or recommend a device that is reliant on a computer, or even a PDA, a palm-pilot type device, they're all covered, they're all available, health based funding programs won't be a problem for you.

Slide 20: Prosthetic Devices

Let's move onto prosthetic devices, just to mention them. The VA and Tricare classify communication devices as prosthetics. They both acknowledge that communication devices are covered, so you won't have to go through a detailed process to prove that point to them, to the extent that you are examining somebody who's a recipient of the benefits, or someone who's insured by Tricare. If you have an insurer who for some reason has a very poor DME benefit, I would then go looking for prosthetic devices in the policy documents. You would approach it the same way.

The key terms in the Medicare definitions and again these definitions are going to be copied by insurers too, I just used Medicare and Medicaid because they're easy for me to find. The role of a communication device as a prosthetic device is to correct physical malfunction. It provides a functional substitute and the concept of functional substitution is directly in the Medicare definition, which is here as item number two, devices that replace all or part of the function of something that's malfunctioning. Okay, so there's the actual vocabulary of that test, if you remember that graphic that I had, this isn't my idea actually, it comes from Crystal & Varley *Introduction to Speech-Language Pathology*, it's a text, those are two English authors, and it's a standard text on speech pathology.

Slide 21: Medical Needs: SGDs

Let's move beyond coverage into medical need. Again, no universal definition but every health-based program focuses on medical need. Schools focus on educational need, vocational rehabilitation focuses on employment based needs or employment training needs, but health-based programs focus on medical needs.

Just as there are common questions, there are common principles to medical need, even though the definitions, the vocabulary, of the definition itself will change, and the slide immediately after this is the Medicare definition, you'll see it's very different, but there are four characteristics in common. Each of them talk about the person having a condition. The condition has to cause an adverse effect. The thing that you're seeking, whatever it is, service, item, equipment, has to be treatment, has to be effective and non-experimental.

And then, not stated here, but stated in other definitions of medical need and an inherent principle always is that your role is to recommend the least costly equally effective alternative. Not the least costly alternative, because that often can be no treatment at all, but the least costly equally effective alternative. And where you see that in the New York definition, is that care services and supplies, constitutes the treatment, conditions is condition. Let's do it in order, we said condition comes first, here is the reference to condition, the effect of the condition is this long phrase at the bottom of the definition; illness or infirmity interference for capacity of normal activity threaten the handicap, that's the adverse effect. The treatment would be the services, and as I said least costly equally effective alternative is inherent in all of them. The next slide is simply Medicare's way of saying the same thing.

Slide 22: Medical Needs: SGDs

Many fewer words, all four characteristics are here. The condition is the reference to illness or injury, down here. The adverse effect is embedded in Medicare's definition of necessary. The concept of treatment is right here, mentioned. And, then again least costly, equally effective alternative and Medicare has embedded in the definition, with the meaning of the word reasonable. So, you can see two very different phrasings, the same principles, and really the same approach by the speech-pathologist to address the key questions.

Slide 23: Medical Need Documentation

How do you deal with medical need? The role of medical need identification and description is the SLP assessment and the SLP report. You identify medical need by conducting a comprehensive assessment and you document medical need by preparing your report. The guidelines that I mentioned that exist for so many different funding programs expressly guide you through this process. What I offered to you here are some references from the Medicare guidance. RMRP stands for Regional Medical Review Policy, and they direct the speech-language pathologist to explain how the person's daily communication needs aren't being met. Again, showing the adverse effects on the individual, show the impact on daily functional speaking needs, again show the effects, and they ask you to do it twice, which is why I repeated it here, and they're focusing very clearly for you on this.

Now, the RMRP outlines for you what you should do as a speechlanguage pathologist in conducting an assessment. It's not something you have to commit to memory, but it will be something as a practicing SLP that you will have as part of you, right, assessment will be one of your primary tasks, treatment will be another. But, to the extent that you are focusing specifically on a funding program's approach to assessment, a funding program's approach to documentation, the RMRP for Medicare outlines the SLP assessment in a comprehensive fashion, and even though it's a document that was written for Medicare, it's useful for any funding program. So, to the extent that you have any questions particularly as young people you're beginning, here's a template to use, follow it, use it regardless if it is Medicare. And, in your report you can say that you're using this, because again you're showing you're following an accepted protocol for the purposes of conducting your assessment. Now where do you find it? It's provided for you at the RERC website. The whole idea of that website is to make it easy for you to do your work. Now, the next slide outlines some of the things that are available for you to help you from your introduction to your client, to the completion of your report.

Slide 24: SLP Report for Medicare Funded SGD

If the RMRP tells you the outline, there's a document called the protocol, which is a step-by-step set of instructions on how to do your assessment. What information you would want to gather at each individual step in the process, and what tests or procedures you can use in order to get those data. In addition, there are sample reports so you can see how those data will actually be incorporated into a report, that too is here too at the website that is listed here.

Slide 25: SLP Assessment & Report Tools

The protocol is listed here again and the protocol is also at the website.

Slide 26: SLP Assessment & Report Tools

You're going to generate all sorts of data in the course of your evaluation. It will have to be assembled into some coherent format for you to make a recommendation and make the recommendation sound logical, to write a funding report and make the funding report sound as if it's coherent. And there is a tool that will be available to help you through that process as well. It is not yet posted at the website, it will be by the end of the year or early January, to the extent you want to use it, I'll give it to you by just contacting me by email. But, by the time anybody sees this it will probably available on the website and my email account won't be overrun by this. But, the goal of the report coach is to make your time as efficient as possible. If you go through the assessment, if you use the protocol to generate your data, the role of the report coach is to allow you to take the key data that you find and quickly present it in the form of a report. And from that, you can submit it to your physician for the purposes of getting a prescription and starting the formal funding process by submitting the documentation to the supplier.

Slide 27: Medical Need Issues: SGDs

Now medical need is something that there will be issues about, or there can be issues about, I don't want to make it sound like you are guaranteed to have problems with this. One of the first questions is how much treatment is a person entitled to, and the standard for that has pretty much resolved itself over time. There used to be concepts of basic communication needs or communicate basic needs, there's no translation of that into speech-language pathology principles, instead the general speech-language pathology principle for all treatment is to ensure that the person is able to meet communication needs arising in all daily activities. The communication device is simply the tool to do it.

We mentioned before the idea that communication to someone about something or taking place in a particular location is not what medical need is about. All daily communication needs need to be assessed and referenced in order to ensure that the person can actually engage in all of those forms of communication and places of communication and conversations. But it doesn't define whether there's a need, it just defines the scope of the need. And one of the things that is important to remember is that most communication that's oral, occurs face to face, but in addition people may very well communicate by telephone, and it should be something that should be included in your report. First of all, anyone who does have daily communication needs involving the telephone has to have a communication device. Right, if they can't effectively communicate orally by telephone, you can't write it out, they need something to generate speech for them. So, that's one thing that gets you into speech-generating devices as a tool simply by an identified need. In addition, for funding purposes, there happens to be a non-health related program that specifically provides funding for telephone access, so that's something else to consider.

Let's go to the other step of, I use the phrase 'medical speak.' There had been an effort, and there may be again, of tying medical need for communication, to communication of medical words or communication of symptom-based information or communication to caregivers. And it's a practical problem. One, is that it doesn't translate into the devices. There is no device out there that can limit, that can be limited, there's no switch, there is no thing you can pull off it or turn off on it that will restrict what the device can say. The simplest digitized device to the most sophisticated, synthesized device will say whatever you want. A digitized device will be limited in how much you can say because there are time limits on how much recording time it has, but any keyboard based device and all synthesized speech devices have access to keyboards, well you can put the whole alphabet in it.

And, there's no such thing as a medically-related word, because words are contextual, right. Lets talk about just the weather. "It's sunny outside." Well the person can also have a sunny disposition. Okay, those two things also are compatible, they sort of have the same connotations, but do it a different way. Rare enough, it's a blue sky outside in Ithaca in December. But if you're feeling blue, it sends the opposite message, it's the same word but again there's no such thing as a medically related word. Heart, you know, "He has a lot of heart." Everybody has one, nobody has more of one than another, it clearly has a different context, and to the extent that you want to be clever, you can make up whatever you want in order to answer that question. If somebody ever says, well you should do medically-related words, my suggestion is next time you go to a conference, is pickup one of the laminated boards with the alphabet on that Dynovox offers as a giveaway, and lay that down in front of the person who's asking that and say "Which of these letters don't you need for medically-related words, which one can you blow off," none of them, you can't do that, that's not the way it works.

The very first case I did in 1982, the Medicaid program here in New York said that the person sought a device that was more than they needed because there were only 100 medically-related words. Even though there was no device that would generate 100 words and no more, but that was they way that the person spoke, and the solution to that, that ended it and led to the favorable decision was here's a pad and a piece of paper, list them. Tell me what 100 medically-related words are, because no matter what they put down, there's always one more, there's always two more, three more, ten more, so why are these more important than these others, and the answer is they are not. It's something that becomes a mental process that leads you down the wrong path, but it doesn't lead to anything useful for us, really anything useful even for the funding agency, it doesn't tell them how to decide the case other than say no. It's not as though you are substituting one device for another, it's that no device fits because the person can say too much. One other thing, don't use the phrase 'unlimited vocabulary.' Why is that? Because a dictionary has a back cover and front cover. There's only so many words, nothing is unlimited. Again, it's like assistive technology, it's a phrase you use without thinking and you're just asking for trouble.

Slide 28: Special Eligibility Rules

Special eligibility rules. These, happily, we don't have to discuss in whole lot of detail. One, because we don't have a whole lot of time. But in addition, age restrictions are pretty much historic, they don't exist anymore. There were problems in the 1980s when Medicaid wanted to

cover only children in a number of places, and we were able to establish very easily that there's no medical basis to distinguish child and an adult, medical needs are the same, ability to benefit is the same, and the court struck down those restrictions.

Slide 29: Age or Place of Service Limits

Place of service restrictions are applicable to both Medicaid and Medicare, actually they're applicable to insurance too. Insurance typically will not cover people who reside in nursing facilities. There is longterm care insurance that people would acquire. Medicare does not provide durable medical equipment to people who reside in nursing facilities or people who receive hospice services, and that can be in a hospice like we have here in Ithaca, or hospice services that are provided at home. DME just isn't provided as a benefit. In Medicaid, nursing facility services will cover durable medical equipment, so if you are a Medicaid recipient living in a nursing facility, you can either depending on what state you live in, and 25 states are in one group and 25 states are in another, you can either have the ordinary process of getting a communication device followed, meaning that the general Medicaid budget will pay for it. Or if you're in the other group of states, and New York is now in this other group, the expectation is that the nursing facility itself will buy the device. And, that has practical problems for getting through the funding process, but it's not a question as regard to coverage, it's not a question in regard of having a medical need unmet, it's simply a pragmatic problem of will it be easy to get a device, or will it be difficult to get a device.

Slide 30: Dedicated "Speech Generating Devices"

The thing that's listed here for dedicated devices is again, that is an issue related to Medicare, a couple of years ago New York Medicaid took up a campaign to make life miserable for people in regard to funding these devices and started focusing on all sorts of functions as an Mp3 player, it controls a remote control, and all of these things were somehow problematic to them even though they've been in devices, well the remote control aspect has been in devices since as the devices have come into existence.

Slide 31: Exclusions

Now they have dropped those objections and come up with this new phrase forever dedicated SGDs which reminds me of the phrase in the movie *Animal House* where someone in the fraternity got double secret probation. It's just a reporting term, it's not a coverage term, it doesn't limit anybody's ability to get any device that you as speech pathologists would recommend, but they want you to contrast what you are

recommending against what they believe to be, what Medicaid and in New York believe to be a forever dedicated device and there is some question as to whether anything is actually forever dedicated. Exclusions are worth more time and let's go to slide 32 to talk about those for a second.

Slide 32: SGDs are not "Convenience Items"

Insurers have in the past and still exclude communication devices as convenience items. This slide and the next one explain why speech generating devices aren't. The easiest one sentence response, to the extent that you would ever see this, is that the only funding program that ever thought that an AAC devices was a convenience item and that was Medicare. And it expressly reversed that conclusion and now it's the largest single funder of communication devices in existence. And they're not convenience items because of these values that we recognize as communication and speech in particular as having.

Slide 33: What Is My Role: How Do SLPs Participate in SGD Funding?

In addition, Medicare and Tricare both have definitions of convenience items as part of their guidance. And communication devices if you look at those guidelines, communication devices don't have anything to do with what those programs recognize as a convenience item. They say barber services, TV or radio services for persons in hospital would be a convenience, and that's not what a speech-generating device or any form of speech treatment is about. And in addition, you can always point out the fact that they have these definitions and they have also speech generating device coverage criteria so it's obvious they don't feel that a communication device is a convenience item. Congress actually said that Tricare should cover communication devices. It's the only time that any law, at the federal level, mentions communication devices. So it's obvious that Congress doesn't think that communication devices are convenience items.

Let's move towards closure by talking about what your role is, and it's easy. Your role is assessment and documentation. A SLP report, an assessment, leads to a report, the report goes to the physician for a prescription. All of these programs require a prescription. The expectation though is that you're the determiner of medical need, not the ordinary circumstances that you simply provided advice from the doctor, actually the opposite, the doctor is relying on you to make these determinations.

One of the other roles that you have is you'll be expected to identify the range of funding programs. Sometimes it's more than one medical based funding program or health based funding program at a time, people can

be eligible for insurance from Medicare or Medicaid at the same time for example. In addition, there may very well be other funding programs that a person will be eligible for. So everyone between 3 and 21 is going to be eligible for public school instruction and they're a funding source. There's the program I mentioned before about the telephone, and very often programs coordinate their benefits, they pay in part each in order to reach the whole, and that starting of that process is the role of the speech pathologist. There also is a private program that you should be aware of. The Muscular Dystrophy Association, or MDA, will provide up to \$2000 per person for a person with ALS to get a communication device. And any program like Medicare for example which has a co-payment requirement, that \$2000 will pay the co-payment so the family will not be out of pocket, they can rely on this, and there is no financial criteria, it's a very generous offer.

Slide 34: If Denied: Appeal

There are going to be times in the experience that all of you have, where despite your best efforts, you're going to be turned down, the client's going to be turned down. The recommendation that I have is that the SLP should educate their client that for every recommendation there should be a device. That should be your operating mantra, and they should appeal because the expectation that a denial is wrong. To the extent that there's limits on your time, limits on your sense of ability moving away from speech-language pathology into appeals which tend to be administrative or legal. Fine, seek out assistance. I do this all the time, it's pretty much my full-time job. You can always contact me to get that sort of assistance. But the family should process an appeal, the first level of an appeal is always just a letter and that's something that I think you should be able to stick with the client, at least that far.

Slide 35: Scope of Practice

Going back over the goals of the program as we reach our conclusion, we've touched on each of these five topics. I hope that you realize that we've answered the 'who' and the 'why.' I've tried to explain in less than as fast as I possibly can, how funding programs decide what they'll pay for. Your role as speech pathologists clearly are data gathering, data assessment, data presentation, and then creating expectations on the part of your clients that they're going to get the device that you're recommending for them. And also, providing you with a resource on where you can go for help to the extent that it is needed.

Slide 36: SLP Funding Resources

The last group of slides identify resources that are available to you. The first are those at the RERC website. We've mentioned three things that

are available there. To the extent that anyone is ever interested in some additional reading on the medical basis and the professional literature related to AAC, interventions, the document that contains the best outline of it is available at augcominc. It's called the formal request that we wrote to Medicare they insisted that we do a literature review, and it's outlined there for you.

These letters: AMA is American Medical Association, AAN is American Academy of Neurology, and the last is the American Academy of Physical Medicine and Rehabilitation. Each of these organizations wrote letters as part of our effort to get Medicare to cover communication devices, to say very specifically that they recognize that augmentative communication devices are medically necessary as treatment for severe communication impairments, and sometimes listing the condition like Dysarthria. So to the extent that you ever again have some form of discussion with a funding program staff person, you can always direct them to those letters, saying 'Well the AMA says this, so why would your doctor, meaning the insurance review doctor, get any more weight or be anymore persuasive than the American Medical Association. Typically doctors agree with what the AMA says, rather than create conflicts with them, and those are posted as well and you can download and print them to the extent that it would ever be useful to you at augcominc.

Slide 37: Advocacy Resources

This is how you can reach me. The very last slide which is not part of your materials but it's just something I'd like to close with is this is why we're doing it.

Slide 38: This is why we are doing this...

This statement which is, "The day Will got his communication device was as important as the day he was born: one gave him life; and the other he became a whole person." This is why we are doing this. The statement that is quoted here was made by the mother of Will T, a six-year-old, who was the main plaintiff in a case involving Georgia Medicaid in the mid-1990s, and this was her statement to the court as to why she agreed to allow her son to be named in this case. So thank you very much for your attention.

Slide 39: For more information on funding

Slide 40: Webcast Production Team